UNIVERSITY OF SOUTHAMPTON

A QUESTION OF BALANCE

The Social Situation of Schizophrenic Patients Living in the Community

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UNIVERSITY OF SOUTHAMPTON

ABSTRACT

FACULTY OF SOCIAL SCIENCES

SOCIOLOGY AND SOCIAL ADMINISTRATION

Master of Philosophy

A QUESTION OF BALANCE

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The social situation of 91 schizophrenic out-patients receiving long-acting neuroleptics was explored in order to describe the environments in which these patients were living in Portsmouth. Use made of community resources by the respondents has been described and areas of particular need have been highlighted by the researcher in the light of standards based on research reported in the literature. Individual needs of patients were identified by the respondents themselves. The title of the research refers to the necessary balance of care required by schizophrenic patients in the community, in order that they may reach their full potential. Information was obtained by the means of a structured interview. The interviews took place between February and August, 1985 and covered such aspects as the structure of, and contact with the family, accommodation, education, employment, income, occupation during the day, relationships and psychiatric history.

One of the main findings was that there were major differences between the males and females in the sample - for example, the men appeared to experience more difficulties with relationships than did the women. Significantly more women (45%) than men (14%) were married at the time of interview and more men (22%) than women (7%) still lived with their parents. Generally, the women seemed more able to occupy themselves during the day and had a useful role to play within the home. Perhaps because of these difficulties experienced by the men, they appeared to be more dependent on the hospital for support.

On employment, 87% of the sample were unemployed at the time of interview, compared to a local unemployment level of about 12%. Despite the fact that the majority of respondents had held responsible positions in the past most unoccupied patients had been unemployed for more than two years and held out little hope of gaining future employment. The researcher felt that this high level of unemployment demonstrated the devastating effect schizophrenia has on the lives of its victims.

However, the most poignant commentary received from respondents was of their difficulties experienced in relationships with others. Although most patients had reasonable contact with, and support from their relatives, many single respondents, in particular, lacked friendship and experienced isolation and loneliness.

Gaps in the services provided were identified by the researcher and these included a lack of provision of hostel-type accommodation by the statutory services; inadequate provision of day-care services and facilities offering sheltered employment; a loss of individual choice for some patients, particularly in relation to accommodation; and a general lack of support in the community for a number of patients and their relatives. However, it was also acknowledged that for many patients, living in the community meant living full, satisfying lives and for these patients a correct balance had been achieved.

SORROW

Life is a ball of sorrow
That slowly floats in pale green air.
With tiny music its heart is crying
And the murmers of the heart
Are all the music hears.

The strings are plucked, the feathers plumed,
And blood and pain are bought and sold,
Cash continues to define the values
of the souls whose feet are scratched.

A crazy rhetoric rules the world.
With iron fist the fat of money
Hurts the heart
Whose bars are bent and crushed.
The music floats to death and into dream
And I cry to you, my darling,
To show me some last sweetness in this life.

I know only the slow things,
The gradual filling of the cup that brings release,
The final draught of air to save me from my fear,
My fear of drowning in the blackness of my heart.

My heart is like an animal in a cage
Who leaps on heated coals and
Fears the prod and goad of stick.
I have orchestrated summers in my mind
And died to find these summers in some place
Where peace can breathe.

But sorrow lives in my landscape
And the music fades to black.

I died without a birth
Into the world where hearts are free
And health can sing its songs.
But the songs were murdered years ago,
By an archdemon of the spleen
Who killed his heart to hear it scream.

I died without a birth.
And never knew my mother's kiss.
My father sucked my life with twisted lips
And drunk my life to dull his tortured mind.

So joy dies with me now;
Life is a ball of sorrow.

Philip Harrison

Chapter 1

The Nature of the Problem

Glenda

I first met Glenda at the age of twenty-two. She had been discharged from hospital having recovered from an acute psychotic episode. She was now considered to be well enough to carry on her life as normal - to go back to where she was before her admission.

Glenda lived on a council estate in Portsmouth with her parents and younger brother. She worked as a machinist in a local clothing factory, and had had the reputation of being one of the fastest workers in the factory. Because of this competence, she had always earned a good bonus on top of her normal wage. She had many friends at work and in her local community. But things were never to be the same again.

I visited the factory on several occasions to meet the Personnel Officer and some of Glenda's colleagues, who were all trying to understand what had happened. They wanted to help, although, as the time went on, found this increasingly difficult.

They complained that her poor concentration had made her work fall behind. Not only did Glenda lose her bonuses, but the other girls on the line were also penalised. The standard of her work fell and many items were rejected. There were complaints, too, about her personal hygiene and appearance.

Things were no better at home. Because of the fall in her wages, there were many rows between Glenda and her mother, who refused to accept her daughter's illness, insisting that all she need do was to 'pull her socks up'. Her father was more sympathetic, although felt lost and helpless in this situation. Glenda was caught in this web of stress and gradually deteriorated. After a while she found it impossible to go to work at all and she lost her job.

The situation at home then took a turn for the worse - there were many rows between her parents and between Glenda and her mother. Because of her financial situation and her guilt, Glenda felt she could not leave home; her father became over-protective and clinging; her mother continued to deny the existence of any illness and waited for her daughter to find another job. Glenda lost her boyfriend; her workmates stopped visiting; and her peers in the local community avoided her. Glenda was alone. Glenda is a schizophrenic.

The Illness

> 'Schizophrenia is a destroyer of the beauty and individual colour of the personality.'
>
> - Sir Martin Roth (1985)

The incidence of schizophrenia is high. It is estimated that there may be nine million sufferers throughout the world, and that one per cent of the population receive a diagnosis of schizophrenia at some time in their lives. At any one time there are over 200,000 people in England that are suffering from relapsing, or chronic schizophrenia. (Wing, 1977)

The onset often occurs in the mid to late teens and the acute syndrome 'characterised by symptoms of the first rank are frequently preceeded, accompanied, or followed by more long-lasting impairments...' (Wing, 1977,p7) Because of this, schizophrenia is one of the most tragically disabling illnesses of mankind.

The syndrome, or group of illnesses, were named schizophrenia by Eugen Bleuler (1857-1930). The term meant a splitting of the mind, or of psychic functions. Several 'types' of the illness have been identified: these include the simple, hebephrenic, catatonic and the paranoid types. Each 'type' shows varying degrees of primary and secondary symptoms, often referred to as '<u>positive</u>' and '<u>negative</u>' symptoms.

The Acute Psychoses

The acute, or positive symptoms of schizophrenia include

' "loud thoughts", thought echo, thought substitution or insertion, thought broadcast, voices commenting on the patient's thoughts or actions, voices talking to each other, feelings that the patient's will or emotions or behaviour are taken over and controlled by external agents or forces. Consciousness is clear and no organic impairment is present.' (Wing, 1978b,p5)

The above symptoms are the discriminating features of the 'central syndrome' of schizophrenia. Wing describes how each symptom has precise definition and emphasises the importance of correct identification of these symptoms in diagnosing schizophrenia. A standard interviewing technique known as the Present State Examination, (Wing et al, 1974) is used to aid accurate diagnosis, although confusion could occur, particularly with the symptomatology of amphetamine-induced psychoses, alcohol psychoses, and some features of depression and mania. In a recent address to the National Schizophrenia Fellowship in October, 1985, Sir Martin Roth suggested that perhaps we should consider a broader concept of schizophrenia and include the above psychoses. Roth acknowledged that there are some similarities between certain manic-depressive, amphetamine and alcohol psychoses and schizophrenia, and that they all respond to neuroleptics. However, for our purposes, we will exclude these psychoses from the study, as, in the U.K., they are not diagnosed as schizophrenia and, therefore, not treated as such. However, it was found that a broader concept of schizophrenia existed in New York, and that some illnesses were diagnosed as schizophrenia that would not be regarded as such in London. These included depressive illnesses, neurotic illnesses, and, in particular, mania. (Cooper et al, 1972)

The Chronic Condition

The chronic schizophrenic syndrome can be separated into the 'clinical poverty syndrome' and 'schizophrenic thought disorder'. The latter had been identified by Bleuler as a 'loosening of the associations', and describes how, in mid-sentence, a sudden turn in direction occurs and results in the consequent loss of meaning. (Bleuler, 1911) This is called 'knight's move thinking'.

The 'clinical poverty syndrome' is dominated by 'negative' symptoms that 'tend to cluster together: emotional apathy, slowness of thought and movement, underactivity, lack of drive, poverty of speech, and social withdrawal.' (Wing, 1978b, p 10)

It is known that neuroleptic drugs are effective in controlling the acute, or positive symptoms (Leff & Wing, 1971), but are less effective in influencing the chronic condition. (Stevens, 1973; Carney & Rutherford, 1981) People suffering from the chronic condition often suffer extreme hardship and isolation because of their handicaps. (Korer, 1977; Korer et al, 1978)

Cromwell (1984) maintains that negative and positive symptoms produce different reactions. An acutely ill patient attracts such remarks as 'He is different.....disturbed.....mentally ill. Is he dangerous? He needs help. He should be put away.....taken care of.' (p 15) Whereas a sufferer of negative symptoms is seen as being intentionally lazy or obstinate.

Wing says 'Numerous studies have shown that negative impairments can be influenced by the social environment in which the patient is living, although there is often a residual impairment, even in the most satisfactory environment.' (Wing, 1978b, p 11) Some of these studies are mentioned below, and are described in more detail in Chapter 2.

The Institution

It was the studies of the effects of the institution on the long-stay patients in mental hospitals that first suggested the important influence the social environment has on the course of schizophrenia. (Goffman, 1961; Wing and Brown, 1961; Wing and Brown, 1970)

It was found that the institutional environment had a negative effect on the lives of chronic schizophrenics because the custodial practices controlled every aspect of the individual's life, which, in turn led to apathy, inertia, a lack of spontaneity and initiative. This state is called '<u>institutionalisation</u>'. Wing and Brown (1970) found that such factors as the number of personal possessions, contact with the outside world, the amount of time spent doing nothing and restrictiveness of ward regimes affected certain symptoms of schizophrenia, for example, social withdrawal and blunting of affect. An improvement in the social environment resulted in a reduction of these symptoms.

The Development of Community Care

A deeper awareness and understanding of the negative effects of institutional care, together with the new developments in pharmacology led the way into the present era of caring for the mentally ill <u>outside</u> the institution. Government policies for the care of the mentally ill and the development of community services have been stated in the White Paper <u>Better Services for the Mentally Ill</u> (1975). The number of in-patient beds in mental illness hospitals has steadily declined over the past two decades. The following figures show the pattern of this reduction.

Table 1:

SUMMARY OF THE TRENDS OVER THE PERIOD 1972 - 1983

YEAR	Mental Illness Hospitals and Units in England. Numbers '000's' of Resident Patients	Resident Patients on Dec. 31st in St. James' Hospital. (Nos. in brackets apply to resident long-stay patients)
1972	99.1	Not available
1973	94.3	543 (288)
1974	89.4	522 (274**)
1975	87.1	488 (273**)
1976	83.3	468 (235)
1977	80.7	439 (226)
1978	78.2	435 (221)
1979	76.4	433 (214)
1980	74.8	431 (211)
1981	73.2	434 (197)
1982	70.8*	434 (201)
1983	Not available	408 (181)

* Provisional figures

** Numbers taken on Nov. 1st, as data for Dec. 31st not available.

Source: (i) DHSS (1985, p 33)

(ii) Medical Records, St. James Hospital, Portsmouth

On the other hand, at a national level, the number of admissions has increased from 175,000 in 1972 to 183,000 in 1982. This suggests that more people are moving through the system. Of these particular trends, the Social Services Committee noted that

'there is some scepticism as to the likelihood of the process continuing, and as to the likelihood that any hospital will actually close. The fact is that more than 20 years after the 1962 Hospital Plan, no major hospital has closed, but that a growing number of mental illness hospitals are within sight of closure or massive reductions by the end of the decade.' (Social Services Committee, 1985, p xix)

It must be remembered that the majority of mentally ill people are being treated and cared for in the community, and have been for some time. The recent Social Services Committee Report acknowledges this fact:

'The almost obsessive concentration in public policy on the mechanisms for "getting people out of hospital" has sometimes obscured the basic fact that most mentally ill or handicapped people already live in the community, whether in their families, in lodgings, group homes, hostels or private accommodation.' (Social Services Committee, 1985, p xv, xvi)

Definition of Community Care

Confusion exists about what is actually meant by 'community care'. It is a phrase often used simply to describe services outside the institutional environment - that is, those services that already exist. Yet the hospital, or institution, should be part of that community. It is also used prescriptively - 'as an ideal or principle in the light of which existing services are to be judged and new ones developed.'
(Social Services Committee, 1985, p x)

What it should not mean is simply the transfer of care from a statutory body to the families of patients or to the voluntary sector. Nor should it represent a cheaper option than institutional care, or a total transfer of responsibility to Local Authorities from the Health Service. The Social Services Committee has defined the principle of community care as:

'Appropriate care should be provided for individuals in such a way as to enable them to lead as normal an existence as possible given their particular disabilities and to minimise disruption of life within their community.' (Social Services Committee, 1985, p x)

The Objectives of Community Care

The first, fundamental objective of community care is that the patient is treated and cared for in his own home, rather than in a hospital or institution, wherever possible.

In its ideal form, community care means the patient will be in a familiar, comfortable environment with his family, neighbours and friends. These people are informal carers, and are often under stress because of the responsibility of caring for a dependent. Advice, support and relief must be provided for informal carers.

There must be accessibility to support networks. It has often been reported that relatives have had difficulties in obtaining help and support when it has been required, and have learnt to cope in the best way they can. (Creer & Wing, 1974)

The help and support provided should be appropriate and meet the needs and wishes of the patient and his family. The services provided should be cost-effective, and cause as little disruption to the recipients as possible.

Aid provided should relieve the stresses and strains caused by the patient's illness.

The development of a network of services is necessary in order to meet the needs of the patient and his relatives. This network should include Health and Social Services; other statutory services, including local government departments; local community provision and neighbourhood schemes; the church and voluntary organisations; and relatives and other informal carers.

Network of Services

The institution provided a whole range of facilities, for example, accommodation, meals and probably some form of occupation. The pressure on services is considerably increased when care is transferred from the institution to the community, as the needs of the patients have to be met by a variety of services from numerous sources. It is vital that there is liaison, planning and cooperation between these services in order to provide appropriate and effective care, as a 'lack of any element in the network of general and specialist services can reduce the effectiveness of other elements - for example, lack of employment or other appropriate day activity to complement residential care.' (DHSS, 1985, p 7)

The Memorandum submitted by the DHSS to the Social Services Committee recognises that the primary care services play a major role in treatment and that these services 'can provide anticipatory guidance, supportive intervention, early treatment and appropriate referral.' (DHSS, 1985, p 5)

The paper also acknowledges the importance of the specialist psychiatric unit or mental illness hospital in providing community resources as well as in-patient facilities. These services also need to provide 'out-patient and day-patient assessment, treatment and rehabilitation, including support where necessary for those discharged from hospital.' (p 5)

There is a need for specialist services, for example, forensic units and services for adolescents. There is also a need for multi-disciplinary teams consisting of psychiatrists, community psychiatric nurses, occupational therapists, social workers and psychologists. The Memorandum continues:

'Development of local authority services and of an integrated District service requires the redeployment of resources from these old hospitals not needed for the new services (and which have already reduced greatly in size), training for staff who have to meet the demands of the new service, and joint financing and planning.' (p 5)

Not only do the services need to exist, but access is also of crucial importance. The patient and his/her relatives need to know what is available and which service is appropriate for their particular needs. They also need to understand the route of referral and process of admission to the system.

One of the main criticisms of institutional care was the total lack of individual care. The patient had to conform to the rigid rules of the institution, and thus individuality was lost. The network of community services must be flexible enough to be able to meet the individual needs of the patient, which, of course, firstly need to be identified. An important component of this individual care is the availability of choice, where appropriate. The institution took choice away from the patient; community care can now give that choice back.

Integration

'The overriding objective of the new mental health service will be to extend support to individuals through a combination of statutory and informal systems of care within the least segregated environment, consistent with individuals disability. The service should provide formal staffed care which do not impede the informal networks.' (MIND, 1985, p 125)

Living in the community means an integration into local community life and sharing the facilities and services available. Mental illness has always carried an enormous amount of social stigma - particularly if the illness leaves the patient with many social handicaps and eccentricities of behaviour. Public education is required in order to attempt to change these fixed attitudes, so that patients will be accepted by the community, and therefore in the community.

The community needs assistance to understand and accept mentally ill patients, and it will only be with the help of a long-term, positive Government initiative to promote community care that this acceptance will come about. The Social Services Committee recommends the development of 'a positive programme designed to procure a greater degree of community acceptance of community care policies....' (Social Services Committee, 1985, p lxviii)

Accommodation

'Sufferers from schizophrenia - because the illness commonly begins in adolescence or early adult life - rarely have a home of their own. Discharge after a first hospital admission can rarely be to independent living since this has never been achieved or cannot be sustained.' (National Schizophrenia Fellowship, 1985, p 209)

Many schizophrenic patients, particularly those suffering from the chronic condition, have numerous social handicaps and cannot cope with living a fully independent life in the community. Large numbers of patients do, in fact, live with their families (NSF, 1985) However, for the remainder, there needs to be a full range of residential accommodation available in each Health District in order to accommodate the varying needs of the patient population.

Guidelines were laid down by the Government White Paper Better Services for the Mentally Ill (DHSS, 1975)

It was envisaged that 15 long-stay residential places per 100,000 population would need to be provided in an area of 'average' need; and in areas of 'high need', this number would increase to 24 places per 100,000 population. Critics feel this estimate is inadequate to cope with the demand for places. (Morris, 1981)

There needs to be a full range of facilities available in order to accommodate the differing needs of the patient population. These needs will range from a total dependency on services to a minimum amount of support and virtual independence. Therefore, such facilities need to include hospital-hostel type accommodation or local authority hostels with full supervision and hotel services; rest-homes, guest houses and private landladies with full services and supervision; hostels with continuing rehabilitation programmes; group homes and flats; lodgings with sympathetic landladies; flats and bedsits - the latter being provided in communal and non-communal houses. This network of facilities must allow movement up and down the range for individual patients whose needs may, and often do, alter.

Patients Living With Their Families

'Sufferers from schizophrenia are mostly cared for by their families, with little or no support from anyone and no idea of how to cope, till they painfully learn by trial and error, or give up in despair.' (National Schizophrenia Fellowship, 1985, p 209) Although provision of a wide range of accommodation is crucial, it must be remembered that many patients do, in fact, live with their relatives. It has been estimated that only about one in 80 schizophrenics living in the community are in residential accommodation, and that at least 90% of care is given by the relatives of patients. (NSF, 1985) Many of these relatives are under great stress and have very little support.

'Even for robust parents or spouses, living, every hour of every day - and night - for years on end, with a schizophrenia sufferer is a wearing and cumulative ordeal. That it should happen to an ailing ageing widow or wife with young children, without even advice, let alone support, is intolerable in a 'developed' country.' (National Schizophrenia Fellowship, 1985, p 208)

The important role the relatives play in the community care of schizophrenic patients has been acknowledged. (Creer and Wing, 1974; Wing, 1978a) Vital research has been carried out concerning the home environment of the schizophrenic patient living with his relatives and, although these studies are discussed more fully in Chapter 2, it is worth mentioning them here.

It was Brown and his colleagues who recognised the importance of the patient's living group (Brown et al, 1966) and the emotional atmosphere that was present (Brown and Rutter, 1966; Brown et al, 1966; Brown et al, 1972; Vaughn and Leff, 1976) Brown identified three factors as being significantly associated with relapse - the amount of critical comments, hostility and emotional over-involvement. The amount of Expressed Emotion (EE) based on these factors determined which patients were in High or Low EE homes. The researchers found a higher rate of relapse in high EE homes than in the homes of low EE.

Significant factors affecting the relapse rate of patients in high EE homes included the amount of face-to-face contact with relatives, and whether or not the patient was taking regular medication. A poor outcome could be predicted if patients lived in a high EE home, with a high amount of contact with relatives (more than 35 hours a week), and were not receiving maintenance therapy. If patients from high EE homes were protected by low contact and maintenance therapy, then their prognosis is greatly improved.

Julian Leff and his colleagues have carried this research further. (Leff et al, 1982, 1983 and 1985). The researchers conducted a controlled trial of social intervention, in order to find out whether reducing the relatives' EE and face-to-face contact would help to prevent relapse, and therefore add to the beneficial effect of maintenance neuroleptics. The results showed that the intervention did have the desired effect in the majority of cases and that the reduction of EE and face-to-face contact was protective.

Occupation and Employment

For some patients, integration into community life, whether with family or alternative support, will prove to be too difficult and painful. Special facilities need to be provided for patients with severe social handicaps - for example, day units backed up by coffee shops, contact clubs and other sheltered social environments.

An important element here is that of choice. In the institution the patient had to accept what was on offer and often this was very limited. If we are to avoid creating another form of institutional care outside hospital, then all efforts must be employed to create a choice of activities.

Past research has shown that schizophrenic patients are particularly sensitive to changes and stimuli in their environment. For example, not only do they adversely react to under-stimulation, but also to an excess of stimulation (Wing et al, 1964). This is why it is important to get the balance right - to provide the services that can give the correct amount of stimulation. For chronic schizophrenics, one of the most damaging factors is the amount of time spent doing nothing, in that it promotes flatness of affect, social withdrawal and poverty of speech (Wing and Brown, 1970). The researchers also found that industrial work provides an environment where the stimulus and interaction is non-emotional and neutral and, therefore, less stressful.

In the current climate of high incidence of unemployment, opportunity for employment remains remote for the majority of the mentally ill. But for many, a higher degree of confidence, self-respect, independence and integration would be achieved if some form of employment was available. The Social Services Committee recommend 'that the DHSS, together with the Department of Employment and representatives of employers and trades unions, now explore the practical possibilities for expanding the present narrow base of sheltered employment.' (Social Services Committee 1985, p xlviii)

Income

An obvious reward of work is the financial gain - a good wage can perhaps provide the motivation required for an otherwise poorly motivated patient (Wansborough, 1981). However, as has been maintained, for many schizophrenic patients employment is an unobtainable goal, and therefore these patients will be dependent on social security benefits. No doubt, a number of patients will find difficulty in managing their income - it is usual that rents and boarding fees are paid direct and the patient is then left with a small amount of 'pocket money'. The possibility of patients in private lodgings or nursing homes earning enough from work to cover their rents and pocket money is extremely unlikely. For these, there is no alternative but to continue drawing benefit from the State.

Community Care - Reality or Rhetoric?

The strength and pace at which current policy is now being implemented can leave a total lack of awareness of the social circumstances in which the patients are living. The government have promised that no hospital will close until a comprehensive network of services exist in the community (DHSS, 1975). The components of a comprehensive network have already been identified. There is much concern whether or not this can, or will, be accomplished:

'Putting pressure on authorities to close or run down hospitals without similar incentives or resources to develop alternative services is putting the cart before the horse.' (Social Services Committee, 1985, p xviii) The same report acknowledges the fact that 'the pace of removal of hospital facilities for mental illness had far outrun the provision of services in the community to replace them.' (p xviii)

There is a great fear that we could be creating the biggest social problem of the twentieth century.

We have inherited a psychiatric service built up over 150 years, and much evidence has been presented about the negative aspects of institutional care. At a National Schizophrenia Fellowship conference in October, 1985, Dr. Anthony Clare described this system as one of neglect and forgotten by the medical professions, politicians and the general public. He claimed that, at present, we tend to cling on to the institution because we are frightened of the lack of alternatives. An attraction of the mental hospital is that it has a structure: that everyone knows what they are doing and what is expected of them. There is a tradition, an inheritance of posts, and a strong feeling of belonging. The staff 'look outside and see a crazy world.' (Clare, 1985)

Clare claimed that what we are in danger of is being left with the worst of both worlds. At present there is a '<u>patchwork quilt</u>' of mental illness services throughout the country. The Memorandum by MIND submitted to the Social Services Select Committee on Community Care, echoes this concern:

'Nothing less than a full scale transfer from one pattern of care to another is required and Government must be persuaded that sufficient resources should be made available from central taxation to enable this process of change to succeed. Without adequate resources, "community care" will remain a romantic theory in many parts of the country. MIND does not believe that the current, severe constraints on public expenditure should be used to jettison the practical benefits of community care in favour of maintaining an unsatisfactory status quo.' (MIND, 1985, P 122)

It has been argued that difficulties in liaison exist between the Health and Social Services, and that this lack of coordination contributes towards the disintegrated community services. (Priestley, 1979). The Social Services Select Committee acknowledge that 'There is considerable room for improvement in joint planning and in joint service provision.' (Social Services Committee, 1985, p 1). An improvement in liaison between and within the services would lead to an improvement in services.

Research has shown that the integration of patients into the community is often a myth - that many patients are living isolated lives and, in fact, segregation is the reality. (McCowen and Wilder, 1975; Korer et al, 1978; Hopkins, unpublished) This is particularly true of patients who live alone. Those patients who live with their families, whether in parental or marital homes, tend to be less isolated. Yet often the families of schizophrenic patients experience the isolation and have little, or no support to help them cope. (Creer and Wing, 1974; NSF, 1974a;NSF, 1979) The care given by the families is often the only support the patient has - that is, 'community care' means 'family care' in this situation.

Patients who move in to nursing homes, or rest homes, probably receive help and support from the statutory services as well as from the staff in the residences. The dangers here could be that instead of deinstitutionalisation, a process of transinstitutionalisation takes place. In other words, the practices in the nursing homes could mirror those in the institution. Also, if patients are 'placed' in the homes by social workers or by community psychiatric nurses, which is often the case, then the ability to choose one's accommodation is taken away from the patient. A lack of suitable accommodation reinforces this absence of choice. The Social Services Select Committee recommends

'that the Department lay an obligation on authorities to ascertain so far as practicable, and give due consideration to, the wishes and feelings of mentally disabled individuals for whom a service is provided, and in particular where closure of a long-stay facility is contemplated.' (Social Services Committee, 1985, p lxxvii)

One of the major criticisms of care in the institution has been the lack of occupation of the patients during the day. This is particularly damaging for patients suffering from chronic schizophrenia (Wing and Brown, 1970) The absence of suitable sheltered employment and occupational or industrial therapy units in the community encourages this situation to continue outside the institution. It has been seen that many patients are unoccupied during the day and some, in fact, spend much time doing nothing (McCowen and Wilder, 1975; Korer et al, 1978; Hopkins, unpublished). Even if these services were provided, the reality would probably be that large numbers of patients would not meet the criteria stipulated for entry into the system, and thus would fall through the net of care. This is particularly true of patients suffering from chronic illnesses and who are therefore often extremely handicapped. This is why a wide range of services is required in order to accommodate all degrees of handicap.

A Question of Balance

What is required in the development and implementation of community services for the schizophrenic patient is an acute awareness of creating the right balance. Until recent years, the only care available for a schizophrenia sufferer was within the walls of the asylum - now we want to shift that care to the other side of the walls. If the movement is too rapid without careful planning, then that is precisely what we will do - simply shift institutional care to the other side of the wall. If services are not developing in the community as psychiatric hospitals are reducing in size, then the balance will be upset on either side of the wall.

Community care involves relationships between the patient and others in the community, whether these are relatives, friends, neighbours, or involvement in local community life. Care and support needs to be at the right level so as not to be intrusive in these relationships. The support, care and advice must not remove the individual's choice, as far as is possible. Intervention must not become interference.

The provision of services must be adequate to accommodate patients ranging from those who are capable of independent living, to those who will need full support and will therefore be fully dependent on the services. The support system must be flexible enough to allow movement within it to meet the changing needs of the patients, together with the ability to accommodate a certain amount of personal choice.

How patients spend their time during the day is of crucial importance. We know that schizophrenic patients adversely react to both under-stimulation and over-stimulation and it is important to get the right balance. As well as in their activities, this balance is important in their personal relationships. Over and under-involvement with other people can cause a deterioration in the patients' mental state, and they need to find their own limits, as far as this is possible.

Full integration into community life will no doubt be impossible for many schizophrenics. But we must not allow this inability to integrate to generate a life of segregation. Not only should the appropriate support services be developed, but on-going public education must be promoted in an attempt to change attitudes towards the mentally ill. Only then will integration stand a chance.

The Italian Experience

The Italian experience has it's origins in the philosophy of Franco Basaglia, who

> 'maintained that the causes of psychiatric disorder are essentially social in nature, and that the only valid treatments are political struggle and the revival of the patient's aggressiveness. Therefore, no institution can be therapeutic for the patient, since it's aim must be his custody and violent destruction.' (Papeschi, 1985, p 247)

Basaglia felt that the causes of mental illness were merely of academic interest and that 'what counts is only the consequence of this illness, which is different according to the relationship that exists between patient and doctor, which in turn depends on the socio-economic status of the patient.' (Papeschi, 1985, p 247) He maintained that there exists a strong inter-dependence on economic, social and psychiatric deviance - 'the first is said to be the cause of the second, which in turn is the cause of the third.' (p 249) Basaglia claims that in an industrial society one needs to have the ability to work - those who worked were seen as 'sane' whereas those who could not were 'sick' (Jones and Poletti,1985)

Basaglia was the medical director of the San Giovanni psychiatric hospital in Trieste from 1971 to 1978. When he arrived there, the hospital was highly institutionalised with an in-patient population of 1200. In five years this number had been reduced to 500 and some community day support had been set up.

Psichiatria Democratica, the pressure group supporting his ideas, was set up in 1974. Kathleen Jones describes Basaglia as a 'warm and charasmatic character, and his enthusiasm was catching.' (Jones and Poletti, 1985,p 342) She continues 'Basaglia has been called a prophet, a visionary, a revolutionary and a demagogue. He inspired great loyalty in his followers, and perhaps one anecdote will illustrate something of his character: he loved England, and he loved English pubs.' (p 342)

His ideas gained much support in Britain and the majority of the press have presented the Italian experience as a huge success story.

Basaglia believed that the treatment of mental illness should not include the older therapeutic approaches, for example, psychotherapy or chemotherapy, as these 'are directed only against the patient and tend to "objectivise" him.' (Papeschi, 1985, p 250) He felt the only way to help the mentally ill patient was in a political way: that what was required was a radical change in the political-economic system. However, he did accept the present therapeutic approaches, but only practised within the community outside the asylums.

Law 180, passed in May, 1978, prohibited the admission of new patients to mental hospitals, although ex-patients could be admitted until December, 1980. No patients were to be admitted after January 1st, 1981; no new state hospitals were to be built and existing asylums 'were not to be used as general hospital departments.' (Becker, 1985, p 254); and psychiatric wards in general hospitals would have no more than 15 beds and would provide in-patient care. A network of community-based facilities would be provided across the country - the staff being recruited from the mental hospitals. Psychiatric nurse training was abolished in 1975.

Law 180 has not been without it's critics. 'According to them Italy's new mental health law is a mere "dehospitalisation" programme and its conception of the new services is considered short-sighted and sketchy.' (Becker,1985,p259) Although conditions had been poor in the institutions, accounts emerged of the plight of some patients in the community after 1978. The law had been rushed through parliament and some areas have quickly implemented the new regulations - with a lack of alternative structures. Jones argues that a moderate reform movement had been in existence prior to 1978 and that the hospital population 'had been halved before the new law took effect. The reduction since has been only of the order of 10,000 and at least 35,000 patients are still in hospital.' (Jones and Poletti, 1985, p 344)

Many of the original wards are still in existence, but have been re-named 'family homes'; psychogeriatric patients are no longer included in the figures; patients who remain in hospital have been re-classified as 'guests'; many 'community' patients have gone to prison and there is an increase in the number of patients in the five forensic hospitals. 'Some wander the streets, increasing the problem of homelessness in the urban centres. Private nursing homes have mushroomed.' (p 344)

Jones visited Italy to investigate the state of care and found that many anomalies existed. Hospitals were still open: staff worked long hours as the hospitals were very under-staffed; the buildings had deteriorated since the law abolished repair work; services were totally lacking and patients were unoccupied throughout the day. 'We saw alternative structures - "family homes" or "villas" - and often did not realise what they were at the time, because they looked like ordinary mental hospitals.' (p 345)

There was little in the way of community service provision. Jones describes the rapid growth in the number of private nursing homes. These are without public inspection and concern was expressed about the existing conditions in the homes and potential abuse of the system. She claims that, from the Italian experience, Britain may learn many lessons. Although the community services in existence in Britain are inadequate, they form a basic structure for development. The danger is in closing down the institutions before these services have been developed.

Of Italy, Jones says:

'If the old system was regimented and repressive, laissez-faire merely substituted a chaotic poverty of provision. Is the amount of misery caused greater or less than the old system? We have no techniques for measuring human misery.' (p 346)

The Need for a Local Study

The aim of the study is to investigate and describe, as far as possible, the lives of a group of schizophrenic patients living 'in the community' in Portsmouth. Whilst working as a generic Community Psychiatric Nurse in the city, I became acutely aware that there was a total ignorance about how, and where, these patients were living - how they were coping with accommodation, income, meals, personal relationships, medication, employment, and occupation during the day. In short, what quality of life did they have?

There was also grave concern about the stress experienced by the relatives of schizophrenic patients. With the shift of care from the institution to 'the community' were we placing a burden onto the community, and in particular onto the relatives, that was proving difficult to bear?

There was no good information available to give the answers to these questions. My own experience told that, in many cases, things were not as they should be - that there was a lack of appropriate services and support networks. An example of this was when I attempted to trace a single, middle-aged, male schizophrenic patient who had failed to attend the hospital for his monthly injection. He lived in a block of flats on a council estate near the city centre. I found that he had become so isolated in his envirohment that he was afraid to leave his home. The graffitti scrawled across the front door and wall told the story of his plight. It read: 'The mad-man lives here. Don't go near him.'

However, there were no means of knowing how typical this situation was, or whether it was an isolated case. There was an urgent need to investigate the social environment in which schizophrenic patients lived in the community because of the on-going development of community services for the mentally ill.

The Aims of the Research

The research was intended to investigate and describe the social environment, and services provided, for a particular group of schizophrenic patients who were maintained in the community with the help of long-acting neuroleptics (depot injections of long-acting tranquillisers).

The research was intended to provide documentation and evaluation of the patients' social situation and to describe the use made of NHS and non-NHS resources by the patients. It was intended that areas of particular need would be highlighted by the researcher, in the light of standards based on research reported in the literature. The patients' individual needs would be identified by the patients themselves. The interviews would include demographic information and details of accommodation; education, employment and occupation during the day; income; aspects of the patients' personal lives and relationships; contacts with the hospital and other professionals; and a brief psychiatric history.

It was intended that the research would aid future planning of psychiatric services for schizophrenic patients in the community. The knowledge gained would enable the planning of more effective use of resources and contribute towards aspects of improved patient care, including prevention of further breakdown or hospital admission, treatment, rehabilitation and resettlement.

The research should have some value in nurse education for such courses as ENB 810 (Nursing Care of the Mentally Ill in the Community) and ENB 995 (An Introduction to the Understanding and Appreciation of Research), as well as for student nurse and in-service training. The study may also be of value to other professionals, for example, social workers and to interested groups, such as the National Schizophrenia Fellowship.

CHAPTER 2

A Review of the Literature

The concept of the present day care of the schizophrenic patient has evolved from a history of changing attitudes as well as pharmaceutical developments and the accumulation of knowledge through research. The illness, or group of illnesses, is often life-long and nearly always very crippling, and therefore affects every aspect of living, not only for the patient, but often for family and friends. Because of this, together with the fairly recent shift from care in the institution to care in the community, much divergence of opinion and comment has come about in recent years. Thus, the amount of literature available is vast and this project therefore requires selectivity.

The literature search was restricted to schizophrenia and the effects of the social environment on the course of the illness, and in particular the environment outside the hospital, that is, 'in the community'. However, particular reference has been made to literature concerned with the effects of the institution on chronically ill patients, as this commentary encouraged the change of direction from the asylum to the present day community care of this patient population. Policy documents about this changing concept of care is included in the review.

The social environment of the patient includes the areas of accommodation; education and employment; occupation during the day, including the organisation of domestic work within the home; family and social contacts; professional contacts and the amount of contact the patient has with the psychiatric hospital. Research has shown that many patients suffering from chronic schizophrenia remain extremely handicapped in some, if not all, of these areas. These studies have been selected, although it should be pointed out that American studies have been omitted and that only British literature has been included. There are two main reasons for this. Firstly, there are apparant differences in diagnosis criteria (Cooper et al, 1972) and it is probable that American studies include patients that would not be diagnosed as schizophrenic in Britain. Secondly, because of cultural and social differences, generalisations cannot be made by comparisons between the two societies.

Several papers looking at different aspects of pharmaceutical developments have been selected. Publications by drug companies were avoided, so as to minimise any bias. The effects of chemotherapy are particularly important to observe, as all patients to be included in this study will be receiving long-acting intra-muscular injections.

An Historical Perspective

The paper starts with a description of the development of the concept of schizophrenia by Smith (1982) and Arieti (1974), and the changing attitudes towards the care of the mentally ill by Wing (Wing 1978b; Wing & Olsen 1979). Examples of extracts from the original sources are taken from Three Hundred Years of Psychiatry 1535-1860 (Hunter & Macalpine, 1963) and Medieval and Early Modern Theories of Mental Illness, a paper by Richard Neugebauer (1979).

Andrew Croyden Smith in Schizophrenia and Madness explores the historical evidence in order 'to examine the forms of madness that existed in earlier times' (Smith, 1982, p 60) He begins his search with the Greek tragedies and describes such examples as Euripides being portrayed as seeing hallucinations and illusions. Hippocrates described a medical viewpoint and pointed out the importance of the role of the brain in the organisation of human behaviour. Non-fictional accounts of mad individuals have been found in the writings of ancient historians, such as Herodotus. Smith then looks at the Old Testament accounts of 'striking behaviour' such as Saul's:

'On another occasion he took off his clothes and prophesied naked for a day and a night. More disturbing were violent moods and uncontrolled rages and it was believed that he was tormented by an evil spirit: He attacked David because he brooded that he might supplant him, and another time set upon his own son Jonathon with a spear.' (p 65)

The prophets of this time were often eccentric and behaved peculiarly. Smith describes the importance of the role of the prophets in Palestine and neighbouring areas but says:

'However, their behaviour was extraordinary not only to us but also to the people of the time, as they fasted, wandered, entered trances to speak the Lord's messages, donned sack-cloth and ashes, and emphasised their message in symbolic mime.' (p 66)

Describing the Middle Ages, he points out that the development of the scientific enquiry was only at an embryonic stage, and therefore that traditional and folk beliefs 'were usually concerned with religion and heresy, and the development of beliefs in demons, magic and witchcraft.' (p 69)

It was the Church that led the understanding and treatment of mental disorder. 'Nevertheless, the rational, professional, medical approach to mental disorder that was attempted in the Middle Ages was never negligible, and developed considerably during the period.' (p 70) Smith gives examples of the writings of such authors as Bartholomaeus Anglicus and Bernard de Gordon, which were based on the Greek medical tradition. The need for special arrangements for the mentally abnormal was recognised from about the thirteenth century when the Crown saw itself as responsible for the protection of, and the property of 'natural fools' and made a law to accommodate this.

Richard Neugebauer claims that the Prerogativa Regis is the first document we possess on this subject. It 'sets forth various royal powers and prerogatives, including the king's authority over mentally disabled persons.' (Neugebauer, 1979, p 479). Two categories of mental disability were described: natural fools or idiots referred specifically to congenital subnormality; persons non compos mentis included all mental disabilities not included in the above category. In the fifteenth century, the term lunatics replaced the latter classification. Sections 11 and 12 of Prerogativa Regis discussed the Crown's right of intervention:

'the king shall have the custody of the lands of natural fools taking the profits of them without waste or destruction and shall find from their necessaries............And after the death of such idiots he shall render it to the right heirs, so that such idiots shall not alien nor their heirs.......be disinherited.' (p 479)

At this time the mentally ill remained in the community on the whole, sometimes wandering. Hospital care was extremely scant and Andrew Croyden Smith concludes that the first proper mental hospital may have been in existence from 1377 near Charing Cross. This was called the Stone House. An account is given of the behaviour of King Henry VI and Smith states that the probable diagnosis is that of catatonic schizophrenia and says 'We can here detect, therefore, a reasonably typical case of schizophrenia over five hundred years ago.' (p 74)

Medical books of the Renaissance and seventeenth century Britain saw the important link between the brain and mental disorder. Smith mentions only briefly the 'witch-craze of the 16th and 17th centuries' (p 74). He says that, although some of the accused were mentally abnormal, many were not.

Mentally ill wandered the streets and countryside as hardly any institutions existed at this time other than Bethlem Hospital in London. Descriptions of madness can be found in the writings of such people as Shakespeare (England), Rabelais (France), Cervantes (Spain). Religious beliefs strongly influenced the understanding of mental illness. The eighteenth century philosophers studies the mind but not mental illness. However, there was a shift away from religious connotations by the more educated.

'When God is less in evidence in everyday life, being seen as an unmoved mover of the Universe, and when the personal reality of the Devil is no longer preached from the pulpit, madness is not attributed to demonic possession, holiness or any supernatural occurrence.' (p 78)

Nevertheless the level of theory remained fairly static and rather primitive.

From descriptions of asylum patients in the eighteenth and nineteenth century it is clear that many of the patients suffered from schizophrenia, although it was not until the end of the latter century that the concept of an illness entity was developed.

William Perfect (1737-1809), a general practitioner and a specialist in insanity, who was also the owner of a private madhouse in Kent, described a male patient as

'intolerably jealous, disrespectful to his family connexions, insolent and rude to every one who came in his way, intemperately passionate, and misanthropic to the greatest degree; in this manner his insanity began to appear: he next drew upon his banker for sums immensely beyond what his account could afford.........he often insisted upon his being the Lord Chancellor, King of Spain, Duke of Bavaria, or some other great personage.. ....his imaginary greatness and self-importance, however, gradually dwindled into a total decay as he approached to the verge of idiotism.' (Hunter & Macalpine, 1963, p 505)

Silvano Arieti in <u>Interpretation of Schizophrenia</u> does not include the 'pre-Kraepelinian conceptions' as, he says, they now only have an historical interest (Arieti, 1974). Arieti looks at the contributions of six authors in particular. Emil Kraepelin, 1855-1926, identified a 'pathological entity' he called 'dementia praecox', so termed because a dementia state commenced at an early age. He divided patients into three groups - hebephrenic, catatonic and paranoid. He described the symptoms of the syndrome in minute detail, and in fact was the first to describe some of the symptoms, such as negativism. He accepted a fourth type - the simple - as suggested by some other authors. Aetiology he saw as endogonous and not due to external causes. Arieti says

'The patient appears as a collection of symptoms, not as a person; or, if he appears as a person, he looks as if he belongs to a special species and thus should be differentiated from the rest of humanity and put into the insane asylum. The psychiatric hospital is a zoological garden with many differentiated species.' (p 11/12)

Eugen Bleuler, 1857-1930, accepted most of Kraepelin's views, but tried to go beyond the purely descriptive approach. He renamed the syndrome 'schizophrenia' - which meant the splitting of various psychic functions, not a dementia process, that is not an organic deterioration of mental function. He included in this group of illnesses other psychiatric states, for example, manic depressive psychosis and alcoholic hallucinosis. He identified a new sub-type - the 'simple' type. Bleuler attempted to explain symptoms, not just to describe them. Emphasis was placed on affect, that it was not absent, but that it probably played an important role. He also developed the concepts of autistic thinking and ambivalence.

Adolf Meyer, 1866-1950, emphasised the need for a longitudinal study of the patient, and felt that dementia praecox was the result of the faulty habits of reaction. His work was important because it stressed the importance of psychogenic factors.

The interest of Sigmund Freud, 1855-1939, initially centred on the study of psychoneurosis, and therefore he saw the psychosis as having the same basic functions and mechanisms. Arieti recognises that many of Freud's theories have to be discarded, but says

'Freud was the first author who really succeeded in explaining the content of the psychosis in psychological terms. He was also the first to disclose in a convincing manner the importance of psychological factors in the etiology of this condition. He did not limit himself, as Meyer did, to the interpretation of the symptoms as faulty patterns, but also uncovered their symbolic meaning.' (p 22)

Carl G. Jung, 1875-1961, claims Arieti, 'was the first to make outstanding contributions to the field of schizophrenia.' (p 22). Examples of his contributions include his application of psycho-analytic concepts to schizophrenia and his identification of the link between the introvert personality and schizophrenia, which he compared with the extrovert personality and hysteria.

Harry Stack Sullivan, 1892-1949, is described by Arieti as 'the first author to offer a deep and convincing psychodynamic interpretation of schizophrenia.' (p 25) Sullivan sees that schizophrenia is engendered by poor interpersonal relations, especially parent-child, although he had not developed his study to the overall sociological forces acting upon the individual. Arieti concludes 'More than any of his contemporaries, Sullivan felt that schizophrenia could be treated psychotherapeutically. He made psychotherapeutic treatment of the schizophrenic the primary work of his life.' (p 29)

Changing Patterns of Care

Alongside the growth of knowledge in this area, attitudes to the care of the mentally disordered were changing. J.K. Wing in Reasoning About Madness describes how, in the early eighteenth century England, pauper lunatics were dealt with by parish overseers under the old Poor Law. The mentally ill were either sent to prison or private mad-houses; a few were sent to Bethlem Hospital, confined under the vagrancy laws in local bridewells or houses of correction, and a substantial number were confined alone in 'single care' - this 'care' often meaning such situations as being chained in coal cellars. (Wing, 1978a; Jones, 1955)

Illustrations of 'psychiatry from the inside' are given of Bethlem Hospital by Hunter and Macalpine (1963, p 427). The following texts were taken from the Committee Books of 1764-79:

'21 Dec. 1771. It is ordered that every man who has been a patient in this Hospital and is discharged from it either sick or incurable, shall, previous to his being taken away from the house, be stripped and examined by the Basketman to whose care he has been entrusted to see that he be sent out from the Hospital clean and free from vermin. And in likewise manner every woman patient.'

'17 Jan. 1778. It is the Opinion of this Committee that the Feet of every Patient in Chains or Straw be carefully examin'd, well rubb'd and covered with Flannel by the respective Basket Man or Gallery Maid every Night and Morning during the Winter Season and if necessary that immediate Notice be given to the Surgeon.' (Hunter & Macalpine, 1963, p 429)

In 1809, John Haslam, the medical officer to Bethlem Hospital, describes methods of restraint used in the hospital at that time.

'In the most violent state of the disease, the patient should be kept alone in a dark and quiet room, so that he may not be affected by the stimuli of light or sound, such abstraction more readily disposing to sleep. ....The hands should be properly secured, and the patient should also be confined by one leg; this will prevent him from committing any violence.' (Hunter & Macalpine, 1963, p 635)

Haslam goes on to describe his method of ensuring patients take their medicine 'where patients have been obstinately bent on starving themselves, or where they have become determined to resist the introduction of remedies calculated for their relief.............' (p 636)

'The manner in which this compulsory operation is performed, consists in placing the head of the patient between the knees of the person who is to use the instrument: a second assistant secures the hands, (if the straight waistcoat be not employed) and a third keeps down the legs. As soon as the mouth is opened, the instrument may be introduced; it presses down the tongue, and keeps the jaws sufficiently asunder to admit of the introduction of the medicine.........The nose of the patient being held by the left hand of the person who uses the instrument, a small quantity of the medicine is to be poured into the mouth, and when deglutition has commenced, is to be repeated, so as to continue the act of swallowing until the whole be taken.' (p 636)

A government inquiry into madhouses was made in 1815 to 1816. The Committee's findings had considerable impact and their evidence 'focused interest on the fate of the neglected insane and created a body of progressive public opinion in favour of new legislation for the inspection and supervision of madhouses and asylums by the State.' (p 697). (John Haslam, quoted above, was in fact dismissed from post before the new legislation came about.) Hunter and Macalpine selected evidence from the Committee's report.

Godfrey Higgins, Justice of the Peace of the West Riding of Yorkshire, discovered the abuses at York Asylum, and described a visit there:

'When the door was opened, I went into the passage, and I found four cells, I think, of about eight feet square, in a very horrid and filthy situation, the straw appeared to be almost saturated with urine and excrement; there was some bedding laid upon the straw in one cell, in the others only loose straw.......the walls were daubed with excrement; the air holes, of which there were one in each cell, were partly filled with it.........I then went up stairs, and he shewed me into a room, which I caused him to measure, and the size of which he told me was twelve feet by seven feet ten inches, and in which there were thirteen women, who he told me had all come out of those cells that morning.' (p 698)

The general assumption at that time was that the able-bodied unemployed or destitute deserved their fate and they all tended to be sent to the workhouses. The 1834 Poor Law meant that everyone who was receiving public assistance was sent to the workhouse - meaning that the paupers' situation was to be less attractive than that of the lowest paid labourer. Infirmaries were set up and became a system of second-class public hospitals. The first public mental hospitals were set up in reaction against intolerable conditions, with the aim of encouraging self-restraint 'and thus do away with the need for leather muffs with wrist locks, boot hobbles, straight jackets, and other ingenious devices' (p 196)

The movement to improve conditions had started in the latter part of the eighteenth century when Pinel had struck the chains off the patients at the Bicetre, and in 1813, Samuel Tuke published his accounts of the Retreat of York. Advocates of 'non restraint' included Edward Charlesworth and Robert Gardiner Hill of the Lincoln Asylum, and John Conolly. Gardiner Hill in his lecture on the 'Total Abolition of Personal Restraint in the Treatment of the Insane' said:

'I wish to complete that which Pinel began. I assert then in plain and distinct terms, that in a properly constructed building, with a sufficient number of suitable attendants, restraint is never necessary, never justifiable, and always injurios, in all cases of Lunacy whatever. I assert the possibility of the total banishment of instruments of restraint, and all other cruelties whatsoever.' (Hunter & Macalpine, 1963, p 890)

The principles spread widely, but this era of reform did not last. The 1845 Lunatics Act was concerned with the welfare of the mentally ill and it became mandatory for counties to erect asylums. These large asylums were built but rapidly became overcrowded. Smith says

'Their great size depressed morale and the doctors protested, but still the patients came. The average size of public asylums rose from 116 patients in 1827 to 1221 in 1930. (Many mental hospitals have had over 2000 patients, and the largest ever had 14,200)' (Smith, 1982, p 86)

Smith gives a description of what conditions were like in these large asylums in the mid nineteenth century and gives such examples as few patients being taken for walks and that patients bathed together in the same bathwater. Before the end of the century, the 'moral' treatment had changed to 'custodial'.

J.K. Wing in Community Care for the Mentally Disabled says,

'Why this promise not only did not fulfil itself but was actually reversed towards the end of the nineteenth century is still not completely clear, though a change in public attitudes which resulted in the restrictive Lunacy Acts of 1890 and 1891 has been blamed' (Wing, 1979, p 1)

These acts 'contained a mass of provisions for documentation of admissions, and for certification by magistrates, designed to close all loopholes through which a sane man could be wrongly detained.' (Smith, 1982, p 89)

This custodial era continued until the 1930 Mental Treatment Act introduced informal admissions and out-patient facilities at general hospitals. This was a change of direction for mental health services. Doors were opened; therapeutic communities were developed; programmes of rehabilitation were set up and 'community care' began, e.g. day centres and half-way houses were set up. The 1959 Mental Health Act emphasised the hospital's role as that of a treatment centre and not of custodial care.

Pharmaceutical Developments

Advances in the care of the mentally ill were, of course, accelerated by the pharmaceutical developments.

The government publication, Better Services for the Mentally Ill (October 1975) describes that, from the time of the building of the large mental hospitals 'right up to the year 1954, the number of resident patients in mental illness hospitals went on steadily increasing save for a small temporary reduction during each of the two World Wars.' (p 11). In the 1950's, the drug group known as the phenothiazines were developed (particularly Chlorpromazine). These drugs were a major breakthrough in the treatment of the psychotic patient and 'as a result not only was the need for locked doors greatly reduced, but it was also possible for doctors and nurses to develop contact with patients who had hitherto been almost entirely cut off from the real world around them by their psychotic illness.' (p 11)

There became a need for scientific investigation into this area of chemotherapy, in order to evaluate the use of phenothiazines in the treatment of schizophrenia. J.P. Leff and J.K. Wing conducted a double-blind, placebo-controlled trial in order to determine the value of maintenance therapy with phenothiazines in a sample of 35 outpatients who had recently recovered from an acute episode of schizophrenia (Leff & Wing, 1971). The data was collected between April 1968 and December 1969 from three London hospitals (Bethlem Royal, Maudsley and Cane Hill Hospital). Patients were allocated at random to an experimental or a control group receiving varying dosages of trifluoperazine or chlorpromazine or an appropriate placebo.

Out of the trial patients, 15 were on placebo and 20 on an active drug; and of the latter group 13 received trifluoperazine and 5 received chlorpromazine (two patients dropped out early in the trial). 7 patients on an active drug (35%) and 12 patients (80%) on placebo relapsed during the period of observation (One Year). The authors conclude that

'The drug was shown to be significantly more effective than the placebo in preventing relapse. The relationship of the trial patients to the population from which they were selected was defined in terms of clinical, historical and social data. Maintenance therapy seems of little value in patients with a good prognosis and in the severely ill, but it is of value in the indeterminate group between the two extremes.' (p 599)

However, although the phenothiazine group of drugs were a breakthrough in the treatment of schizophrenia, the next problem was the patient's failure to continue taking his medication.

Willcox, Gillan and Hare (1965) found that of patients attending hospital out-patients departments, 48% do not take their drugs regularly. Patients with schizophrenia are often particularly unreliable because of a lack of insight, odd or delusional ideas and social handicaps. Thus, the introduction of the long-acting phenothiazine injectable drugs was another great step forward in the treatment of long-term illnesses in particular.

Robert Crawford and Alistair Forrest conducted a double-blind trial in order to test whether there would be a lower rate of relapse in relapsing schizophrenic patients treated with fluphenazine decancate (a long-acting phenothiazine) than in a control group treated with trifluoperazine as maintenance therapy. (Crawford & Forrest, 1974). Of the 29 patients who completed the trial, no patients were re-admitted from the group on active long-acting injections, whereas 4 of the group receiving oral trifluoperazine were re-admitted. The authors conclude that although this result is not significant on a 5% level, '....there was an evident trend suggesting the injection regime was superior in preventing relapse.' (p 389)

Hirsch, Gaind, Rohde, Stevens and Wing conducted a double-blind trial of fluphenazine decancate to determine its value in maintenance therapy of chronic schizophrenic outpatients (Hirsch et al, 1973). From a sample of 81 patients from two London hospitals (St. Olav's Hospital and St. Francis Hospital), the patients were randomly selected into two groups - one on active drugs and the second on a placebo. The trial was for 9 months and was tested by a single criterion - that the patient had to be taken out of the trial because he/she had deteriorated to such an extent that active medication was necessary.

The authors found that 'The results of the main trial show unequivocally that patients on active medication did better than those on placebo.' (p 635) They found that the fluphenazine treatment produced no extra need for anti-depressant medication, although patients did require more treatment for Parkinsonian side-effects.

Barbara Stevens, a sociologist involved in the research, looked at the social results of the trial in <u>Role of Fluphenazine Decancate in Lessening the Burden of Chronic Schizophrenics in the Community</u> (Stevens, 1973). Semi-structured interviews were conducted with the nearest relative or informant who had daily contact with the patient, for example, warden or employer. Stevens found that there was a significant deterioration in relationships between patients on placebo and their nearest relative or informant as compared with those on active drug.

There was greater anxiety about the patient's behaviour among informants of patients on placebo and the main source of this was found to include an increase in aggression, noisiness, strange ideas and subsequent socially embarrassing behaviour. The author concluded that the negative aspects of schizophrenia for example, social withdrawal and self-neglect, are less adequately controlled by the drug than positive psychotic features, such as aggression and talking about strange ideas. But Stevens added 'However, during the trial the decrease in general sociability outside the home among patients on placebo appeared both socially and statistically significant.' (p 156)

Some years later, M.W.P. Carney and P. Rutherford arrive at similar conclusions in their study of Clopenthixol Decanoate in Schizophrenia (Carney & Rutherford, 1981). They ran an 11 month open study of clopenthixol decanoate (an alternative depot injection) as a preliminary study to a controlled trial. After 4 months of the trial, all 23 patients showed significant improvement in all scores, including apathy and withdrawal. However, after 11 months, 20 patients continued to show significant improvement overall but failed to show this improvement on apathy and withdrawal. They say

'It was noteworthy, however, that over the whole period the effect on "positive" symptoms was substantially greater than that on "negative" symptoms such as apathy and withdrawal. Indeed, these latter symptoms showed no further significant improvement after the first two months of the investigation. The improvement was evidently not due to oral antipsychotic drugs.' (p 210)

The Symptomatology of Schizophrenia

Positive, primary or first-rank symptoms can now be controlled by modern pharmaceutical methods. First-rank symptoms include thought disorder; disorder of the emotions, such as flattening of affect, delusions and hallucinations. In the chronic condition secondary or 'negative' traits occur, for example, apathy, social withdrawal, poverty of speech and thought and general underactivity. As was previously mentioned, several different types of the condition have been identified where the above conditions appear in varying degrees of intensity.

The 'simple' type usually starts in, or just after, adolescence and onset is slow and insidious. Typical symptomatology include shallowness and incongruity of affect; apathy and underactivity and a general deterioration in personality. The 'hebephrenic' type again usually develops at an early age; the characteristics include thought disorder; shallowness and incongruity of affect; delusions and hallucinations. Hypochondriasis is common and so is euphoria. The 'catatonic' type of schizophrenia can involve a complete withdrawal from the outside environment. The patient can become entirely immobile and unable to communicate with others. Inactivity can be preceeded or interrupted by sudden overactivity and excitement. Because of modern pharmaceutical treatment severe types of this condition are extremely rare. 'Paranoid' schizophrenia develops later in life, usually towards middle-age. Major delusions may persist and the sufferer feels persecuted by those around him and by his 'voices'. However, the personality usually remains fairly well preserved.

Adverse secondary reactions accompany the chronic condition. J.K. Wing says,

'Relatives, employers, work-mates, friends, and professional people reflect back to the person handicapped by <u>intrinsic impairments</u> or <u>external disadvantages</u>, or a combination of both, an indication of their opinion of his social status and worth. If they think he is less of a man because of his illness, he will tend to think so too.' (Wing, 1977, p 20)

Wing carries on to say 'The most obvious example of adverse <u>secondary reaction</u> in schizophrenia is <u>institutionalism</u>, at the heart of which is a gradually acquired contentment with life in the institution which culminates in the individual no longer wishing to live any other. Institutionalism is thus caused partly by a reflection back to the handicapped person of his own altered status as a human being.' (p 20)

The Effects of the Institution

Erving Goffman's sociological analysis of the effects of institutional life on the individual focused on the situation from the perspective of the 'inmates' (Goffman, 1961). He introduced the term <u>total institution</u>, and claimed that all such institutions, whether a mental hospital, prison, army barracks, convent or boarding school, share important common characteristics and have a similar effect on their inmates. Goffman said

'A basic social arrangement in modern society is that the individual tends to sleep, play, and work in different places, with different co-participants, under different authorities, and without an over-all rational plan. The central feature of total institutions can be described as a breakdown of the barriers ordinarily separating these three spheres of life.' (p 17)

In total institutions the inmates tend to sleep, work and play in the same place; all activities are carried out in the company of others, who find themselves in the same situation (batch living); these activities fit into a tight schedule, are formally administered, and are aimed at obtaining the goals of the institution.

Goffman's four essays described the reaction of the inmate to their 'imprisonment' and the adjustments that are made by the individual in order to cope with the situation in which he finds himself. An example of this is withdrawal by an inmate in order to cut himself off from any contact with his environment. However, many inmates do become converts and accept the institution's view and behave accordingly.

Goffman described the social structure of the institution and the staff/ inmate relationship. The inmates have a prescribed career: the pre-patient phase, admission procedure and the in-patient phase. By conforming to this career, with as little disturbance as possible, certain privileges are awarded by the staff. Staff and patients are segregated in that the staff are the managers - with the power and therefore in control; whereas the inmates are the managed - with no power and therefore not in control of their own destiny. These two distinct groups tend to have stereotyped images of each other, and the only contact made between them is official. The inmates tend to become the 'raw materials' of the work of the staff.

Goffman's essays have had a great impact in that they have caused much discussion since their publication. Kathleen Jones and A.J. Fowles said 'The analysis focussed and articulated the experience of many people who had lived and worked (whether as patients or as staff) in institutions.' (Jones and Fowles, 1984, p 22). They continued, 'But if the picture is true, it has to be said that it is not the whole truth; and of course, Goffman did not intend it to be. His aim was to set up a model against which reality could be measured, rather than to describe reality itself.' (p22)

In Britain, there was also a deeper awareness of the institutional effects on the individual patient, particularly the ways in which the social environment of the institution affected the course of chronic illness. J.K. Wing and G.W. Brown conducted an investigation to examine whether social events or environment can influence the course of chronic schizophrenia. (Wing & Brown, 1961; Wing & Brown, 1970). They recognised that mental hospitals had been changing rapidly during the decade of the 1950's, and that the process of advance varied considerably between hospitals. The hospitals selected were likely to have made different degrees of progress towards the goals of the 'therapeutic community'.

They looked at three hospitals (in London, Chelmsford and Nottingham) where it was known that different stages of reform had been reached. Their sample (n = 273) were all female patients with a diagnosis of schizophrenia and who had been resident at the hospital for more than two years. The patients' clinical condition and attitudes to discharge were obtained by interview with the patient and ward behaviour and social conditions were obtained by interview with the ward sister and/or nurse. This latter interview included such areas as time budget, personal possessions of the patient, nurses' opinions of the patient and ward restrictiveness.

Marked differences were found in that Hospital A (where the main emphasis of care was of the long-stay patient) showed least clinical disturbance among the patients. Here the authors found the greatest amount of personal freedom of the patient existed. Hospital C (where reform had not yet progressed so far)most clinical disturbance among patients and least personal freedom was evident. Hospital B was found to be intermediate in both respects. It was found that patients who had little contact with the outside world were also likely to have few personal possessions; to have little constructive occupation; to spend much time doing nothing; and to be regarded pessimistically by ward nurses. It also appeared that social withdrawal, flatness of affect and poverty of speech were clearly related and that patients in the most under-stimulating environment were most likely to show the greatest clinical poverty. This became more severe the longer the patient remained in hospital. Also, unfavourable attitudes to discharge were associated with both environmental and clinical poverty; again, this was more unfavourable with the length of stay. This process was named '<u>institutionalism</u>'.

The Effects of the Environment

The concept of 'community care' as we know it today was accelerated as the frontiers of knowledge were extended by research. There was a growing awareness of the effects of the patient's social environment on the course of mental illness. This awareness also involves the consideration that mental illness not only effects the patient, but also others in his/her environment.

J.K. Wing and Rolph Olsen said

'His or her family, neighbours, employers, workmates and other professional helpers, as well as society at large, are involved. On the one hand, there are the specifics of impairment; the delusions and hallucinations, the slowness and underactivity, the inability to understand social rules, the poor memory. On the other hand, social factors can exacerbate or ameliorate impairment, contribute to adverse personal reactions or to a positive use of talents, and affect the coping ability not only of the disabled individual but of all the other people involved with him or her.' (Wing & Olsen, 1979, p 172).

Brown, Bone, Dalison and Wing conducted a research project in order

'to describe the social and clinical course of schizophrenia under the new conditions of early discharge, to compare the outcome in three areas where the problems of community care have been dealt with in rather different ways, and to examine systematically some of the consequences for the family.' (Brown et al, 1966, p 202)

It was an attempt to describe the social environment of discharged schizophrenic patients in order to gain a deeper understanding of what it was like to live with a disabling, sometimes chronic illness - both for the patients and their families.

They conducted a five year follow-up of schizophrenic patients who had been admitted to one of three hospitals in 1956 (Netherne Hospital, Severalls Hospital and Mapperley Hospital). The number of patients they looked at was 339. Their information was obtained from hospital and local authority records, from local employment exchanges and interviews with patients and relatives. They looked at such areas as domestic living group, the process of admission to hospital (length of stay in hospital, likelihood of readmission - clinical and social events which preceeded admission or readmission); employment (including decline in occupational status and a time budget), and clinical and social problems in the community (including occurrence of symptoms, assessment of social disturbance, distress caused by patients in the community, problems reported by relatives and attitudes of relatives). They found that only 24 of the total patients remained in hospital throughout the whole of the 5 year follow-up period, and that the median stay of readmission was only 10 weeks.

On employment, they found that half the male patients were employed at time of follow-up and that there was considerable stability of employment status during the five years. Here, it must be noted that probably the situation of the 1980's will differ from this period of study (more recent studies will be mentioned later). It was found that just over two-thirds of first admitted and a half previously admitted women were performing their domestic duties competently or were employed. However, the authors felt that the degree of disability among housewives was underestimated. They found that the occupational level of patients declined, both compared with their fathers' and with the patient's own peak level of employment.

When looking at the time budgets, the authors found that the unemployed patients spent an average of ten hours in their homes and a considerable amount of this time was spent doing nothing or watching television. Most of these patients were unmarried, relatively young men and women who had been unemployed for most of the previous five years. The authors also found that just over a half of the patients spent every evening of the week at home, and that there was little difference between the employed, housewife or unemployed.

'The employed patients who did go out tended to do so more frequently than the others. They also tended to have a wider range of leisure pursuits, such as going to clubs, dances, theatres, sports and meeting friends, than the unemployed, who mostly spent their time at the cinema or in a pub.' (p 90)

Of the unemployed, the authors say, 'While we cannot make value judgements about their way of life, we can say that it is unlikely to be one suited to stimulating an interest in life outside the home and helping them to overcome their handicaps, and that unless stringent attempts are made to take them out of their homes, retrain them and find them work they will probably remain unemployed and possibly deteriorate. The situation may, in fact, be little different from that of severely handicapped long-stay schizophrenic patients for whom inactivity is recognised to be a harmful thing.' (p 91)

The problems reported by the relatives included ill health of the relative, adverse effects on the children, financial difficulties, restrictions on leisure activities and inability to entertain guests. On looking at the attitudes of relatives, it was found that nearly three-quarters of the relatives welcomed the patient at home; fifteen per cent were accepting and tolerant, but not welcoming; and twelve per cent said they wished he was in hospital or elsewhere. Attitudes, it was found, were highly related to the degree of disturbance at the time. It was found that parents who looked after patients were often advancing in years (40% were over seventy years of age).

'Most severely disturbed patients (28% of those at home) were causing severe distress but the tolerance of parents was very striking. Parents often made little complaint even when they felt great distress and a number developed skilled methods of managing disturbed behaviour.' (p 134)

Life Events

The effects of the patient's social environment on the course of schizophrenia was explored in order to gain a deeper understanding of this very crippling illness. J.L.T. Birley and G.W. Brown looked at the occurrence of life events of patients in order to examine the area of life changes and crises that frequently precipitate the acute onset, the relapse or exacerbation of schizophrenic states. (Brown & Birley, 1968; Birley & Brown, 1970). Fifty patients suffering from schizophrenia and who were admitted to hospitals in a South East London catchment area were interviewed about occurrences of previously defined and datable events that had occurred to the patient or close relative of the patient. At least one other informant was also interviewed. Events were classified as independent or possibly independent. 'Independent' events were those considered to be outside the patient's control - such as discovering a burglary or hearing of a brother's serious illness. 'Possibly independent' events were considered to be within the patient's control, yet not brought about by any unusual behaviour by the patient, such as a change of job or opposite sex friends. The authors comment that sometimes a loss of job would be rated as 'independent', for example, if a firm closed down.

It was found that there was a real increase in life events both 'independent' and 'possibly independent' in the three weeks prior to admission to hospital. It was also found that 13 patients had reduced, or stopped, taking phenothiazines. The proportion of these patients (31%) who had experienced life events in the three weeks preceding admission was significantly lower than for the remainder of the sample (72%). However, the researchers found that all the patients who relapsed while taking phenothiazines had experienced a disturbing event. The researchers conclude that both life events and reducing, or stopping, phenothiazines contribute towards precipitating a schizophrenic relapse.

Expressed Emotion

Brown and Birley collaborated with J.K. Wing in their study of 'expressed emotion' (EE), (Brown, Birley & Wing, 1972). They were interested in the amount of emotion expressed by the relatives of patients. EE has a mainly negative connotation. The most harmful aspect of high EE was found to be criticism, hostility and over-involvement. 'The hypothesis under test is that a high degree of expressed emotion is an index of characteristics in the relatives which are likely to cause a florid relapse of symptoms, independent of other factors such as length of history, type of symptomatology or severity of previous behaviour disturbance' (p 242)

They looked at 101 schizophrenic patients who were living at an address in Camberwell and who were beginning a new period of out-patient or in-patient care in any one of the five hospitals serving the area. All the patients selected were living with relatives. The researchers conducted a series of interviews with both the patient and his/her family and looked at the current mental state of the patient and the family environment.

They found a strong association with symptomatic relapse during the nine months following discharge and high degree of emotion expressed by the relatives at the time of the key admission. Expressed emotion is independently associated with relapse, while previous work impairment and behavioural disturbance are only associated with relapse because of their association with the level of expressed emotion. They found that regular phenothiazine medication showed a close to significant relationship with a favourable outcome. An important factor was the amount of face-to-face contact - that 35 hours a week was the critical period. Above this amount of time would greatly increase the chances of relapse. The authors felt that social withdrawal could be a protective factor, particularly for unmarried patients.

C.E. Vaughn and J.P. Leff extended Brown et al's idea further (Vaughn & Leff, 1976). They again used hospitals in South East London (Bethlem, Maudsley and St. Francis). They replicated Brown and Wing's work on 'expressed emotion' and extended this by comparing the schizophrenic group with a depressed group in order to see whether the EE effect on relapse was specific to schizophrenia. As with the previous study, they conducted a nine month follow up of the patient following his/her discharge, and the authors collected their information between October 1971 and January 1975. Their findings compared with the former study, that is, that the amount of expressed emotion expressed by a key relative about the patient at the time of the key admission proved to be the best single factor of prediction of a symptomatic relapse in the nine months after discharge. But this was not the only indicator as more than half the patients from high EE homes remained well. The authors felt that it was the patients living in high EE homes, who spent much time with their relatives and were not protected by maintenance therapy, who had a very poor outcome.

That is, protective factors for patients in high EE homes are firstly reduced face-to-face contact with relatives, and secondly, maintenance therapy. The authors' results show that patterns of relapse in the two clinical groups are different. Therefore, there appears to be something specific in the ways in which schizophrenics respond to their environment. The authors give the example of the following situation.

A common reaction among schizophrenic patients confronted by a high EE relative, is lowered face-to-face contact by withdrawal or avoidance. This is a protective manoeuvre. The reaction of the depressed patients cannot be interpreted in this way. 'There is more likely to be a generally poor relationship between the patient and the relative which predates the illness and is characterised by low face-to-face contact and poor communication.' (Vaughn & Leff, 1976, p 135)

Julian Leff took the research a step further by conducting an experimental study of a controlled trial of social intervention (Leff et al, 1982). This nine-month trial was conducted 'specifically to test a possible causal relationship between relatives' EE and relapse of schizophrenia.' (Leff and Vaughn, 1985, p 125-126). Patients from high EE homes, and who were receiving maintenance neuroleptics, were selected and randomly assigned to the control or experimental group. Social intervention consisted of an educational programme, family sessions and a relatives' support group. Intervention was introduced to the families in the experimental group; the aim of which was to reduce EE and/or face-to-face contact and therefore add to the beneficial effect of maintenance neuroleptics.

The results of the trial showed that the relapse rate in the control group was 50%, and in families of the experimental group, where the aims of the researchers had been achieved (in 75% families), the relapse rate was nil. These figures met with the theoretical expectations of the investigators.

A two-year follow-up was conducted in order to assess any long-term advantages of social intervention (Leff et al, 1985). Data was collected from patients who had not relapsed in the first nine months of the trial. Five patients were excluded from the two-year follow-up as they had discontinued medication (control group, n = 3; experimental group, n = 2), leaving nineteen subjects (control group, n = 9, experimental group n = 10). The contact the experimental families had kept with professionals during the two-year period was recorded. Of the nine control patients on medication, seven had relapsed; whereas the number of relapses reduced to two in the experimental patients. However, the researchers point out that of these two relapses in the latter group, one had successfully commited suicide and one had suffered severe brain-damage from an attempted suicide and had subsequently died. The researchers commented 'whether or not the suicides in the experimental group were the consequence of a return of schizophrenic symptoms, they undoubtedly represent failures of management.' (p 597)

Leff and his colleagues conclude that

> 'the two year results complement the findings of the nine-month follow-up, since the group with the best outcome consisted of those experimental patients remaining on medication in whose families a reduction had occurred in EE and/or face-to-face contact from high to low at the nine-month assessment.' (p 599)

The Development of Community Care

A growth in the knowledge and awareness of the needs of the schizophrenic patient, of the problems encountered by the relatives and of the effects the social environment has on the course of the illness was necessary if the care of these patients was to be extended outside of the institution into the community. This growth, together with the development of pharmaceutical treatments and changing attitudes to the concepts of care, heralded the new era of 'community care'. J.K. Wing claimed that 'Virtually all the ideas now current in "community care" were introduced in the 1950's by pioneering psychiatrists.' (Wing, 1979, p 2). It was envisaged that a network of services would replace the large, old, Victorian institutions. 'The underlying movement was becoming clearly discernible, namely of bringing into closer relationship services for the mentally ill whether in hospital or outside it, with services for other forms of illness and handicap.' (DHSS, 1975, p 12)

Community Care can be provided in an 'informal' way - by family, friends, neighbours; 'quasi-formal' - by voluntary organisations; or 'formally' by statutory social services. (Walker, 1982). Walker says 'the distinction is between care provided through primary relationships and care provided through formal, secondary relationships.' (p 5). Community care is distinguished from institutional care and treatment, as it is help and support provided in non-institutional settings. Walker goes on to say that a great deal of care is self-care and

> 'it has an important bearing on the extent to which formal and informal carers can increase or decrease dependency. Professional and lay carers' assumptions about capacity for self-care are constrained by factors such as professional values, work routines, efficiency, norms concerning factors such as cleanliness and the desire to fulfil a nursing or caring role.' (p 6)

The 1959 Mental Health Act endeavoured to shift the emphasis from care in the institution to care in the community. Walker describes the principles of community care at that time as

'ensuring that individuals remain integrated with their own families, friends and neighbours; a social pattern of care in non-institutional settings; the provision of support in the home from a wide range of services and preventive measures to ensure that family breakdown and admission to a residential institution does not occur.' (p 16)

However, principles were not backed up with a programme of resource allocation and the development of services and Walker adds that 'Subsequent official statements have not only failed to redress these deficiencies, but have also begun to undermine even this limited goal.' (p 16). Barbara Castle, the former Secretary of State for Social Services, said in her foreword to the White Paper Better Services for the Mentally Ill (1975): 'Specialist care is still mainly based in large, geographically isolated mental hospitals, nearly all dating from the last century and designed for custodial care.' (p ii) She recognised that, even if the economic climate was favourable, the change-over of care would take a long time. In the present climate, there is 'Little or no scope for substantial additional expenditure on health and personal social services, at least for the next few years.' (p iii), and therefore 'Without increased community resources the numbers in mental hospitals cannot be expected to fall at the rate they might otherwise have done' (p iii)

Community care as conceived in the White Paper included the development of some residential institutions and hospitals 'rather than remaining as an alternative to institutional forms of care' (Walker, p 16). The White Paper says

'Nevertheless, there will remain some people who, although their more acute symptoms can be relieved, will need more or less permanent medical, social and nursing support in a sheltered environment. While this group may be relatively few in number their needs must be recognised, especially as the implications in terms of resources are quite disproportionate to their numbers' (p 6)

It recognises the needs of the mentally ill to include prevention, early recognition of the condition, assessment of needs, clinical treatment, social rehabilitation, help for family, accommodation, employment and flexibility and co-operation between the developing services. But it states that

'Multi-professional teamwork, adequate assessment, consultation and arrangements for after-care, and social work support are as yet sadly all too often theoretical ideas which bear scant relation to the practical realities' (p 83)

Walker criticises government policies by claiming that they are ambiguous and that 'community care' '.....is taken to mean different things at different times and in relation to different groups in need' (p 19). He sees that the main goal of government policies is co-ordination between services 'rather than the committed and imaginative expansion of domiciliary services and the closure of institutions' (p 17). The government sees it's difficulties mainly as financial constraints and the time taken for public attitudes to change and demonstrate a 'willingness to continue changing to accept an increased responsibility for those of its members who are or have been mentally ill' (DHSS 1975, p 85). The paper recognises the many shortcomings in the development of services for the mentally ill.

'The Government is, moreover, aware that both staff and patients and their families have felt that central authorities had not only failed to appreciate the pressures under which the services are operating but were actively encouraging a precipitate rundown of the mental hospitals as a matter of policy; and that closures would be implemented ruthlessly leaving little or nothing in their place. We welcome this opportunity to stress that our aim is not the closure or rundown of the mental illness hospitals as such; but rather to replace them with a local and better range of facilities' (p 84)

The National Schizophrenia Fellowship

Desperation about lack of community facilities was the motivation behind John Pringle's article in The Times, May 9th, 1970. (Pringle 1980). Pringle described some of the problems his family had to face when his son became ill with schizophrenia in his second year at Oxbridge. A family in this situation has to firstly, learn how best to cope with problems of behaviour; and secondly needs to be able to obtain help and advice. Pringle felt that this guidance was not available and that the problem was 'how to penetrate the obfuscating fog of hospital vagueness and evasiveness......' (p 11). He also claimed that there existed a serious lack of facilities for the rehabilitation and retraining of chronic schizophrenics, together with a lack of halfway housing or suitable sheltered accommodation. 'No social provision exists for them, so their future is bleak. As parents die off and other relatives find it impossible to cope, the inevitable trend is for them to drift downwards to the welfare state's bottomest sump.' (p 14)

Pringle continued 'What is wanted are small residential settlements where their simple basic needs, including protection from impossible stress, can be provided in a mutually supportive environment.' (p 14). He concluded that the administrative set-up is far too complex for many patients and that the ideal would be 'for some one authority to be given a co-ordinating role and designated as that to which schizophrenics can turn in all matters affecting them.' (p 15)

The response by other relatives of schizophrenics led the way to the formation of 'Schizophrenia Action Committee', and this later grew to become the 'National Schizophrenia Fellowship' (NSF). The Fellowship acts firstly as a supportive group to relatives and friends, by information, advice and the formation of local groups; secondly, acting as a pressure group in order to improve community care; and thirdly to promote and support research 'into the causes, treatment, care and management of schizophrenia' (NSF information leaflet, p 4)

Research and Publications by the Fellowship

The Fellowship has sponsored and supported several publications and research projects. One such project, Schizophrenia at Home, conducted by Clare Creer and John Wing, deals with the problems of relatives of people with schizophrenia (Creer and Wing, 1974). The authors selected a sample of n = 50 from the NSF, covering London, Midlands and North; and a sample of n = 30 from Camberwell (total sample n = 80). This latter group were included 'to increase the range of problems represented and this was certainly achieved' (p 4). The sample was not randomly selected, nor was it representative of the country as a whole. Therefore, the findings contain a bias. Nevertheless, the results provoke some valuable discussion.

The report describes the patients' behaviour as seen by the relatives; the social performance of the patients; the personal problems described by the relatives; and the services that they felt would be helpful. This latter section describes relatives' satisfaction with the services as well as the different areas of need. Of the NSF sample, only 5 members were satisfied with services, whereas 25 were moderately dissatisfied and 20 very dissatisfied. By comparison, 15 (50%) of the Camberwell group were satisfied with services; 10 were moderately dissatisfied and only 5 were very dissatisfied. However, the authors did note that there were differences between the samples, i.e. that the NSF members were self-selected to join the Fellowship (the Camberwell sample were non-selected); nearly all the NSF sample had non-manual occupations, compared with a third of the Camberwell sample; the NSF sample were likely to own or privately rent accommodation, whereas the Camberwell relatives were less likely to do so; the NSF patients were more likely to be young men with socially embarrassing behaviour and poor social performance (this was less likely in the Camberwell sample). The authors felt that the Camberwell sample probably understated their difficulties, and that relatives tended to put up with a great deal if they felt emotionally rewarded. Previously, Brown et al, Schizophrenia and Social Care (1966), had found that parents often made little complaint, even when there was evidence of great distress.

Creer and Wing found that two-thirds of relatives were tolerant or accepting towards the patient; one-third were very dissatisfied with services. Many aspects of the services presented problems and difficulties for relatives. These included the need for initial information, hospital care, medication, hospital after-care, the need for genetic counselling and advice on family planning, the role of social workers, practical help, hostel provision, financial problems and the need for occupation. The results of the survey showed that the most common problem with behaviour was withdrawal from social contacts together with associated characteristics, such as lack of conversation, slowness, underactivity and a lack of leisure interests. Oddities of behaviour and speech appeared to be most difficult to deal with; violence was rare (in fact most patients were timid); depression was common. A substantial part of relatives' concern was centred on domestic and social performance. Two-thirds of patients not living with marital partners contributed little in the way of financial or help in the household, companionship and support. Married partners were considerably more competent, but emotional relationships between husband and wife were often unsatisfactory.

The experiences of relatives were also documented in the NSF publication Living With Schizophrenia - By The Relatives (NSF, 1974a). The series of descriptions are of what it is like to live with schizophrenia. From this publication, and the research conducted by Clare Creer and John Wing described above (carried out between March and December 1973), the NSF submitted Recommendations to the Secretary of State, the Rt. Hon. Barbara Castle, M.P. in June 1974 (Social Provision for Sufferers from Chronic Schizophrenia). It claimed that the relatives of schizophrenic patients living in the community are the 'primary care' agents and that this should be recognised, and various improvements in services were recommended: these included appropriate matching of support services to degree of handicap; counselling services for patients and relatives; improvement in the training of professional staff, the appointment of 'key workers' in Social Services Departments and a Special Welfare Officer in the Supplementary Benefits Commission; improvements in accomodation and arrangements for claiming benefits and employment.

The NSF Memorandum to the Royal Commission on the NHS (January 1977) commented on the current government policies described in Better Services for the Mentally Ill and Priorities for Health and Personal Social Services in England (DHSS, 1975; DHSS, 1976). These policies included the development of community services, improved organisational links and the raising of standards in existing mental hospitals. The memorandum criticises the government in 'that chronic schizophrenic patients are often discharged or not readmitted by NHS mental illness hospitals, on the ground that they are not considered likely to benefit from further treatment' (p 4). It continues '.....the chronic schizophrenic and his family (if any) are often abandoned by the NHS hospital which sees its role as an active therapeutic one and is increasingly unwilling to act as a social care custodian' (p 4). The Memorandum urged that present buildings should be upgraded and that development of, and rehousing in smaller dwellings for the long-stay population must be a priority.

A further NSF publication, Tied Together with String, describes a two year project carried out in Surrey (Priestley, 1979). The author was appointed as advisor and coordinator of the services for schizophrenic patients in the county of Surrey in August, 1976. The project emerged from evidence presented in NSF literature and the report, Schizophrenia at Home (Creer and Wing, 1974).

Priestley approached the situation by looking at the Health Service provision for the mentally ill in Surrey; opportunities for employment for those with a schizophrenic condition; and finally, the voluntary sector. Priestley concluded that community support was 'aggravated by difference in structure, tradition and ethos between health and social service workers' and that 'the only rational solution was for the Health Service to be administered by local government' (p 45). Differences also existed in theories of, and, therefore approaches to schizophrenia. 'At multi-disciplinary team level discussions about different and complementary roles take place but any coordination or consensus will depend on the attitudes and skill of the consultant psychiatrist......' (p 46). On joint funding, Priestley states that the availability 'has had very little impact on mental health services as yet'.

The 'New' Long-Stay Patients

Previously, Sheila Mann and Wendy Cree acknowledged that the policy of the DHSS was 'that people with mental illnesses should stay in hospital only for medical or nursing reasons (usually in the acute phase of their illness) and should otherwise be cared for elsewhere in the community.' (Mann and Cree, 1976, p 603)

However, at the end of 1971, 'nearly 23,000 people had accumulated in mental hospitals as a 'new' long-stay group; that is, they had been continuously resident from one to five years.' (p 603). Mann and Cree decided to examine the 'new' long-stay group in an attempt to discover the reasons why they were accumulating in hospital and whether there were more effective and acceptable ways of dealing with them. They took a random sample from each hospital of 25-30 patients per hospital (Total n = 400) who had been continuously in a mental hospital for more than one year, but less than three years. The researchers made a two week visit to each hospital and obtained information from clinical records, interviews with patients and interviews and questionnaires from medical, nursing and social work staff (Hospital and Local Authority). Assessments were made of the need for residential and day care from the data collected.

Schizophrenia was the largest diagnostic category (44% of patients). 75.6% of these had moderate or no symptoms and 24.3% had marked behavioural symptoms. 30% patients said they wanted to leave hospital, 30% said they wanted to stay. Attitudes to discharge were not, on the whole, enthusiastic. The staff (medical, nursing and social work) felt that one-third of the patients needed further in-patient care and another one-third needed other forms of supervised residential accommodation. The research team allocated each individual to the most appropriate type of accommodation, based on the information collected. Overall, similar proportions were allocated to further hospital care (one-third) and to supervised accommodation (one-third). Mann and Cree said

'Among these individuals there appears to be a group whose symptoms are not alleviated by present treatments, and who will require in-patient care at least for some years. For these patients, the hospital would be home as well as a place of treatment and shelter, and it is doubtful whether a busy ward in a district general hospital would be appropriate' (p 613). They go on to say 'If large psychiatric hospitals are to be closed, all their present diverse functions will still need to be provided for; the buck will need to stop somewhere. At the moment, large psychiatric hospitals provide a flexibility which no other service seems able to match' (p 614)

Ward Support for Chronic Psychiatric Patients

This flexible environment that the psychiatric hospital provides was the reasoning behind the development of a ward support system for chronic psychiatric patients in the community (Mitchell & Birley, 1983). The paper gives an account of ward support, it's patients, and the use they make of the facility. Psychiatric and social factors were looked at. The sample of patients were those who attended the ward on five or more occasions between May and October, 1978. Sample n = 56 (Female 34, Male 22). The patients were interviewed using a pre-tested schedule covering time budget and social autonomy; attitudes towards the ward, staff and patients; and their social network. Their current mental state was assessed. Senior nursing staff were interviewed about each patient.

It was found that 15 patients attended for medication only and did not attend the ward for any other purpose. 41 patients comprised the ward support group: slightly more than a half of these were schizophrenic. The majority of patients were unemployed and many of the housewives were functioning inefficiently. Of the 41 accounts of the daily routine only 27 were considered reliable, and of these, 11 men spent the same average amount of time per day doing nothing (about 3 hours). The females (n = 16) were busier, but 50% complained of being bored for most of the time. The majority of men had never married and lived alone, whereas the majority of women were married and were still living with their spouse or co-habitee. 41% of the males and 63% of the females were satisfied with their social contacts. It was found that patients attended the ward for professional help; material support; for example, meals; social support, for example, the social club; and acceptance.

The researchers identified two categories of ward support. The <u>socially unengaged group</u> were those patients who said they attended the ward for company, yet rarely interacted with others. Secondly, the <u>socially engaged group</u> were those patients who attended for social reasons, and who mixed freely with the staff and other patients. It was felt that the men, as a group, were more handicapped than the women. The patients led frequently monotonous lives

'and over half of the group complained of boredom. Forty per cent of the men still hankered for a more institutionalized existence, saying they would prefer to be in hospital. In contrast, only one woman voiced this opinion. Some patients, both men and women, led very institutionalized lives within the community, moving from hostel to day centre by day, and hostel to the ward at the weekend.' (p 14)

Quality of Life

Since the introduction of early discharge from hospital into the community, there has been a growing concern about the quality of life psychiatric patients, particularly those handicapped by chronic illness, lead outside hospital. Several research projects have been conducted in order to examine the social situation of patients and to identify the areas of need that are not being met by the statutory services.

Peter McCowen and John Wilder conducted a research project in the East End of London in order to gain a deeper understanding of the lifestyles of psychiatric patients (McCowen and Wilder, 1975). The sample, n = 100, were half of all the patients admitted from January to April 1974 to three hospital wards. It was found that more than half the men were schizophrenic. The patients were contacted and interviewed in the wards. The researchers found that half the sample expected to sleep, sit, or do nothing during the day when they leave hospital and follow-up visits showed that this was indeed happening.

'Many of these people had chronic illness extending over many years. Their illness had become part of their lifestyle and they did not see the need for, or did they want, help. In many respects they are the hardest group to get back to activity which they would regard as purposeful. The earlier the detection and prevention of falling into this lifestyle the better.' (p 46)

Over 80% of patients expressed isolation and loneliness and nearly half had no-one to turn to when they need help or advice. The authors identified separate need groups including patients with children under eighteen (in particular, one-parent families), single people living with relatives, and those being discharged for the first time.

In Salford, a project was conducted in order to examine the clinical and social situation of schizophrenic patients living in the community. (Korer 1977; Cheadle, Freeman & Korer, 1978; Korer, Freeman and Cheadle, 1978) The researchers assessed both the clinical and social status of the patients and these were described separately. The aim of the research was to investigate the possibility of operating a 'continuous-care' register for this type of patient.

'The purpose of this register would be to monitor all prescribed therapeutic contacts and to alert the relevant services if a patient failed to maintain any of them. It was hoped that this procedure would provide an early-warning system of potential relapse and thus a means of crisis intervention.'
(Korer et al, 1978, p 45)

This monitoring system was carried out for a trial period of twelve months (Freeman et al, 1979b)and will be described later.

The sample was obtained from the Salford case-register and consisted of 190 patients, all diagnosed as schizophrenic and living in the community. The patients had all been in contact with psychiatric services during 1974. The interviews took place between February and July, 1976. It was found that there were significantly more men (69%) than women (32%) who had never married. Of the married women, one quarter were divorced (as compared with 2% of the Salford population). There were more men (42%) than women (19%) living with their parents, and more women (40%) than men (17%) living with their family of marriage. The patient's clinical condition was assessed using the Present State Examination (P.S.E.), 'which elicits the presence or absence of 140 symptoms, which can then be grouped into syndromes by using the test manual.' (Cheadle et al, 1978, p 223). The researchers divided the 35 syndromes into four groups: 'Schizophrenic and Paranoid (S & P); Manic and Other Psychoses (M & O); a borderline group of psychotic syndromes that were difficult to classify (P) and a group of neurotic syndromes (N).' (p 223). 28 patients were free of symptoms at the time of interview, and 50 patients were confined to the neurotic group. The most serious problems were encountered by this latter group: they suffered particularly from self-consciousness and a lack of self-esteem.

The groups were not mutually exclusive and most of the patients showed mixed pictures. Who the patient lived with did not appear to be associated with the clinical condition; the social characteristic having the strongest association with the clinical condition was whether the patient was working or not. Of those who said they were socially isolated, significantly more were in the neurotic group, and the researchers felt that many who did not complain of isolation did appear to be subjected to it. Almost three-quarters of the sample were on treatment - most of these received depot phenothiazines.

The social situation <u>as perceived by the patient</u>, was examined and described by Jacky Korer (Korer et al, 1978; Korer, 1977). The latter publication describes the phenomonological analysis of the patients' subjective views. Korer conducted interviews with the patients based on the ideas of McCowen and Wilder plus the MRC Social Performance Scale. On employment, it was found that 142 people (three quarters of the Total sample) were unemployed and 49 of these (35%) were actively looking for employment. Reactions to the organisation of domestic work ranged from comfortable and satisfying to depression and despair.

It was found that most patients had some family and over three quarters of the sample were satisfied with family relationships. The main problems were an inability to communicate feelings, which led to frustration and loneliness. 82 (43%) of patients said they would turn to a relative if they needed help or advice.

McCowen and Wilder, in their research, had found much isolation and loneliness. In this project, also, loneliness, isolation and self-consciousness was apparent. A quarter of the patients said they had an inability to make friends and form meaningful relationships. Almost one third of the sample said they did not go out as much as they would like to for various reasons, for example, lack of money, lack of inclination. 6 people had nothing to do all day and 58 people had nothing to do for most of the time. Boredom and loneliness led to apathy and resignation. When patients were asked what they felt was missing from their lives, 70 said that nothing was missing. Of the remainder, the largest group said they would like to marry and have a family (20 patients). The other replies included having friends and a social life, a job, children, and money.

The researchers said '........if the progress established by modern treatment regimes is to continue, it must not stop at the suppression of psychotic symptoms, but must seek to create a dynamic and therapeutic environment for those patients who are not yet able to bridge the gulf between social isolation and social integration.' (Korer et al, 1978, p 63)

Korer et al endorsed the recommendations made by Creer and Wing (1974) to provide a range of protected environments. They concluded that

'Once the major symptoms of psychosis have been controlled, the primary aim of community care should be to help the patient play an active part in shaping his future life, master the more elusive social skills, and achieve an even more therapeutic goal - self-respect.' (p 64)

Development of a 'Continuous-Care' Register - Salford

The data from this research formed a base-line in further research to assess a monitoring system, that is, a 'continuous-care' register, for schizophrenic patients in the community. The main purpose of the monitoring system was to maintain unbroken treatment regimes. The method used for the monitoring system was described by the researchers in their first paper (Freeman et al, 1979 a).

The original sample of 190 patients was divided into two groups of 95 patients each. These two groups formed an experimental and a control group. Treatment regimes of all patients were recorded, although the experimental group were the subjects of the monitoring system. This involved recording all appointments with relevant treatment agencies, together with follow-up appointments or treatments, for example, injections of depot neuroleptics. The authors concluded that the system could be extended to cover the whole of the Health District and that

> 'it could focus on the schizophrenic patients selected as being vulnerable to relapse, and it is probably in relation to those that the greatest benefits would be derived from the process of continuous monitoring. Vulnerability might be indicated by factors such as lack of stable family support, major personality handicap or known reluctance to persist with medication in spite of relapses.' (p 416)

The trial was conducted for a year, after which the whole of the sample, where possible, were re-interviewed using the Present State Examination (P.S.E.) The data was analysed into the four syndrome groups previously described. An assessment could therefore be made 'as to whether each member of the sample had improved, remained the same or deteriorated during the relevant period.' (Freeman et al, 1979b, p 417). However, for various reasons (for example, the subjects had moved house or refused an interview), a reduced total of only 102 interviews were conducted (from the original sample of 190 patients). No comparison was made between the groups in this paper. The use made of hospital services was assessed by a scoring system, which was then categorised into Heavy, Medium and Light (use made of hospital services). This scoring was derived from numbers of attendances as day-patients and out-patients, the amount of in-patient care and injections of depot neuroleptics.

Only 8 subjects were found to be Heavy users; 14 subjects were Medium service users; 63 patients, the largest number of patients, were light users of services; and 17 patients obtained treatment only from their G.P's or had no treatment at all. The researchers said

> 'The main finding is one of no clinical change over the year of study in the sample as a whole, and this must emphasize the chronic nature of the condition involved, as well as the fact that most of the patients were on maintenance neuroleptics, which were fairly successful in preventing further acute relapses.' (p 421)

The authors concluded that, on the whole, the sample made relatively small demands on the psychiatric services, and that the previous research had indicated that patients, in general, were free of active psychotic features. They acknowledged that this particular study gave no indications as to how potential drop-outs from treatment could be identified, and noted that the drop-out rate had proved to be minimal during the one year period of investigation. Freeman and his colleagues suggested

'that the control of overt schizophrenic illness is a relatively economical exercise with current therapeutic methods, provided that an integrated system of mental health facilities exists - as it does in the area where this study was carried out. However, the chronic handicaps are another matter.' (p 421)

The Southampton Project

In Southampton, a further study was conducted in order to examine the schizophrenic patient and his social environment outside hospital (Gibbons et al, 1984). The researchers examined the clinical and social situation of schizophrenic patients who were in touch with psychiatric services based in a District General Hospital Unit. The research goes into considerable detail concerning those patients who live with supporters, and looks at the extent of patients' psychiatric symptoms, disturbed behaviour and restricted social performance, together with the hardships, distress and strain experienced by the primary supporters and families.

The information was obtained from case records and interviews with the patients and supporters. The sample consisted of all schizophrenic patients who had contact with psychiatric services based on the DGH Unit for one year from February 1981 to the end of January 1982. Of the total of 364, 183 (50%) were identified as living with a supporter. Only 26% were currently married; 20% were widowed, divorced or separated; while 54% had never married. Women were more likely to have married at some time than men, and more women than men were living with supporters. Unsupported patients were more likely to be single and to have broken marriages.

Of the supporters, mothers living with patient-sons and husbands with wife-patients predominated. 25% of all primary supporters were aged 65 or over, and 11% were over 75.

Almost one-third of all supporters lived alone with the patient. This increased with age: within the group aged 65 or over, 38% were alone with the patient, and this proportion increased to 45% of supporters over 75. 'In such circumstances, the patient was often an important prop to the parent.' (Gibbons et al, 1984)

On employment it was found that only 27% of supported male patients were in full or part-time employment (compared with 80% males in local population) and that only 12% supported women patients worked (compared with 57% females in local population). However, more than half the women had some recognised status and occupation as housewives. Educationally, over two-thirds of the patients had left school without qualifications, although almost a quarter had O levels, C.S.E's or apprenticeships, and 9% had A levels or higher qualifications.

The patient's clinical condition was assessed by completion of the Present State Examination. 42% of supported patients had frank psychotic symptoms at the point of index contact (a similar figure of 42.5% was also identified of non-supported patients). 95% of patients without psychotic symptoms were receiving anti-psychotic medication (82% of the non-supported group). The authors identified the clinical poverty syndrome (that is, negative symptoms of schizophrenia, such as social withdrawal or under-activity) present in a quarter of the patients without frank psychotic or P.S.E. depressive symptoms.

Primary supporters were interviewed using a scaled version of the General Health Questionnaire and the Social Behaviour Assessment Schedule. (A description of the latter schedule is given by the authors, p 71). Of the patients' behaviour, it was found that, overall, 18% were rated as severely disturbed, 47% as moderately disturbed and only 35% were considered to be free, or almost free, of disturbed behaviour. The most distress to supporters was caused by offensive behaviour, rudeness (particularly when directed at supporters), and violence, although other behaviours, such as odd ideas, irritability or heavy drinking were also distressing to supporters.

Looking at the patients' social performance, the researchers reported that 86% of patients 'were playing only a limited part in household care and management. Over 70 per cent had limited spare-time activities and gave little support, affection or sexual love (where appropriate) to the supporter. However, nearly half of the patients who worked or had responsibilities for children were able to maintain full performance in these roles.' (p 75)

The researchers conclusions were that 'Patients who had been in psychiatric treatment for longer than a year displayed significantly less disturbed behaviour, but levels of restricted social performance did not decrease significantly with length of illness.' (p 75)

On the adverse effects on the household, the researchers reported that 72% of supporters showed symptoms of emotional or physical ill-health and 63% of children in the households were adversely effected. Negative effects on the work and/or social life of the supporter and financial hardships were reported by some respondents. The amount of subjective distress was highest for new supporters. The authors suggest that this may be, firstly, due to the supporters becoming resigned, detached and more skilled, or that the long-term supporters are 'a selected group, the strongest survivors who have always coped well.' (p 77)

<u>The Portsmouth Project</u> (Unpublished)

The research of Gibbons et al focused it's attention on schizophrenic patients who lived with supporters. Brian Hopkins' unpublished report describes a project, undertaken in Portsmouth, that examined the <u>quality of life</u> of schizophrenic patients who did <u>not</u> live with their families. (Hopkins, 1983). The patients had all attended the neuroleptic clinic in Portsmouth for a minimum of two years and had a clinical diagnosis of schizophrenia. The sample consisted of patients who lived in non-family accommodation, that is, those who did not live with parents, spouse, siblings or children. The sample (n = 49) was predominantly male (male = 37, female = 12). Half the subjects were interviewed at the clinic and half were interviewed at home.

As previous studies have shown, a higher proportion of men than women had never married. In this study, 30 of the 39 men and 6 of the 12 women were single. From the data collected, it was shown that many of the patients appeared to live <u>isolated</u> lives, although, on the whole, most said they were generally satisfied with defined life areas. About half the patients said they had nothing to do all day. 11 patients who lived alone said they had spent an average of ten hours alone on the previous day. Hopkins found that 15 patients had not seen a family member for at least 3 months and that 21 patients had no good friends. Many patients still related to the hospital and attended more activities in the hospital than outside in the community. The author said 'Most patients still identify with St. James Hospital. If community care is to be achieved, then the community must have more to offer.' (p 45)

On education and employment, 31 patients had left school with no qualifications. Only 4 patients were in paid employment. This meant that 90% of the sample were unemployed. At the time of the study, the unemployment rate in the local community was 12%. However, 16 patients attended the Industrial Therapy at St. James Hospital, Portsmouth. It may well be that this very high unemployment rate was because the selection of the sample was restricted to those schizophrenic patients who lived in non-family situations, and who had been receiving depot injections for a minimum of two years. This latter restriction indicated that the patients' illnesses were long-term and that they may have been handicapped by chronic illnesses.

Accommodation

Although this project focused on the schizophrenic patients who did not live with their families, we have seen from the previous research that many patients do, in fact, live within the households of their own family. But for many, returning to a family environment would either be impossible or would prove unsuitable. The earlier research of Brown et al showed that the schizophrenic patient has a high sensitivity to his social environment. Brown et al discovered that the critical factor of the risk of relapse was 'Expressed Emotion' on the part of the relatives. Vaughn and Leff later identified the upper limit of face-to-face contact in the high EE environments to be 35 hours per week. Hugh L. Freeman says

'There are many cases where contact with the key relative (showing high EE) should be minimized, for example by day care or even moving to a hostel. It would be valuable to have a measurement of EE available as a clinical tool, but this is not yet possible. However, some patients have separated themselves from family contacts, perhaps as a self-protective mechanism.' (Freeman, 1980, p 58).

Unfortunately, alternative suitable accommodation, particularly for the chronically mentally ill, appears to be sadly lacking. As we saw earlier, Mann and Cree in their study of the 'new' long-stay patients, found that one-third of the patients identified needed other forms of supervised residential accommodation.

Sheila Hewett, Peter Ryan and John Wing conducted a pilot study in order to look at non-hospital residential care of mentally ill adults. (Hewett et al, 1975). The data was collected in 1973 and the project was conducted in a London Health Authority Area.

The researchers identified the people who were living in alternative residential care (n = 90, living in 25 different hostels). 'Only one of these hostels was run by a local authority...........86 per cent of Lambeth, 73 per cent of Southwark and 50 per cent of Lewisham referrals were living in voluntary hostels.' (p 394/5).

Interview schedules were given to residents and wardens of hostels. The latter also completed a schedule re social behaviour of residents and the Hospital/Hostel Practice Profile. The researchers found hostels to be fairly 'permissive', although examples of certain restrictive practices are given, such as routine weighing of residents on admission. However, the authors say 'Almost all of the practices retained by both long and short-stay hostels may be interpreted as "caring" rather than restrictive practices' (p 401). The researchers found that in order for people to be accepted in care, emphasis was placed on the ability to work and socially acceptable behaviour. 'Voluntary bodies and local authorities alike appear to be more certain about who they do not want than about who they do want.' (p 404). The researchers conclude that if the standards outside the hospital were lowered then perhaps more handicapped people could be discharged to supervised accommodation.

Peter Ryan in Community Care for the Mentally Disabled said 'The acid test of a community service lies in whether it can meet the needs of those people with severe mental disabilities who, in former times, would have become long-stay patients in psychiatric hospitals' (Ryan, 1979, p 60). The government has said

> 'The housing needs of patients who have been in mental illness hospitals for many years but no longer require continuing medical and nursing care should not be overlooked. Obviously the rate at which such patients can return to the community will be constrained by the community's capacity to meet their need for both housing and social support, but there should be an underlying recognition that hospital is not a satisfactory alternative to home'
> (DHSS, 1975)

Referring to the study by Mann and Cree and the study above by Hewett, Ryan and Wing, John Wing says

> 'There is now good evidence that people who accumulate in long-term residential accommodation, whether hospitals, prisons, nursing homes, hostels or reception centres, are often "homeless, single people", in the sense that they have no home to go to, and that they also have a long history of unemployment and inability to cope with everyday social problems' (Wing, 1978a, p 227)

He continues

'The protected environments in which they accumulate provide an alternative to destitution. What happens when the less capable are discharged or turned out is all too evident. They tend to wander the streets, to end up in lodging houses or unsuitable rooms, or to be exploited by "hotel" proprieters for their social security money.'

When the doors of the mental hospitals were first opened, half-way houses were set up. 'It was assumed that the rehabilitation process started in hospital, would be continued in the half-way house or hostel and that there would be a continual flow of residents from hospital, through the hostel and out into the world.' (Hewett et al, 1975, p 392).

But it was difficult to fill the places with 'suitable' patients, and once filled it was difficult to keep the population moving through the system. There was a fear that new chronic wards would be created in the community. To keep the population moving, much selectivity was required in order to place those patients with the greatest chances of living an independent life in the community. Thus, many of the more chronic patients were remaining in hospital simply because there was nowhere for them to go. Group homes were set up - these were households of three to five patients, an 'artificial family'.

Patricia Benians describes how MIND has been setting up group homes in Inner London, 'a scheme that has found homes for long-stay patients who between them have spent 300 years in hospital' (Benians, 1982, p 1257). The Richmond Fellowship has also provided accommodation for schizophrenic patients in a therapeutic hostel setting and is described by Barry Shenker who says that ' - experience has shown that there is no reason why some of the basic principles and goals of therapeutic hostels generally should not equally apply to one for schizophrenics' (Shenker, 1981, p 6). The government has recognised the importance of the role of voluntary organisations in the provision of suitable accommodation. 'At March 1974 voluntary organisations were providing nearly 30 per cent of the residential homes and hostels and 15 per cent of the day centre places for the mentally ill.' (DHSS, 1975, p 27)

Another alternative to hospital care is boarding out schemes with local landladies. Of the ability to find landladies, Ryan says
'Occasionally, insufficient landladies have been found to make the scheme worthwhile. The more typical experience, however, has been to receive too many offers of help. This has particularly been the case in tourist areas

where "seasonal fluctuations in business have rendered the possibility of a steady all-the-year round income particularly attractive" ' (Ryan,1979,p83) In an article entitled <u>Alone In The Community</u>, Lyn Quine said 'There is no adequate supervision or inspection of board and care facilities for discharged patients. No one knows how many patients are discharged into unregistered hostels and lodging houses.' (Quine, 1981, p 435)

Jane Ritchie and Jill Keegan conducted a search of housing provision in England and Wales for mentally ill and mentally handicapped people for the Department of the Environment (Ritchie & Keegan, 1983). The data collection was 'to provide a profile of the amount and type of accommodation currently provided by local housing authorities, housing associations or voluntary organisations.' (p 1). Detailed case studies were taken 'to review and assess different forms of housing provision with particular reference to their development, organisation and support.' (p 1)

There were marked regional variations; the highest amount of provision existed in the Greater London area, the N.W. and the S.E. The proportions of provision were 65% in housing department properties, 28% in housing association properties, and 6% provided by voluntary organisations. Unstaffed group homes accounted for 84% of the provision for the mentally ill.

'Although both housing departments and housing associations were providing a majority of unstaffed group homes, this form of provision was particularly dominant in the local authority sector (91% for mentally ill people....). By contrast, around 30% of housing association provision was of some other kind, a high proportion of which was cluster schemes.' (p 2)

The researchers said, 'Turning to the future, the report argues that there is a sizeable and urgent need for more community based housing for both mentally ill and mentally handicapped people.' (p 7). They continued,

'As far as types of provision are concerned it is generally agreed that housing provision for mentally ill and mentally handicapped people needs to include a range of provision. The types of provision suggested within that range includes fully staffed hostels for rehabilitation; low staffed hostels for resettlement; staffed and unstaffed group homes; bedsitters or flats with community facilities; clustered self-contained units for one or two people; and ordinary individual lets.' (p 7)

The urgent requirement of suitable accommodation for the schizophrenic patient in the community is only one area of need concerning this specific patient population. From the evidence presented, we are acquiring a growing body of knowledge that should enable us to understand more fully the needs of this particular group from every aspect.

Work

'It is useful to distinguish between two functions of work in relation to mentally ill people in industrialised societies. The first is a means to rehabilitation; the second as an end in itself, evidence of wellness and citizenship.' (Wansbrough, 1981, p 81).

Wing and Brown (1970) had reported on the importance of occupation in their study on Institutionalism and Schizophrenia, and had found that a reduction of inactivity helped towards a clinical improvement in female schizophrenic patients by reducing primary handicaps. Work acts as a motivator because it is paid occupation: an important factor for schizophrenic patients whose own drives have deteriorated because of their illness.

Industrial work provides an environment in which the schizophrenic patient can socialise and be stimulated without over-involvement. Agnes Miles (1971, 1972) found that the Industrial Therapy Department provided a socialising environment where the patients met, made friends and interacted with each other. Morgan and Cheadle (1981) echoed this view of the workplace:

'......a work situation is full of social ingredients, but people often forget this. Without thinking carefully enough, they are liable to see work as designed solely to deal with occupational disabilities, which would leave social disabilities needing to be treated at some other time in some other place. This is not a true picture at all. A workplace provides a setting, a framework within which people have to relate to each other in the course of doing their several different tasks.' (p 38)

Past research has shown that psychiatric patients have difficulties in employment and that after admission they experience difficulties in keeping employment. (Cole et al, 1964; Anthony et al, 1974). Wansbrough and Cooper (1980) looked at Open Employment After Mental Illness. Their investigation showed that the largest number of subjects worked in the semi-skilled manual and manual, non-machine jobs. This category was larger than that of the unskilled worker. A number were in clerical positions.

'Managerial, professional, supervisory, and technical personnel with a psychiatric history are practically never engaged.' (p 170)

They found that ex-patients referred directly from hospital lasted a shorter time in positions than those referred from another source, for example, advertisement or D.R.O. 'The conclusion was inescapable that the transition from the patient to the worker role, for those straight out of hospital, had been too fast.' (p 171)

It was found that only a third of their samples had evoked a response from the employers about eccentricities of behaviour. The most commonly voiced complaints related to absence from work, slowness, inadequacy and oddity.

Floyd, Gregory, Murray and Welchman(1981) conducted a study on Schizophrenia and Employment. Their sample was taken from three mental hospitals and three psychiatric units in and around the London area. The inclusion criteria for the sample included a diagnosis of schizophrenia, age between 18 and 55 and admission to one of the six hospitals between January and June, 1979. The sample was n = 146: 9 patients refused to participate. The interviews were open-ended: an initial interview was conducted whilst the patient was in hospital and a further interview was carried out after discharge at home. Several subjects were also visited at least twelve months after discharge. Further interviews were conducted with the subjects' consultants, occupational therapists and other hospital rehabilitation staff, social workers, the D.R.O., employers (or ex-employers) and with relatives.

It was found that more than half of the 130 subjects who were available for employment were unemployed at the time of interview (n = 74). Of those who were employed, many worked only on a part-time basis. The unemployment rate of the group at any one time was between 60% and 70%, compared with a local rate of less than 5%. The authors state that 'It would appear that our subjects are disabled with regard to employment, but is this attributable to their schizophrenia?' (p 131)

The main finding of the research indicates that the main reason for the high unemployment rate in this sample was that the subjects, particularly the males, tended to stay in their jobs for a short time only. On examination of the reasons for leaving, it was found that the majority of subjects left voluntarily and that only a few subjects were dismissed. Although some subjects left their jobs because they did not like them, the researchers felt that many professional workers would put the reasons down to a 'lack of motivation' on the part of the schizophrenic.

This was not the impression gained by the researchers, who felt that 'A more likely explanation is that they were withdrawing from a situation that they were finding too "stressful"' (p 133). They continue 'By leaving a job that is too "stressful" our subjects may be acting, consciously or unconsciously, to reduce the level of stress, so that it does not rise above the threshold at which it can engender a schizophrenic episode' (p 133)

The authors identified important aspects of the working environments in which the subjects were more likely to stay. These included good supervision; good opportunities for learning and advancement; freedom to organise their time and work; feedback on performance; a good social climate in the work-group; working closely with one other person in a fairly small work-group; and interesting work that depended on quality rather than quantity.

Watts (1978) had commented on the schizophrenic patient and his response to supervision, in particular, a willingness to change jobs and an acceptance of criticism and correction of work. He felt that both these categories involve a sensitivity to failure. These findings have important implications for rehabilitation programmes, further training of individuals and the need for sheltered employment. Floyd and his colleagues concluded:

'In theory of course it ought to be possible to employ everyone, who was capable of doing some work, but payment structures and the present social security system make this difficult at present. The answer may lie in a modified version of the present "quota scheme", such that all employers are obliged to designate 3%, say, of their jobs as sheltered employment situations for disabled people. Employers might then be compensated by government for any loss of productivity that they incur.' (p 143, 144)

In a study of patients who were prescribed active or placebo medication on discharge following a first episode of a schizophrenic illness, Macmillan and colleagues (1986) found that those patients who returned to employment were significantly less likely to relapse: about 50% of the sample were employed at follow-up. A conclusion of the authors was that 'even at this early stage of schizophrenia, the outcome for many patients is poor, but nevertheless, it was not poor in every case.' (p 133). Of the sample, ten patients had made definite attainments, such as completion of a degree course, an apprenticeship and promotion at work. A further conclusion drawn was that, even though this part of the study was not controlled, a higher number of achievers were on placebo as compared with those on active medication and therefore it seems possible that 'the price of the reduced risk of relapse conferred by neuroleptics is a decline in achievement.' (p 133)

Summary

We have followed the development of the care of the schizophrenic patient to the present day, including the history of the development of the concept of the illness, the growth of knowledge in this field, and the changing attitudes towards the care of the mentally disordered. It appears from the evidence in the literature, that 'madness' has existed for many centuries. (Smith, 1982). It was probably in the thirteenth century that special arrangements for the mentally abnormal were first introduced. (Neugebauer, 1979)

It may well be that the first mental hospital was in existence from 1377, although, on the whole, the mentally ill remained in the community. In the eighteenth century, some hospitals had developed, but conditions in the hospital were deplorable, as historical evidence has confirmed (Hunter & Macalpine, 1963). It is evident from various accounts that many patients appeared to be schizophrenic. It was in the early nineteenth century that the government enquired into conditions in the madhouses, and this eventually led to the setting up of public hospitals - the aim of which was to introduce improved conditions for the mentally ill, together with methods of minimal restraint. It became mandatory for counties to build large asylums, but these soon became overcrowded and thus conditions deteriorated. By the end of the century, the only treatment available was custodial care (Smith, 1982; Wing, 1978; Wing ' Olsen, 1979).

It was during the latter part of the nineteenth century that the concept of an illness entity was developed. Major contributions were made at this time: for example, by Emil Kraepelin, who named the syndrome <u>dementia praecox</u> and described the symptoms in great detail; and Eugen Bleuler, who named the syndrome schizophrenia (Arieti, 1974). The twentieth century has seen a complete change in direction, in that the large institutions are gradually being run down, and the emphasis of care has shifted from the institution to the community. This came about because of the growth of knowledge in this field, together with pharmaceutic developments.

In the 1950's the phenothiazine group of drugs were introduced. These were particularly effective in the treatment of schizophrenia (Leff & Wing, 1971), although schizophrenics were unreliable in taking regular medication and were therefore liable to further breakdown. The development of the injectable, long-acting phenothiazines were a great step forward in the care of the schizophrenic patient because they were more successful in preventing relapse (Hirsch et al, 1973; Crawford & Forrest, 1974). However, it was found that the drugs available were more effective in treating positive symptoms of schizophrenia than negative symptoms (Stevens, 1973; Carney & Rutherford, 1981). Positive or first-rank symptoms of schizophrenia include thought disorder, disorder of the emotions, hallucinations and delusions. In the chronic condition, negative or secondary symptoms are often present. These include social withdrawal, apathy, poverty of speech and thought, and general slowness and under-activity (Wing, 1978a).

In recent decades, investigations have been conducted in order to examine the environment of the schizophrenic patient, as it was believed that the social environment did have an effect on the onset and course of the illness. Studies of the institution showed that this was so, Wing and Brown (1961) described how schizophrenic patients were more likely to show clinical poverty (such as social withdrawal or flatness of effect) in an understimulating environment, than in an environment that provided more stimulation and personal freedom. They found that clinical poverty increased with length of stay in hospital, and that unfavourable attitudes to discharge were associated with clinical and environmental poverty. This process is called institutionalism. The process of adjustment to this state occurs, not only in mental hospitals, but also in other total institutions, for example, prisons or army barracks. (Goffman, 1961)

Research into the patients' environment gave, not only a deeper insight into the care and treatment needed by the schizophrenic patient, but also expanded the knowledge available into the possible causes of the illness. A study in South East London had shown that schizophrenic patients had experienced an increase in life events (for example, births, marriages and deaths) prior to the acute onset of schizophrenia (Brown & Birley, 1968; Birley & Brown, 1970). The patient's environment include his relationships and interactions with other people within that environment, and in particular, the patient's family. It was found that the amount of Expressed Emotion (EE) by the relative had an influence on the symptomatic relapse of a schizophrenic patient (Brown et al, 1972; Vaughn & Leff, 1976). EE has a mainly negative connotation, for example, hostility and criticism. A favourable outcome was more likely if the patients from high EE homes were protected by regular phenothiazine medication and reduced face-to-face contact with relatives who expressed high amounts of EE, and who were not protected by regular medication, had a very poor outcome.

However, in recent years, there has been growing concern about the effects of looking after schizophrenic patients on the families, who are often the primary agents of care. (NSF, 1974). A five-year follow-up of schizophrenic patients admitted to one of three hospitals in 1956 was conducted in order to examine some of the consequences for the families. Problems reported by the relatives included ill health of the relative, adverse effects on children, financial problems, an inability to entertain guests at home and general restrictions on leisure activities (Brown et al, 1966).

The National Schizophrenia Fellowship (NSF) acts as a supportive group to the relatives and friends of the schizophrenic patients. It recognises the many problems encountered by the families and acts as a pressure group to improve community services. A research project, funded by the NSF, found that many NSF relatives were dissatisfied with services (Creer & Wing, 1974). Many problem areas were identified, for example, the need for initial information, hospital after-care, financial problems and the need for occupation.

When looking at the attitudes of relatives, it was found that two-thirds of the relatives were tolerant or accepting towards the patient. It was felt that some relatives tended to understate their difficulties. It had previously been stated that parents often made little complaint, even if under great distress (Brown et al, 1966). In a more recent study, it was found that often supporters were elderly (Gibbons et al, 1984), and that many elderly parents lived alone with the patients. In these cases, the patients were an important prop to the parents.

The most common problems reported by the relatives about patients behaviour included social withdrawal, slowness, underactivity and a lack of leisure interests (Creer & Wing, 1974). Oddities of behaviour, offensive behaviour, rudeness and violence caused most distress to relatives, (Creer & Wing, 1974; Gibbons et al, 1984), although little violence was reported in the earlier study.

Of the patients social performance, many patients gave little financial help or emotional support and companionship in the household, particularly if unmarried or unemployed (Creer & Wing, 1974; Gibbons et al, 1984).

Several studies have been undertaken to explore the social environment of the patient living in the community, from the patient's perspective . There has been a growing concern about the quality of life the schizophrenic patient leads outside hospital, together with a growing awareness of the lack of facilities and services available (DHSS, 1975; NSF, 1977; Walker, 1982).

It has generally been found that more female patients than male patients have married (Korer et al, 1978; Hopkins, 1983; Mitchell & Birley, 1983; Gibbons et al, 1984); although more men than women lived with parents (Korer et al, 1978). Most patients had some family, and on the whole, were satisfied with family relationships (Korer et al, 1978). The main problem was an inability to communicate feelings, which led to frustration and loneliness.

One of the major problems found was isolation and loneliness (McCowen & Wilder, 1975; Korer et al, 1978; Hopkins, 1984). Patients complained of an inability to make friends and sustain meaningful relationships (Korer et al, 1978) and often had no-one to turn to for help or advice (McCowen & Wilder, 1975). Many patients had nothing to do all day (Brown et al, 1966; McCowen & Wilder 1975; Korer et al, 1978; Hopkins, 1984). They were often found to be unemployed, single, young men and women, and many patients did not go out at all in the evenings (Brown et al, 1966).

Looking at occupation during the day, it was found that the women were, on the whole, busier than the men (Mitchell & Birley, 1983). More than half the women, in one survey, had some recognised status and occupation as housewives (Gibbons et al, 1984) and another found that women often performed their domestic duties competently or were employed (Brown et al, 1966). Korer et al (1978) found that attitudes towards the organisation of domestic work ranged from satisfied to depression and despair. Many patients complained of boredom and nothing to do (Mitchell & Birley, 1983) and this often led to apathy and resignation (Korer et al, 1978). Patients who had suffered from chronic illnesses for many years, often accepted this situation as part of their lifestyle and did not want to change (McCowen & Wilder, 1975).

In many instances, patients still related to the psychiatric hospital for professional help, material and social support and acceptance (Hopkins, 1983; Mitchell and Birley, 1983). Recommendations have been made to provide a range of protected environments (Creer & Wing, 1974; Korer et al, 1978) together with integration of the mental health services (Freeman et al, 1979b). A lack of suitable accommodation has been recognised (DHSS, 1975; Mann & Cree, 1976; Ritchie & Keegan, 1983). Mann & Cree (1976) found that one-third of the 'new' long-stay patients could live out of hospital in supervised residential accommodation if it were available. However, it has been suggested that selectivity of patients for available accommodation causes problems in that the standards of requirements are too high, for example the need for an ability to work (Hewett et al, 1975).

Voluntary organisations have provided alternative accommodation, for example, group homes (Benians, 1982) and therapeutic communities (Shenker, 1981). There is a growing number of local landladies providing guest-house accommodation for chronic patients in particular (Ryan, 1979) although there is a lack of suitable supervision of such facilities (Quine, 1981).

Another area of great concern is that of employment for the mentally disabled person. In 1966, it was observed that 'One of the most useful indices of a patient's progress after a period of treatment in hospital is his work record. Unemployment is debilitating and may lead to further breakdown.' (Brown et al, 1966, p 72). Recent studies have shown that the majority of patients are unemployed (Korer et al, 1978; Mitchell & Birley, 1983; Hopkins, 1983; Gibbons et al, 1984). Gibbons et al, (1984) found that only 27% of supported men and 12% of supported women were employed, and Hopkins (1983) had discovered that only 10% of the patients living in non-family situations were employed. It has been recognised that 'Paid work, even in a sheltered setting, has an important role in rehabilitation and also serves to signify to the individual that he is on the way back to health.' (Bebbington & Kuipers, 1982, p 403).

Wansbrough (1981) echoes this and says that not only is work a means to an end, but it gives a feeling of well-being and citizenship. Schizophrenic patients who remain unoccupied during the day deteriorate clinically (Wing and Brown, 1970). The workplace is an environment in which the schizophrenic patient can socialise and develop his/her interpersonal relationships (Miles, 1972; Morgan and Cheadle, 1981).

Nevertheless, evidence has shown that often the psychiatric patient has difficulties in keeping in employment, particularly after discharge from hospital (Cole et al, 1964; Anthony et al, 1974; Floyd et al, 1981) and, in particular, those referred directly from hospital (Wansbrough and Cooper, 1980). It has been found that it is often the employee who decides to leave and that, in the case of the schizophrenic patient, it is a means of withdrawal from a stressful situation (Floyd et al, 1981). Identification of aspects of the working environment that were more likely to encourage patients to stay, showed that good supervision, opportunities for learning and advancement, freedom to organise time and work, feedback on performance, a good social environment, and a lack of isolation in the work situation were all crucial.

Alistair Crine (1981) recognises that

'Nobody seems to be willing or able to identify the size of the army of mentally disabled people who are looking for work across the country.' There is a lack of suitable sheltered workshops and none are "specifically designed for ex-mental patients who find difficulty in punctual attendance at prescribed times, and in working long hours.' (NSF, 1974b, p 10).

Research in the field of mental illness has increased and therefore builds on to that existing body of knowledge. We are now more aware of the reaction of the schizophrenic to his social environment - his family, social networks, accommodation and employment needs. Hugh Freeman says:

'Our knowledge of schizophrenia is therefore considerable though incomplete along any one dimension. The task ahead is to make full use of this knowledge in the services that are actually available to patients and their families.' (Freeman, 1980, p 58).

But although we are a long way forward, we also have a long way to go.

'It is clear that unless and until there are further major breakthroughs in the treatment of the more disabling psychiatric conditions, some chronic mental illness will continue. There is an urgent need for more research into the overall size of the problem: ....little is known about the chronically disabled in the community whose needs are unmet or are being met only at the price of near intolerable strains on their families, or who are perhaps living with elderly relatives who will be unable to cope with them for much longer.' (DHSS, 1975, p 42)

CHAPTER 3

METHODOLOGY

Local Study

The study was carried out in the City of Portsmouth, which is situated on the South Coast of England, 70 miles from London. The city was selected for study, as it is the area in which the researcher has worked as a Community Psychiatric Nurse for the past fourteen years. The research is a small-scale, local study which describes the situation of this patient group in 1985. It is limited in that the investigation was conducted on a part-time basis by the researcher only. The data obtained describes the situation in Portsmouth, and the conclusions relate only to that city, though it might well be similar results could be found elsewhere.

The Area

Portsmouth is a Hampshire city with a long naval history, situated in a central position along the South coast. The population is 188,600 (including students and service personnel). This makes Portsmouth one of the most densely populated cities outside London. (Figures from Portsmouth City Planning Department)

Employment and Educational Opportunities

Although it's history is centred on the Royal Navy and defence, the city now has a more diversified economy: for example, electronic, pharmaceutical and plastics industrial units; I.B.M.; large insurance companies, such as Zurich; and Marconi Space and Defence Systems. There is an expanding Continental Ferry Port with services to St. Malo, Cherbourg, Le Havre and the Channel Islands. Further future developments of the port are planned.

Tourism is a developing industry in the city. Southsea is a resort with an expanse of pebble beach, and is popular for family holidays. Lord Nelson's Flagship, HMS Victory, is situated in the Naval dockyard; and the raising of King Henry VIII's warship, the Mary Rose, in 1982, has attracted many visitors to Portsmouth. There are plans to develop this attraction.

The Portsmouth Polytechnic has over 5,000 students, and is one of the largest polytechnics in the country. The city also has a College of Technology and a College of Art and Design.

At the end of 1984, near the time of the study, the Portsmouth Travel to Work Area (which includes the Portsmouth and South East Hants Health District) had an unemployment rate of over 12%. The rate for the South East Region, as a whole, stood at 10%. The 1981 census showed that semi-skilled or unskilled manual workers accounted for 24% of the employed population, and in the inner-city area, this proportion rose to 37%.

In November, 1985, unemployment figures for Portsmouth stood at 11,524. For the Portsmouth Travel to Work Area, the rate was 12.3%. Although this represented a slight increase over the 1984 figure, it was still just under the national average of 13.3%.

Housing

The City Council manages some 25,000 council properties, and this number accounts for 21% of the total housing stock. Southsea, which is the southern part of the city, has many old, large, Victorian houses, which are now mainly let as bedsits or private flats. The city has schemes for General Improvement Areas and Conservation Areas, and provides community and recreational facilities. Green areas and open spaces are mainly peripheral to the built-up area of the city.

Portsmouth was extensively bombed during the Second World War, particularly in the inner-city and Dockyard areas. These areas were rebuilt with mainly large blocks of council flats, although some smaller blocks of maisonettes and flats and some houses were also erected. Council estates, for example, Paulsgrove, were developed outside the city in order to accommodate the homeless.

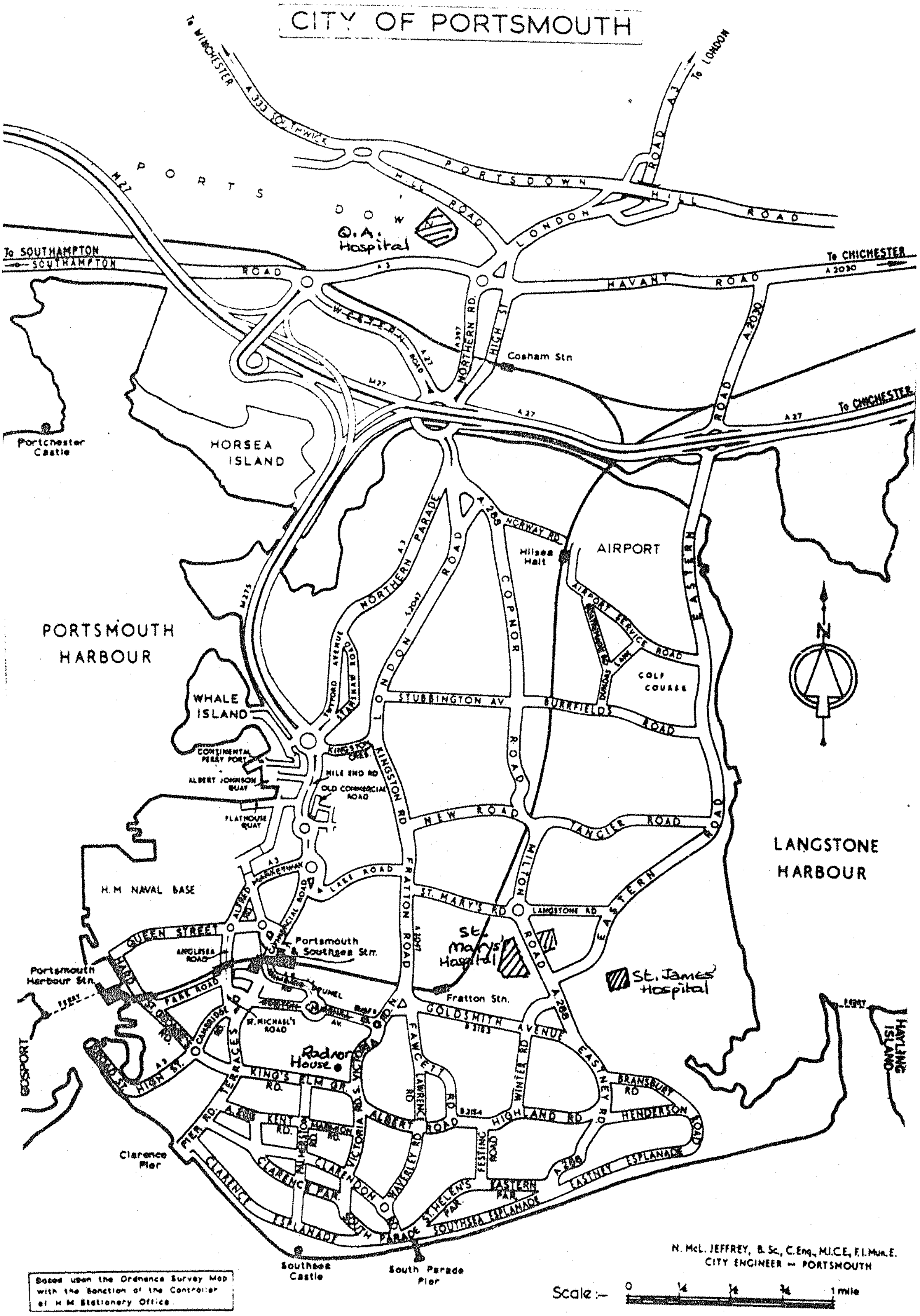
In 1981, there was evidence of over-crowding in 2.4% households (figures from the City Planning Department - 'overcrowding' is defined as households living at more than one person to one room). In one of the inner city wards and in Paulsgrove, this figure rose to 6%. The percentage of households that did not have the sole use of an inside lavatory and fixed bath or shower stood at 11.6%.

Hospitals

Two District General Hospitals are located in the city - St. Mary's Hospital is in a central location in Milton, while Queen Alexandra Hospital is situated in the northern area of Cosham. St. Mary's Hospital has currently 606 beds, including general medical and surgical beds, a district radiotherapy department and a regional renal unit. Queen Alexandra Hospital has 704 beds, including general medical and surgical beds, geriatric wards and an accident and emergency department that serves the district. St. James' Hospital is the district psychiatric hospital and currently has 418 beds. The present active policy is towards a continuing reduction in the number of lòng-stay beds. Unlike many other large, Victorian asylums, it commands a position in the south-east of the city in a now built-up urban area. Accessibility from other areas of the city is not difficult. In addition to the acute psychiatric services, there are specialist services for alcoholism, drug addiction, children and families, and an expanding service for psychogeriatrics. At present, as well as day hospitals for psychogeriatrics, there is also an acute day hospital (Solent Day Hospital) in Portsmouth and another at Havant (Havant Day Hospital). Psychiatric services are more fully documented in Chapter 7, Part 1.

Demographic Drift

Portsmouth has seen a reduction in it's population over the last twenty years, although this decline has slowed down during the early 1980's. At present, the small changes are natural, i.e. the number of deaths are slightly higher than the number of births. There is movement out of Portsmouth to outlying areas in Southern Hampshire (e.g. Havant), but this is balanced by a movement into the City. The County Planning Department predict very little change in the population size up until 1991.



Based upon the Ordnance Survey Map with the Sanction of the Controller of H.M. Stationery Office.

N. McL. JEFFREY, B.Sc., C.Eng., M.I.C.E., F.I.Mun.E.
CITY ENGINEER — PORTSMOUTH

Fig 3 : 1

The Sample

The sample was selected in January, 1985, from those patients who were receiving long-acting neuroleptics as out-patients in the City of Portsmouth. The patients either received their injections at the Modecate Clinic in Solent Day Hospital (which is part of St. James' Hospital, the large psychiatric hospital in Portsmouth), or at home, given by the Community Psychiatric Nurses. Although colloqually the clinic is known as the Modecate Clinic, a range of depot injections are given at the clinic. The most commonly prescribed injections are Modecate and Depixol.

It was decided that the patient population for the study would need to meet the following criteria:

(i) Each patient must have a firm diagnosis of schizophrenia (from case-notes).

(ii) The patient must live <u>outside</u> hospital and be maintained with the help of long-acting neuroleptics.

(iii) The patient would attend either the 'Modecate Clinic' or receive their injections at home, or in the community, from the CPN.

(iv) The patient must be aged between 16 and 65 years, i.e. within the age-limit normally cared for by this service.

(v) The patient must live within the City boundaries.

The population which met with the above criteria numbered 207, from the original total of 239.

Table 3 : 1 Selection of Sample

	TOTAL	Excluded Living Out Of Area	 Over 65	Eligible For Survey	50% of Sample
Attending Clinics	158	5	11	142	71
Injection by CPN	81	0	16	65	33
	239	5	27	207	104

The population was separated into clinic and community patients and were arranged in date-of-birth order. This was to ensure that appropriate proportions of clinic and community patients were selected and that there was a spread across the age groups. Every alternate patient was selected to form the sample of n = 104.

The size of the sample was selected because:

(i) The total population could not be studied in the time available (approximately 6 - 8 months was available for the field-work, on a part-time basis of one day per week).

(ii) In any case, similar sample sizes have been used in other studies of patient's social situations, for example, McCowen and Wilder's study of the life-style of 100 psychiatric patients (McCowen and Wilder, 1975); Creer and Wing's study of the problems encountered by the relatives of schizophrenic patients used a sample size of n = 80 (Creer and Wing, 1974).

Place of Treatment

The place of treatment is usually a joint decision made by the patient and clinician. For example, a large number of patients regularly attend other hospital departments, and therefore find it convenient to attend the clinic for their injections. Patients in full-time employment can avoid the need to take time off work by attending the evening clinic. Some patients find the journey to the hospital difficult, either because of geographical distances and difficulties with public transport, or because of home commitments. For these patients, a visiting Community Psychiatric Nurse can ensure continuity of treatment.

However, there are situations in which the decision about the place of treatment is made by the clinician. This can occur if, for example, a particular patient proves to be unreliable in regularly attending for his/her treatment, and the decision may be made to give the injections at home. In other circumstances, the patient may be encouraged to attend the clinic and not have injections at home. This situation could occur if, for example, the patient was becoming extremely isolated and needed some encouragement to leave the home and experience some form of social interaction.

The place of treatment is not necessarily fixed permanently, although the majority of patients do not change.

However, flexibility in the service is necessary in order to accommodate the needs of individual patients, and some do change. Liaison is kept between the clinic nurses and the Community Psychiatric Nurses.

The main difference in treatment between the two groups of patients is the amount of home involvement by the nurses. The Community Nurses assess and monitor the home situation and can play a therapeutic role within the environment. The Community Nurses often give support to the patients' families, landladies or friends. The assessment of a patient's social environment is very limited in the clinic situation, although the nurses do ask for home assessments if they feel it is necessary.

The purpose of the research was to investigate and describe the overall situation - not to compare one group with another.

Method

The information was gained by:

(i) Examination of case-notes with the agreement of the consultants.

(ii) A structured interview with the patient.

The proposed project was presented to the Ethical Committee of Portsmouth and South East Hampshire Health Authority. The project received approval from the Committee on September 18th, 1984.

The interview schedule was forwarded to the Survey Control Unit, as the Department of Health and Social Security were funding the project in the form of a Nursing Studentship award and this was a requirement of the Department. Notification of the registration of the survey was received from the S.C.U. on January 28th 1985.

An interview was chosen because a good response rate was probable. This was particularly important in this project because of the low motivation that often presents in schizophrenia, making a postal questionnaire most unsuitable. It was also necessary for the interviewer to be able to clarify any points not fully understood by the patient, or to use prompts, if required. This was important as schizophrenia often interferes with thought processes and poor concentration is sometimes evident. The interviews were structured in order to ensure systematic coverage of all points, but some flexibility in administering it proved necessary, for example, some points required discussion to clarify the meaning of the answers.

The interview schedule was designed in the light of information found in the literature and was based on other studies of patients living in the community. (Brown et al, 1966; Creer and Wing, 1974; McCowen and Wilder, 1975; Cheadle et al, 1978; Korer, 1978; Hopkins, 1983 (unpublished))

It was intended that the interview would cover areas such as family structure and contact with the family; accommodation and household composition; household responsibilities; diet; education and employment; occupation during the day; income; personal life; a brief psychiatric history and recent contact with professionals. The respondents were asked about their degree of satisfaction with defined areas. On completion of the interview, they were invited to comment further.

A complete specimen of the questionnaire is included as Appendix 3.

Family Tree

One of the most crucial areas of study was that of Family Networks - an attempt to assess not only the structure of the family, but also the contact the patient had with individual members of his/her family.

A 'Family Tree' was designed in order to obtain some of this data. A similar technique had been used in a study of the social consequences of conviction by J.P. Martin and D. Webster (1971). A simplified version of a Family Tree was designed for this project, based on the one used by the above researchers. (Appendix 2)

The Tree was used early on in the interview. The reasons for this were that it would make the interview more interesting for the respondent, and, therefore, it was envisaged that it would aid the relaxation and concentration of the patient.

It was hoped that, by using this method, the data obtained would be more accurate than it would if questions only were asked. The respondent could take an active role and therefore participate more fully in the interview.

Structure of Family - The respondent would be asked to note all relatives in his/her extended family, to his/her knowledge.

Contact with Family - The respondent would be asked to identify all relatives he/she had seen within the last year. Married respondents would also be asked to note all relatives of their spouse whom they had seen within the last year.

The interview schedule contained additional questions about contacts with the family, as more detailed information was required.

Pre-Pilot Interviews

It was decided that a small number of pre-pilot interviews would be conducted in order to test the wording and order of the questions and the content of the interview. The researcher would also be able to assess the probable length of time the interview would take.

Three such interviews were conducted. The patients who were interviewed were not selected in the sample for the main data collection. As a result of these interviews, some questions were re-structured and the format of the interview schedule was changed, although the overall content remained the same.

Pilot Interviews

It was decided that 4 pilot interviews with the revised questionnaire would be carried out by the researcher. The patients selected for interview were not included in the main survey. The patients were selected by the researcher and asked for their cooperation in the project. Although, initially, all four patients agreed to participate, one patient had changed his mind at the time of interviews.

Following the three pilot interviews, it was decided that:

- The interview schedule appeared to be satisfactory to the requirements of the project
- Not all patients would be capable of completing the Family Tree without the help of the interviewer. However, it did not seem that this would cause any problems in the main data collection.
- The average time taken for each interview would be approximately one hour.

Contact with the Sample

It had been decided that a letter of introduction would be sent to each patient selected for the study. A copy of this letter is included (Appendix 1). The bottom tear-off section gave the patient the opportunity to decline the invitation to participate in the project. The letter was merely an introduction - it was planned that the interviewer would visit the patient prior to the interview, in order to explain the research more fully and to answer any questions the patient had. At this point, the patient could decline the invitation if he/she had not already done so.

However, the researcher found that the first couple of letters sent appeared to have caused some anxiety. One patient seemed concerned about the letter, yet, after further explanation by the researcher, was perfectly happy about it and agreed to participate in the project. Another patient had filled in the refusal slip and had personally delivered the letter to the door of the Community Nurses' Office at St. James' Hospital.

Therefore, it was decided that the researcher would introduce the project by making personal contact with the patients. It was felt that this would help to minimise any anxiety experienced by the patient and that there would probably be a considerable reduction in refusals.

The Clinic Patients

Two clinics per week were held in the Solent Day Hospital. The Tuesday Clinic had been extended to include part of the evening, so as to accommodate employed patients. The Thursday Clinic was held in the daytime only. Arrangements were made for the researcher to attend these sessions for as long as was necessary. A room was set aside for the sole use of the researcher. Permission for access to the clinical notes and contact with the patients had been obtained from the relevant consultants.

Personal introduction to the sample took place in the clinic at the time of the patients' attendance for treatment. An explanation of the proposed research and the interview was given. The patients were informed that the probable amount of time involved would be about an hour. They were given the opportunity to ask questions. Assurance was given about confidentiality.

If the patient agreed to participate, a further appointment was made to see them. The choice of the place of interview was left to the patient. Although it would have been preferable to interview the majority of the patients at home, in order to gain further insight into their living circumstances, this was not always possible. Patients who lived with their relatives, or who lived in lodgings or nursing homes, sometimes chose to be interviewed at the clinic as they felt less inhibited there. Others, perhaps, were happy enough to give an interview, yet were not willing to become involved to the extent of inviting someone to their own home.

At this point, the patient was given the letter of introduction with the date and time of the appointment written on it. This was to act as a reminder and also to give them an opportunity to change their minds, as they could return the refusal slip if they so wished.

If, at the time of personal introduction in the clinic, the patient declined the invitation to take part in the project, then full assurance was given that no further approach would be made.

The 'Home' Patients

Each patient in this category had a Community Psychiatric Nurse as a key worker. Permission was obtained from the relevant consultants to approach the patients and to study their case notes. Community Nurses were also contacted and informed which of their patients had been selected in the sample. Information about the patients' current mental state and ability to participate in the project was obtained from the Community Nurses. In one case, the Community Nurse advised the researcher to postpone the visit as the patient was obviously mentally disturbed at that time. As it was, by the end of the field-work, the patient had fully recovered and participated in the research.

The initial personal introduction took place in the patient's own home. Each patient was visited by the researcher and an explanation of the proposed research and interview was given. In many cases, the Community Nurses had informed the patients of the researcher's intended visit. This was found to be very helpful in allaying unnecessary anxieties about the visit.

If the patient agreed to participate, then a further appointment was made to visit the home. If the patient declined the invitation, then full assurance was given that no further contact would be made.

Confidentiality and Access to Clinical Notes

It was regarded that confidentiality was of utmost importance and this was done in the following way.

All case-notes were made available to the researcher at all times and are normally kept in locked cabinets in a locked office in the Solent Day Hospital. The data on respondents has been recorded in individual files, the key to which is kept by the researcher only. Information on the computer is by number only - the key to the numbers kept only by the investigator.

Lost Cases from the Sample

Of the 104 patients approached for interview, a total of 91 were interviewed; 13 (12.5%) of the cases were lost. The reasons for this are shown below.

Table 3 : 2 Lost Cases From The Sample

	Male	Female	Total
Refusal	6	0	6
Unable to make contact	0	1	1
No trace	4	0	4
Deceased	0	1	1
In hospital throughout survey	0	1	1
TOTALS	10	3	13

All six refusals were made by male respondents, unmarried at the time of the survey, and aged between 26 and 59 years. One individual was no longer receiving an injection. No reasons for refusal were given by the respondents, although it was later discovered that one of the men had suffered a relapse of his illness and had become paranoid. The researcher gained the impression that all these respondents felt the investigation was an intrusion into their private lives and that it was for this reason they refused.

The researcher was unable to make contact with one lady, although several appointments had been made. No reasons were given for the broken appointments, although one may assume that the explanation given above for the refusals may also apply in this case.

There was a failure to trace four of the sample; again, all were male and unmarried at the time of the survey. They were aged between 25 and 51 years. Two patients had moved without trace, one had moved to the Midlands, and one was probably in prison.

One lady, aged 63, had died from natural causes. She had, in fact, agreed to be interviewed, although had become ill soon afterwards. Another lady, aged 19, had been admitted to hospital immediately after the sample selection and had remained in hospital throughout the survey.

It is unfortunate that this number of single males were lost from the sample as the research later shows that it is the single men, in particular, who are often experiencing difficulties in many aspects of their lives. It could well be that the six males who refused were experiencing similar difficulties and that a discussion of the situation would prove to be too painful. Therefore, it may be that these missing cases involve a loss of data which may have served to emphasise the results of the investigation. These factors will be taken into account in the discussion of the results of the research in Chapter 9.

The Sample Interviewed

A total of 91 patients were interviewed between February 28th 1985 and August 9th 1985: 60 interviews were conducted with clinic patients and 31 interviews with community patients. The Clinic patients had the opportunity to select whether the interview took place at the clinic or in their homes: 29 were interviewed at the clinic, the remaining 31 were seen at home. The number of community patients interviewed at home also numbered 31, making a total of 62 home interviews.

Table 3 : 3 The Place of Interview

	Clinic Interviews	Home Interviews	Total Interviews
Clinic Patients	29	31	60
Home Patients	0	31	31
TOTAL	29	62	91

A total of 89 interviews were fully completed: 2 were completed in part only because the patients (both female) refused to answer some of the questions. The reasons given were that they both felt particular questions were too intrusive into certain areas of their lives.

The length of interviews varied from 35 minutes to 2 hours, although the majority of the interviews lasted for about an hour. The interviewer assessed the degree of rapport and cooperation obtained during the interview on a scale from 1 to 5. The result of these assessments are shown below.

Table 3 : 4 Assessment of Interviews

		Number of Interviews
1.	Excellent rapport; high degree of cooperation by patient	53
2.	Good rapport; patient cooperated well	21
3.	Adequate rapport; cooperation O.K.	11
4.	Rapport difficult at times; patient did not cooperate fully	6
5.	Very poor rapport; patient was uncooperative	0
	TOTAL	91

Although these assessments were made subjectively by the researcher at the time of interview, they give an indication of how the patients responded to the investigation. The concern was that if large numbers of patients were felt to be uncooperative in any way, then the results would be affected by this lack of rapport. Fortunately, the majority of patients cooperated fully and were most helpful. The six respondents who were seen to lack a certain amount of rapport included two patients who completed the interview in part only; one patient who was restless and lacked concentration; and three patients who appeared to be somewhat suspicious and paranoid.

The following chapters describe the data obtained from the 91 interviews. A discussion of the results is presented in Chapter 9.

Chapter 4

Demographic Details

Accommodation and the Household and Domestic Arrangements

(i) Demographic Details of the Sample

A total of 49 males and 42 females were interviewed between February and August 1985. All but four of the respondents were of British nationality: two were from Malta, one was African and one had a dual nationality. All the data presented in the following chapters describes the situation at the time of the interview.

The respondents were all aged between 22 years and 65 years. The original population had been arranged in date-of-birth order before the selection of the sample. This was done to ensure an even distribution across the age groups. This distribution is illustrated below (Table 4.1). There were rather fewer patients in the lower age groups, and in fact no patients were selected for interview below the age of 22 years. This may be because of a reluctance by psychiatrists to label a patient as schizophrenic at a very young age, or to treat the individuals with injectable drugs. Overall the women tended to be older than the men: In the study of schizophrenic patients in Southampton, a similar pattern was established (Gibbons et al, 1984).

Table 4.1 Age Distribution of the Sample

Age	Frequency	%
Up to 25 years	3	3.3
26 - 30	6	6.6
31 - 35	8	8.8
36 - 40	14	15.4
41 - 45	14	15.4
46 - 50	10	11.0
51 - 55	15	16.5
56 - 60	8	8.8
61 - 65	13	14.3
TOTALS	91	100.1

Table 4.2 shows the marital status of the sample at the time of the interviews.

Table 4.2

Marital Status of the Respondents

Status	Male	%	Female	%	Total	%
Single	35	71	9	21	44	48.4
Married	7	14	19	45	26	28.6
Cohabiting	0	0	2	5	2	2.2
Separated	1	2	1	2	2	2.2
Divorced	6	12	4	10	10	11.0
Widowed	0	0	7	17	7	7.7
TOTALS	49	99	42	100	91	100.1

The marital state of the sample is very different from that of the adult population aged 21 to 65 in general because nearly half (48.4%) have never married. Locally, the 1981 census showed that 58.9% of males, aged 16-65 were married, compared with the 14% in the sample. The women, too, fell below the local figures as a whole: 65.4% of women between 16 and 65 were married and, in our sample, this figure was 45%. (Figures from Portsmouth Planning Department).

There are major differences between the males and females in the sample. The males are more than three times as likely to be still single as females ($x^2 = 11.92$, P 0.005); 17 percent of the women were widowed as against none of the men; and the females were 3½ times more likely to be married or cohabiting than the men. Past research has shown similar patterns (Korer et al, 1978; Mitchell and Birley, 1983; Gibbons et al, 1984)

Marriage breakdowns among the men were almost twice as high as among the females: of the 14 men who had married at least once, 7 (50%) were divorced or separated, whereas among the women the proportion was only 5 out of 33 (15%). On the other hand, 21% of the womens' marriages were described as having been terminated by widowhood. It was not possible to verify this, and it is possible that some described themselves as widowed when in fact their marriages had broken down. Either way, however, the experience of matrimony had not been particularly happy for men or women. 50% of the mens' marriages had broken down while 36% of the females' had ended through death or breakdown.

The 45 respondents who had married had done so between one and three times. Table 4.3 shows that the majority (82%) had married only once.

Table 4.3

Number of Times the Respondents Had Married

Number of Marriages	Male	%	Female	%	Total	%
Never Married	35	71	9	21	44	48.4
One	12	25	25	60	37	40.7
Two	2	4	5	12	7	7.7
Three	0	0	1	2	1	1.1
Cohabit	0	0	2	5	2	2.2
TOTALS	49	100	42	100	91	100.1

Respondents were asked about the numbers of children they had had and how many children in total lived in the household at the time of the interview. (Table 4.4). More than half (52%) of the respondents had never had children and 36 (77%) of these were males. This result could be expected because of the high number of males who had never married. Of the women, 31 (74%) had had children, and these numbered between one and nine. Half of the mothers (38% of the total females) but only 3 of the men (6% of the total males) had responsibility for children under 16 years of age living in the household.

Therefore, it appeared again that there were major differences between the males and females in that more women than men had experienced parenthood and, in fact, a considerable number of the women were still responsible for children under 16 years of age.

(ii) Geographical Distribution of the Sample

One criterion for the selection of patients was that they lived within the City boundaries. The City of Portsmouth is administratively divided into three areas: the northern patch of the city includes the large council estates of Paulsgrove, Wymering and Portsdown Park, although, at the time of writing, the latter estate is to be re-developed and therefore the residents are being rehoused.

Table 4.4

Children of Respondents

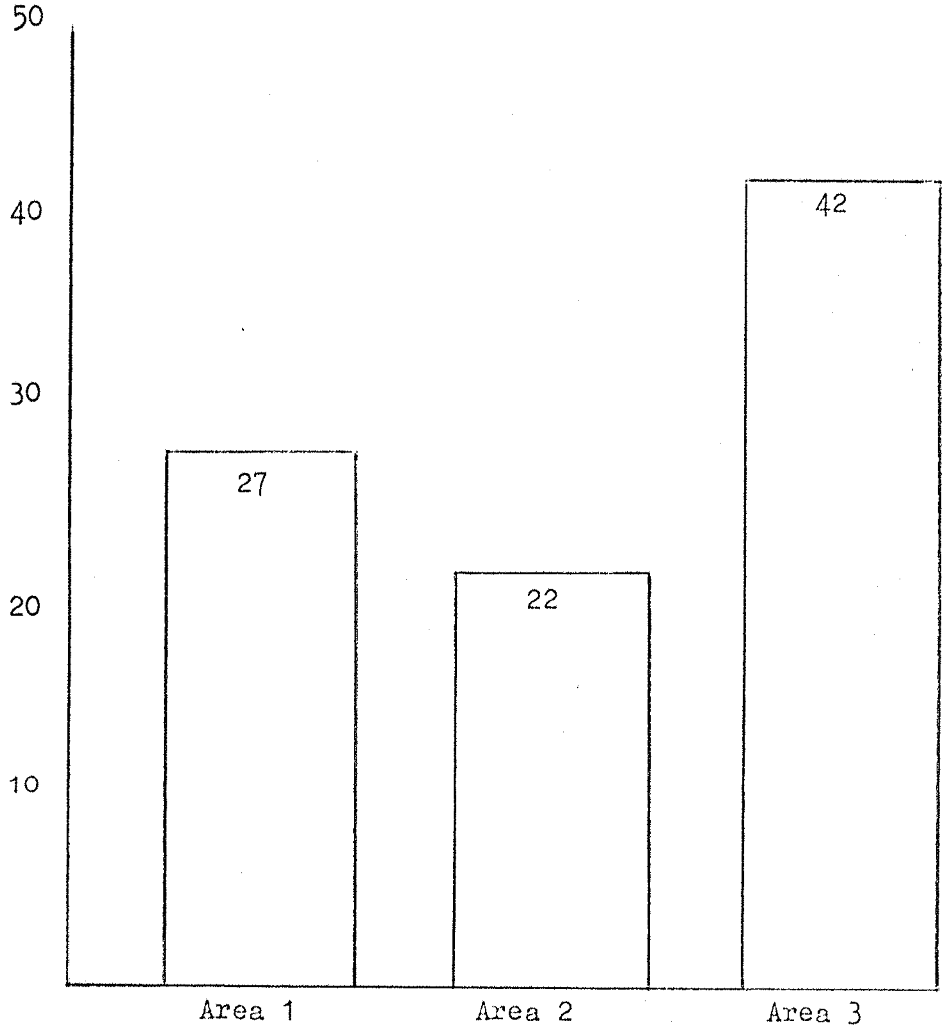
Number of Children	Parent of: Male	Parent of: Female	Parent of: Total	%	Living in Household Male	Living in Household Female	Living in Household Total	%	Living in Household Under 16 years Male	Living in Household Under 16 years Female	Living in Household Under 16 years Total	%
No children	36	11	47	51.6	45	25	70	76.9	47	32	79	86.8
One	5	7	12	13.2	2	5	7	7.7	1	6	7	7.7
Two	6	11	17	18.7	1	5	6	6.6	-	3	3	3.3
Three	-	6	6	6.6	-	2	2	2.2	-	-	-	
Four	2	1	3	3.3	-	1	1	1.1	-	-	-	
Five	-	4	4	4.4	-	-	-		-	-	-	
Seven	-	1	1	1.1	-	1	1	1.1	-	-	-	
Nine	-	1	1	1.1	-	-	-		-	-	-	
Hotel Accommodation with young families	-	-	-		1	1	2	2.2	-	-	-	
One Child temporarily away	-	-	-		-	2	2	2.2	1	1	2	2.2
	49	42	91	100.0	49	42	91	100.0	49	42	91	100.0

However, this has occurred since the interviews took place. The patch also includes large areas of private housing, such as Drayton and Farlington. The central area also has a mixture of private and council housing. The areas of council housing tend to be concentrated near the city centre. The southern patch has private housing, council housing and, in the holiday resort of Southsea, larger, Victorian houses that are often let as flats or bedsits. There is also a concentration of private lodgings and rest-homes in this area.

The distribution of the sample is shown below in Figure 4.1. The largest single group of patients lived in the southern area. A possible reason for this uneven distribution is the differences that may exist in prescribing practice, since each patch has a different consultant psychiatrist. However, a more likely explanation is that the Southsea area, with its private lodgings, offers a more suitable type of accommodation; 38 out of the 91 respondents lived in the Southsea area of the southern patch.

Fig. 4.1

Area Distribution of the Sample



Because the data showed these differences in distribution of the sample, it was decided to look at possible differences between the patches in greater detail in order to identify any special needs in terms of service in each area. The results are described in Chapter 7.

(iii) Accommodation

With the current emphasis on community care, a main area of investigation was that of accommodation. It was vital to establish where and with whom the respondents were living: for example, the number living with family supporters, the number living alone, and the number living in landlady accommodation. (Table 4.5)

Table 4.5

Types of Accommodation

Accommodation	Male	%	Female	%	Total	%
Own Property	7	14	17	40	24	26.4
Council rent	8	16	9	21	17	18.7
Private rent	3	6	2	5	5	5.5
Rented bedsit	2	4	2	5	4	4.4
Unsupervised lodgings	3	6	1	2	4	4.4
Supervised lodgings or nursing home	6	12	8	19	14	15.4
Group home	6	12	0	0	6	6.6
Reception centre	2	4	0	0	2	2.2
Relative's home	12	24	3	7	15	16.5
TOTALS	49	98	42	99	91	100.1

There were major differences between the sexes for home ownership. More than a quarter of the sample owned their own homes and the majority of these were females (71%). This was probably due to the higher number of married women as 79% (3 males and 16 females) of home owners were married or had been married, and only 5 were single (4 males and 1 female). It is probable that this single group had inherited the property from parents. Of the female home-owners who were no longer married, 2 were divorced and 1 was widowed.

Nearly one third of the sample interviewed lived in council, or privately rented accommodation, including bedsit or unsupervised lodgings. No respondents living in these latter two groups were married at the time of the survey.

The 14 respondents living in supervised lodgings or nursing homes were all unmarried and there were no significant differences between the sexes in this group. However, the 6 patients living in the group homes and the 2 patients living in reception centres were all males. A much higher number of males than females lived in relatives' homes. Of these, only one was living with his sister. The remaining 11 men and 3 women were all single and living with their parents.

Therefore, the evidence showed that again there were major differences between the sexes in this particular area of accommodation. More females than males owned their own homes and more males than females lived in group homes and with parents. The differences in marital state no doubt play a significant part in these divisions.

(iv) Length of Time in Accommodation and Access to Facilities

More than half the respondents had lived in their accommodation for more than 5 years: in fact, 34 had lived there for more than 10 years (Table 4.6). Only 10 patients had had their accommodation for less than 6 months: the 8 males in this group lived in a variety of settings, including landlady accommodation (3 men), reception centre (1 man), council and private rented property (2 men) and with relatives (2 men).

Table 4.6 Length of Stay in Accommodation

Length of Stay	Male	%	Female	%	Total	%
Less than 6 months	8	16	2	5	10	11.0
6 months - 1 year	5	10	4	10	9	9.9
1 - 2 years	4	8	3	7	7	7.7
Over 2 years, less than 5 years	10	20	8	19	18	19.8
5 - 10 years	4	8	9	21	13	14.3
More than 10 years	18	36	16	38	34	37.4
TOTALS	49	98	42	100	91	100.1

Basically, then, the groups were surprisingly stable: 44% of males and 59% of females had lived in their accommodation for five years or more. Those who had lived in accommodation for less than 6 months were predominately males, half of whom lived in landlady accommodation or reception centres. Interestingly, differences between the sexes also existed in the group 5 - 10 years; the other groups showed little differences proportionally.

Other than those living in bedsits, most patients had access to more than one room. Of course, those living in lodgings, nursing homes and group homes were restricted to their own rooms plus communal facilities. On the whole, access to these facilities appeared to be generous. Some lodgings or rest-homes allowed only supervised access to specific areas, for example, offices or kitchens.

More than half the patients had their own bedrooms; a quarter of the respondents who were married shared their bedroom with their spouse; and, other than one man and one woman, the remainder were those who lived in supervised lodgings or nursing homes and usually shared with one or more non-relatives. However, 3 such residents had their own bedrooms. Neither of the two patients mentioned above slept in a bedroom. The male patient, although he did have a bedroom, always slept fully clothed in an armchair. The female was sleeping on a mattress in the sparsely furnished bedsit of her brother.

A total of 16 patients had no access to cooking facilities. Most of these were living in supervised accommodation where all meals were provided by the landlady, and 2 respondents were living in bed and breakfast accommodation. One other male living in unsupervised lodgings had obtained a cooking ring, unknown to the landlord. The other 80% of the sample had full access to a kitchen or kitchenette.

The majority of patients had access to a sitting room. Those who did not (12%) tended to live in bed and breakfast accommodation or a bedsitting room. Slightly more than a quarter of the respondents shared with more than one non-relative and these were mainly those patients living in group homes and supervised or unsupervised lodgings. Almost half the patients (48%) shared with one or more relatives and 12 (13%) had their own sitting room.

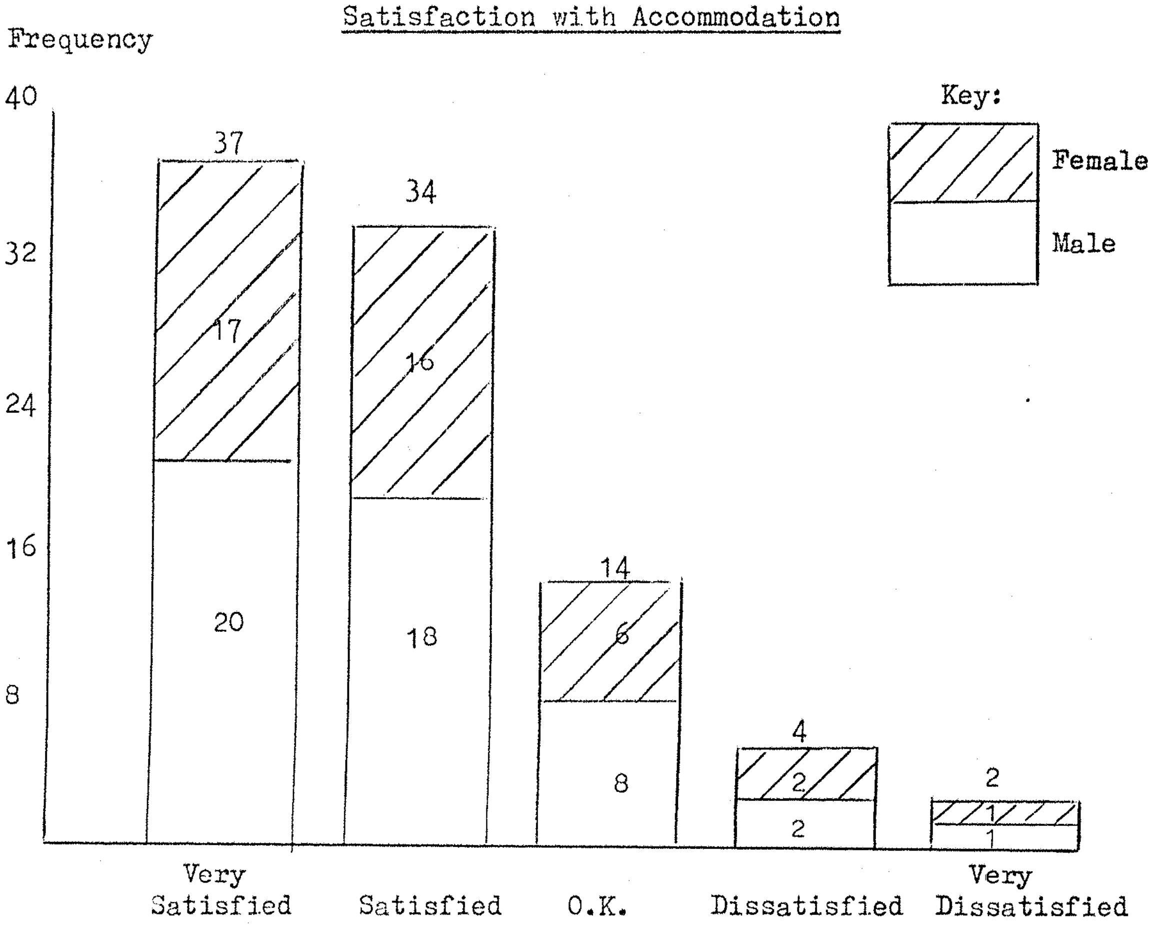
The researcher was interested in whether or not the respondents had access to a garden, partly to gain an idea of availability of space and fresh air to the individual, and also whether or not the patient had an opportunity to develop gardening as a hobby. Only 20 (22%) did not have a garden, or access to one. These patients tended to be those living in flats, bedsitting rooms or bed and breakfast accommodation. All supervised lodgings and nursing homes had gardens and residents had free access to them.

Overall, the respondents appeared to have reasonable access to facilities. Those who lived in rest homes or landlady accommodation appeared to be more restricted than those living in their own, or family accommodation, although any restrictions were kept to a minimum.

(v) Satisfaction with Accommodation

The respondents were asked if they were satisfied with their accommodation. Their response is illustrated in Figure 4.2

Fig 4.2.



Most respondents were satisfied with their accommodation (78%) and 14 (15%) said it was O.K. There was an even distribution of males and females. Only 6 respondents showed any dissatisfaction. Of the dissatisfied females, one owned her own home, one lived with her brother and one lived in supervised accommodation. Of the males, one lived in a group home and the other two lived with their parents.

(vi) Household Composition

The sample were asked who was the primary, or key person with whom they lived (Table 4.7). The largest group of females (50%) lived with their spouse or cohabitee, whereas only 14% of males did so. The largest, single group of males (22%) lived with their parents; only 7% of females lived in the parental home. The males of this group were aged between 22 and 45 years of age and were all single. It is possible that the majority of this group have never left the parental home because all but one had lived there for ten years or longer.

The largest group of men lived alone: 4 lived in their own property, possibly inherited from their parents, 1 lived in a flat owned by his mother, 2 had stayed on in council flats after the deaths of parents, 2 were in privately rented flats and 1 lived in lodgings. Therefore, it is possible that 70% of this group had been living with parents, or were helped by them.

Table 4.7 Household Composition

Household	Male	%	Female	%	Total	%
Lives alone	10	20	4	10	14	15.4
Lives with Parents	11	22	3	7	14	15.4
Lives with Spouse	7	14	19	45	26	28.6
Lives with Cohabitee	0	0	2	5	2	2.2
Lives with Other Relative	4	8	4	8	8	8.8
Lives with Landlady	8	16	5	12	13	14.3
Group Home	6	12	0	0	6	6.6
Other	3	6	4	10	7	7.7
No reply	0	0	1	2	1	1.1
TOTALS	49	98	42	99	91	100.1

Most of the respondents coded as 'Other' lived in lodgings where the landlady or landlord lived off the premises and employed staff to supervise the residents in their absence. It could be said, overall, that the majority of men were, in effect, living as lodgers, whether with landladies or relatives.

(vii) Household Responsibilities

The sample were asked whether or not they had responsibility at home for housework, shopping, laundry and cooking in order to establish whether or not they participated in these activities and if there were any differences between the men and women. (Table 4.8)

More than half the patients (56%) took sole or shared responsibility for the housework: 8 men and 12 women did the housework alone and 16 men and 15 women shared the role with one other. Landladies or homehelps took responsibility for 21 patients (11 males and 10 females). The main difference between the sexes was when the responsibility for this role was taken by a relative: 13 males and 14 females were in this third group. This result was because of the higher number of males (15) than females (6) in the sample who lived with either their parents or another relative. The majority of married women took all, or some part in housework.

More than two-thirds (29) of the female respondents either shared or took sole responsibility for the shopping but 13 women took no part (8 of this latter group lived in rest-homes). Proportionally, less men took responsibility for shopping: slightly more than half of the males (26) either shared the shopping or shopped alone. Of the 23 who did no shopping, half had their shopping done by another relative. Again, this was because of the number of men living with their parents or another relative. The 4 men who were categorised as 'none' were those who relied entirely on the meals taken at St. James' Hospital, cafeterias or take-aways.

The above pattern became exaggerated when the respondents were asked about their laundry. Half (24) of the males had their washing done by another relative; 19 took responsibility for their own laundry (5 of these shared the responsibility) and a landlady or homehelp did the washing of the remaining men. The pattern for female respondents was similar with that of shopping responsibility. Two-thirds (28) of the women took some, or all responsibility and one-third had their laundry done by a landlady (7) or other relative (7).

Table 4.8

Domestic Responsibilities

Participant	Housework Male	Housework Female	Housework Total	%	Shopping Male	Shopping Female	Shopping Total	%	Laundry Male	Laundry Female	Laundry Total	%	Cooking Male	Cooking Female	Cooking Total	%
Self	8	12	20	22	13	16	29	32	14	19	33	36	12	12	24	26
Self/Spouse	2	8	10	11	4	8	12	13	2	5	7	8	0	0	0	0
Self/Other	14	7	21	23	9	5	14	15	3	4	7	8	4	12	16	18
Spouse	2	3	5	6	1	2	3	3	3	4	7	8	3	3	6	7
Other Relative	11	1	12	13	10	3	13	14	21	3	24	26	14	4	18	20
Home Help/ Housekeeper	3	1	4	4	0	0	0	0	1	0	1	1	2	0	2	2
Landladies' Responsibility	8	9	17	19	8	8	16	18	5	7	12	13	7	8	15	17
None	1	1	2	2	4	0	4	4	0	0	0	0	7	3	10	11
TOTALS	49	42	91	100	49	42	91	99	49	42	91	100	49	42	91	101

Two-thirds of the men (33) took no part in the cooking and half these (17) had their meals prepared by another relative. Proportionally, less females took part or sole responsibility for cooking than for the other household chores: nearly half the women (18) took no part in cooking meals and of the remaining female respondents, half shared the responsibility. It is interesting to note that no married respondents shared the cooking with their spouses, unlike the other household chores.

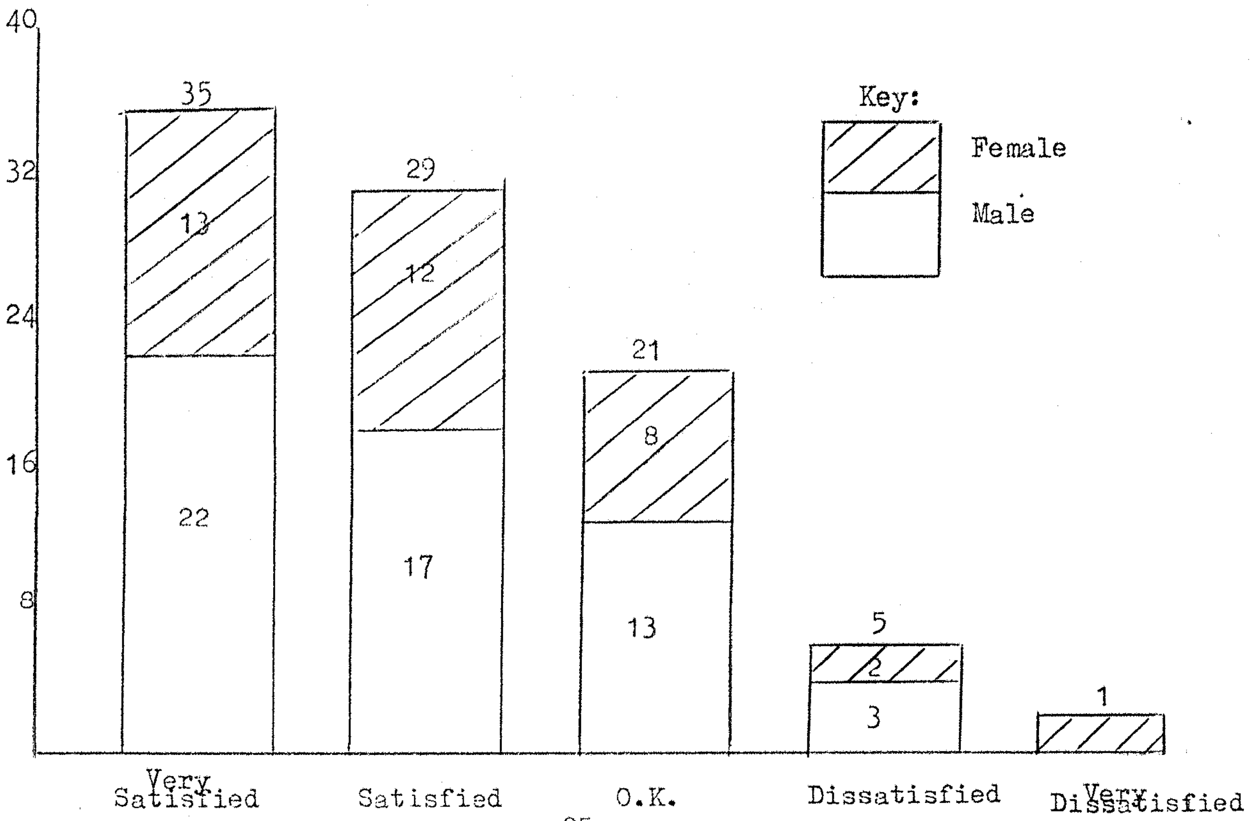
Overall, it did appear that the women took a more active role in the home than did the men. However, this is not to say that the men took little part: indeed, a considerable number participated in some, if not all activities within the household.

Relatives supported the patients in many cases and took sole responsibility in some, if not all the areas. Landladies provided full supporting services in the majority of cases. In two of the rest-homes visited, patients were encouraged to take part in some domestic chores (only if they wished) and for this a small wage was earned.

(viii) Satisfaction with Domestic Arrangements

The respondents were asked if they were satisfied with their domestic arrangements in the areas studied. Their response is illustrated below. (Figure 4.3)

Fig. 4.3 Satisfaction with Domestic Arrangements



Only 6 respondents showed any dissatisfaction with their domestic arrangements. These respondents were invited to make additional comments if they wished in order to give them the opportunity to expand on the areas in which they were experiencing difficulties. This practice was continued throughout the interview because it was envisaged that it would provide a vivid insight into the lives of the patients.

Case 012, female, aged 56

'The food is horrible, although they keep it clean.'

Case 024, female, aged 49

'The eggs are not cooked. Also, I only have a radiator behind the wardrobe. I need to dry my clothes on it.'

Case 028, male, aged 46

'The launderette is £2 a week. That's a lot of money for me.'

Case 039, male, aged 42

'I'm not used to it here. I was used to the other group home. I feel I would like a rest, but can't as it goes on all the time. What does the future hold for me?'

Case 044, female, aged 40

'I don't feel the kids pull their weight enough. Things are not as clean and tidy as I want them to be. I'm working and things get in a pickle.'

(ix) Diet

One aspect the researcher wanted to investigate was that of diet and how the patients were managing with meals. It was decided that each respondent would be asked to give details of all meals, snacks and beverages taken during the previous day. Care was taken to ensure that patients were not interviewed on Mondays as an account of the meals taken on Sunday would probably not have given a typical impression.

The dietician at St. James' Hospital examined the menu plans and graded each diet into Good, Moderate or Poor diet. Appendix 4 describes the method used to make these calculations.

Slightly more than half the sample interviewed (25 males and 22 females) had followed a good diet on the previous day; a quarter (13 males and 9 females) had followed a moderate diet; and just under a quarter (11 males and 9 females) had had a poor diet. No information was given by two of the respondents.

The table below (Table 4.9) shows the distribution of the diets followed and where the patients were living.

Table 4.9

Standard of Diet Followed by Respondents

Accommodation	Good Diet	%	Moderate Diet	%	Poor Diet	%	Total	%
Own Property	10	43	6	26	7	30	23	99
Council Rent	8	47	5	29	4	24	17	100
Private Rent	3	60	1	20	1	20	5	100
Rented Bedsit	2	50	2	50	0	0	4	100
Unsupervised Lodgings	2	50	2	50	0	0	4	100
Supervised Lodgings	13	100	0	0	0	0	13	100
Living With Relatives	6	40	4	27	5	33	15	100
Group Home	1	17	2	33	3	50	6	100
Reception Centre	2	100	0	0	0	0	2	100
No Information	-	-	-	-	-	-	2	-
TOTALS	47		22		20		91	

The 'Poor Diet' group seem to be concentrated in their own homes or relatives' homes. This could be because of poverty and/or little idea of nutrition and following a balanced diet. In fact, nearly a third of all patients living in their own homes and a third of patients living with a relative had taken a poor diet.

Of those patients in group homes, 3 had followed a poor diet. However, one of the group homes visited had only that day obtained the services of a paid housekeeper, part of whose role was to cook the residents a meal.

All those patients living in fully supervised accommodation received a good diet and none of the sample living on unsupervised lodgings had received a poor diet.

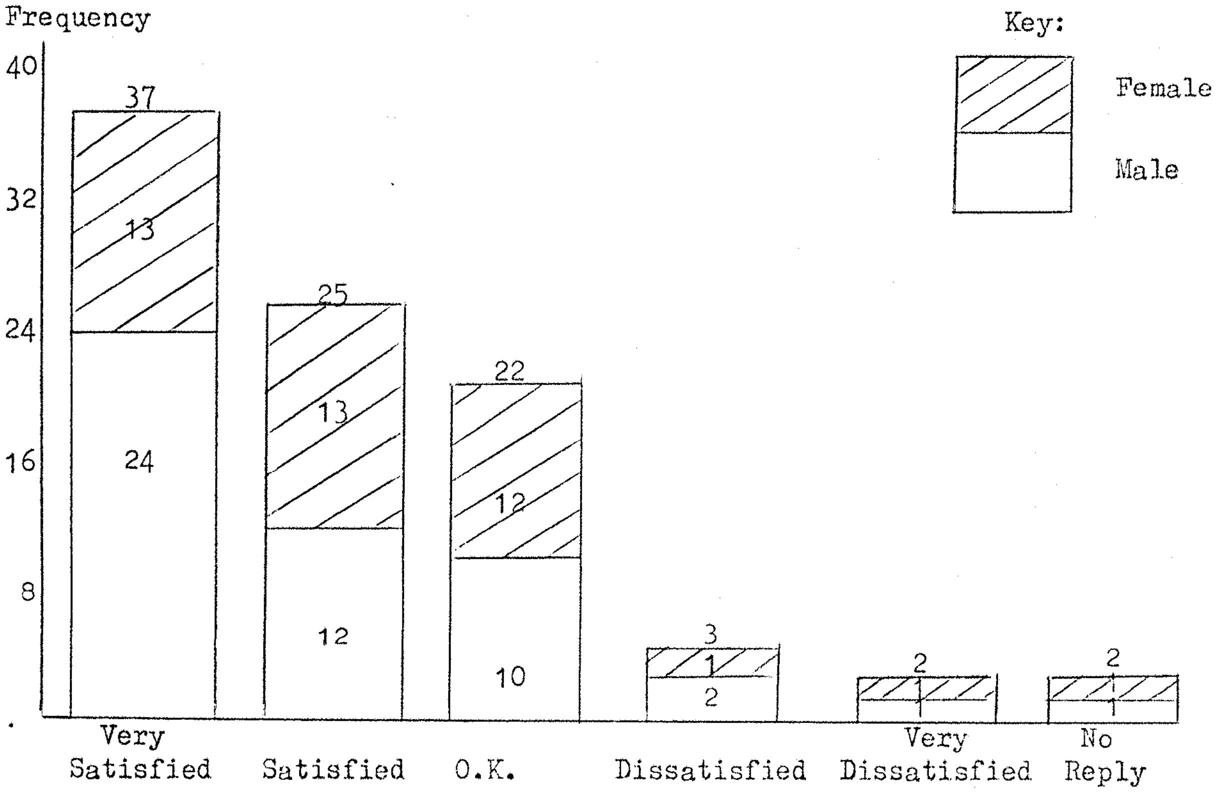
More than half the sample interviewed (57%) normally took three or more meals a day and 24% normally had two meals a day. The remaining 19% took only one meal a day. There were no significant differences between the males and females. None of the group who took one meal a day lived in a supervised setting.

For the patients who attended St. James' Hospital as day-patients, a mid-day meal was provided at one of the centres in the hospital. The researcher gained the impression that these patients relied upon this support, and that, on the whole, they would experience difficulties without it.

(x) Satisfaction with Meal Arrangements

The respondents were asked about their degree of satisfaction with their meal arrangements. The majority of the sample (92%) showed no dissatisfaction; 5 patients (6%) said they were dissatisfied and 2 females gave no reply.

Fig. 4.4 Satisfaction with Meal Arrangements



One pattern that has emerged from the data is that there were major differences between the males and females in the sample interviewed, and these differences have been highlighted. On the whole, the male respondents in the sample seemed to experience more difficulties than the females in many of the areas looked at so far, although little dissatisfaction was expressed by the respondents. A higher number of females appeared to take on a more active role in the home than did the males. Therefore, it will be interesting to see if the males in the sample had a role to play outside the home: that is, whether or not they were able to achieve some occupational status. The following section examines the educational standard achieved and occupational status of the respondents.

Chapter 5

Education, Occupation During the Day and Income

(i) Education

The investigation looked at two main aspects of education: that of formal education, whether at school, college or university, and work-training. The majority of the sample had left school at the minimum school leaving age. A total of 9 respondents had not left school until eighteen years or older, and in this group major differences existed between the sexes as only one was female. (Table 5.1)

The researcher was interested in comparing the respondents' educational and work-training opportunities with their levels of achievement. More than three-quarters of the respondents had left school with no qualifications, the remainder (14 males and 7 females) having obtained either the School Certificate, 'O' and 'A' levels (3 patients had 'A' level certificates) or secretarial qualifications. (Table 5.1). The data showed that 5 respondents (4 males and 1 female) had pursued degrees: 2 had not completed their first degrees and 3 males had failed to obtain post-graduate degrees, although they had successfully obtained first degrees. Of these 5 respondents, 4 had abandoned their studies because of psychiatric illness. In these cases, each individual's maximum potential had not been reached because of the crippling effects of schizophrenia.

Almost half the respondents had had some form of work-training, for example, 3 women had received professional training and 10 males had obtained apprenticeships. Again, there were differences between the sexes in all groups: more males than females had work-training, particularly among those who had left school at fifteen years or below. More than two-thirds of the respondents who had participated in some form of work-training or further education completed their courses. The respondents who failed to complete were invited to comment further. Their replies are summarised in Table 5.2. Of the 29 men (59% of the total males) who attempted further work-training, 11 (38%) failed to complete their training. Among the women, only 12 (29%) continued in further training, although the drop-out rate was smaller compared to that of the men. Half of the group failed to complete their courses because of psychiatric illness and, interestingly, all of these were participating in higher education.

Table 5.1

Formal Education and Work-Training of the Sample

Highest Level of Education Achieved/Attempted	Males	%	Females	%	Total	%
Left school at 14 years						
- no further training	4	8	11	26	15	16
- apprenticeship/work training	6	12	1	2	7	8
Left school at 15 years						
- no further training	10	20	14	33	24	26
- apprenticehip/work training	9	18	5	12	14	15
Left school at 16 years						
- no further training	3	6	5	12	8	9
- apprenticeship/work training	9*	18	5*	12	14	15
* One male and one female from these groups attempted first degrees, but failed						
Left school at 18 years or above						
- no further training	3	6	0	0	3	3
- apprenticeship/work training	2	4	1	2	3	3
- gained first degree	3*	6	0	0	3	3
* These three males also attempted Master's Degrees, but failed						
TOTALS	49	98	42	99	91	98

Table 5.2

Reasons for Non-Completion of Higher Education/Work-Training

Reason Given for Failure to Complete	Male	Female	Total
Had a nervous breakdown	4	2	6
Involved in illegal drug taking	1	0	1
It was the wrong job	1	0	1
Did not have the ability	2	0	2
Financial difficulties	1	0	1
The firm went bankrupt	1	0	1
Moved house and area during the war	1	0	1
TOTALS	11	2	13

Overall, it appeared that the men in the sample had more educational opportunities than the women, both in formal education and work-training. Two-thirds of the sample left school at fifteen years of age or younger, and only 19% of the women in this group attempted work-training, compared with 52% of men in the group. This gap was narrowed somewhat in the group that left school at sixteen years or above: 55% of women in this group, compared to 70% of men, took on further training.

The study looked at the employment levels of the sample at the time of interview: the following section describes this data. Alarmingly, it became apparent that despite past achievements, both in formal education and work-training, many of the patients were unemployed. Therefore it could be said that schizophrenia had destroyed much of the potential of its victims.

(ii) Present Occupation

The employment situation of the members of the sample is summarised in Table 5.3, and it will be seen that the vast majority were unemployed at the time of the interview (87%). Only 7 (8%) were in full-time employment and all of these were over 30 years of age. Another four respondents were working part-time, or occasionally. One was on sick-leave, waiting for early retirement.

Table 5.3: Employment Situation of the Sample

Employment	Male	%	Female	%	Total	%
Unemployed	41	83	38	90	79	86.8
Full-time	5	10	2	5	7	7.7
Part-time	1	2	2	5	3	3.3
Casual	1	2	0	0	1	1.1
Awaiting early Retirement	1	2	0	0	1	1.1
TOTALS	49	99	42	100	91	100.0

The unemployment level at the time of the interviews in Portsmouth stood at a little over 12%. The unemployment level for the south-eastern region as a whole was 10%. Therefore, major differences existed between the sample and the general population: on the whole, living with schizophrenia meant living without a job.

Of those in employment, 1 male had managerial status, 4 respondents (2 males and 2 females) had non-manual occupations, 5 (3 males and 2 females) had semi-skilled manual jobs and 2 males were employed as unskilled labour.

Somewhat surprisingly, those in employment had good records. Five of the eight men had held their jobs for more than five years, and only three patients (1 male and 2 females) had been in their situation for less than six months.

Only one man showed any dissatisfaction with his job (Table 5.4): he was on sick leave, waiting for early retirement

Table 5.4

Satisfaction with Occupation

Degree of Satisfaction	Male	Female	Total	%
Very Satisfied	4	0	4	33
Satisfied	3	2	5	42
O.K.	0	2	2	17
Dissatisfied	0	0	0	0
Very Dissatisfied	1	0	1	8
TOTALS	8	4	12	100

(iii) Past Employment

Although few of the sample were still working, almost all had had some work experience, as shown in Table 5.5. Only two men had never worked. Most of the respondents, however, had not worked recently, that is, within the two year period before interview: in fact, all patients over 45 years of age were in this group.

Table 5.5

Last Job Held

Length of Time Not Working	Male	%	Female	%	Total	%
Less than 6 months	3	6	1	2	4	4.4
6 months - 1 year	1	2	2	5	3	3.3
More than 1 year, less than 2 yrs	5	10	1	2	6	6.6
2 years or longer	30	61	34	81	64	70.3
Never worked	2	4	0	0	2	2.2
Presently Employed	8	16	4	10	12	13.2
TOTALS	49	99	42	100	91	100.0

The majority of respondents had, at some time, held a job for more than a year: only 8 of those who had previously worked (5 males and 3 females) had never held a job for this long (Table 5.6)

Table 5.6

Longest Length of Time in Any One Job

Length of Time in Job	Male	%	Female	%	Total	%
More than a month, less than 6 months	1	2	1	2	2	2.2
6 months - 1 year	4	8	2	5	6	6.6
More than 1 year, less than 3 years	11	22	10	24	21	23.1
More than 3 years, less than 5 years	4	8	5	12	9	9.9
5 years or longer	26	53	19	45	45	49.5
Never Held a job	2	4	0	0	2	2.2
Not known	1	2	5	12	6	6.6
TOTALS	49	99	42	100	91	100.1

Many of the respondents had held responsible positions in the past: Table 5.7 identifies the best, or most responsible jobs the individuals in the sample had held. Since the majority of the sample were unemployed at the time of the interviews, it must be true to say that the degree of handicap experienced by the respondents had led to a subsequent decline in their employability on the open market, which, in turn, would have affected the other areas of their lives.

More than half (53%) of the respondents had been in skilled manual, non-manual, managerial or professional occupations. It would seem probable that the respondents who had been in such positions had varying degrees of autonomy and responsibility. Most of these were not now working.

Overall, the employment situation of the sample gave rise to grave concern, since 87% were unemployed at the time of interview, even though the majority, in the past, had held jobs of varying responsibility for a year, or more. Despite the fact that more than three-quarters of the sample had left school with no qualifications, more than half the respondents had undergone some form of work-training. In fact, 3 women had had professional training, 10 men had completed apprenticeships and 5 respondents (4 males and 1 female) had participated in one or more degree courses.

Table 5.7

Past Employment Levels Achieved by the Respondents

Occupation	Male	%	Female	%	Total	%
Professional	1	2	0	0	1	1.1
Managerial/Executive	6	12	3	7	9	9:9
Non-Manual	8	16	13	31	21	23.1
Skilled Manual	10	20	7	17	17	18.7
Semi-Skilled Manual	7	14	12	29	19	20.9
Unskilled Manual	9	18	3	7	12	13.2
Armed Forces	6	12	4	10	10	11.0
No Job	2	4	0	0	2	2.2
TOTALS	49	98	42	101	91	100.1

Despite this past achievement, only 12 respondents (8 males and 4 females) held jobs at the time of interview. In fact, only 28% of the sample (17 males and 8 females) had worked at all in the two years before interview.

There were differences between the sexes in that more males left school with qualifications, continued in higher education, had some form of work-training and were employed at the time of interview.

(iv) The Unemployed

The members of the sample who were not in employment, that is, the large majority, posed a problem for themselves and for the medical and social services for, as we have seen in Chapters 1 and 2, schizophrenia is best controlled when patients achieve a balance between being over-stimulated on the one hand and sinking into a passive state on the other.

However, despite this, only 17 patients were attending a centre at St. James' Hospital and only 2 of these were females. Of these patients, 6 (5 males and 1 female) attended the Industrial Therapy Department, 4 men attended Occupational Therapy and a further 3 men did the gardening at the hospital. Of the remaining males, 1 attended both Industrial and Occupational Therapy, 1 attended Art Therapy for one session per week and 1 attended the Canteen and Entertainments Hall on a non-structured basis. One female worked at the Nurse Teaching Unit where she completed general tasks, such as making coffee. Twelve of the patients attended five days a week and the other five attended for part of the week only. Only 3 patients had been attending for less than a year.

Only 1 male attended a centre outside the hospital, which was run by a local church. None of the patients were attending the Employment Rehabilitation Centre or the Skill Centre in Portsmouth at the time of interview.

Of those unemployed patients not attending a centre during the day, 17 (12 males and 5 females) were currently looking for work. A small proportion (1 male and 6 females) had retired and a further 12 females said they had a role looking after the house and family. The remaining 26 patients were invited to comment on why they were not looking for employment: the largest group (15 patients) said it was because of their illnesses, either that they could not cope with a job or because of specific symptoms; 2 said it was because of side-effects of medication; another 2 respondents felt they were nearing retirement anyway; 3 gave financial reasons and 2 said they were quite happy as they were. Some example of the replies are presented below.

Case 012, female, aged 56

'I did work, but the money was not good enough. I am better off as I am.'

Case 046, male, aged 39

'I'm quite happy on the dole. I've been disillusioned so many times that I've given up. You need 'O' levels to be a dustman these days.'

Case 051, female, aged 37

'I was looking for something part-time, but there's nothing around. A whole day would be too much for me to cope with.'

Case 056, male, aged 34

'I'm schizophrenic and can't cope with work........people would notice I'm a bit odd. Once you've mentioned this place (St. James' Hospital) you've had it.'

Case 068, male, aged 24

'I can't look for a job whilst on medication. It makes me shaky and therefore I couldn't use machinery.'

Case 102, female, aged 31

'I haven't enough bus-fares to get around.'

(v) Occupation during the Day

The patients were asked to describe their previous day in some detail, for example, their activities and with whom they spent their time. (See the Time Budget included in Appendix 3). Brown and his colleagues had used a similar method in their study of discharged schizophrenic patients (Brown et al,1966) and so had Mitchell and Birley (1983) in their study into the use community psychiatric patients made of ward support.

The aim in this study was to gain some insight into how this particular group of patients spent their time. No interviews had taken place on Sundays or Mondays and this, therefore, avoided a description of the week-end days which probably would not have given a true impression of the time spent.

As much detail as possible was taken of the respondents' previous days. Nevertheless, the accuracy of some of the accounts could not be verified and, therefore, it must be assumed there is some degree of error. All but two of the respondents (1 male and 1 female) completed the time-budgets. The sample interviewed spent an average of 14 hours as waking hours: the maximum being 20 waking hours and the minimum was a 34 year old man who had spent only 8½ hours awake. Most respondents (69%) had spent between 12 and 16 hours awake.

The research looked at how the patients had spent their waking hours during the previous 24 hours (Table 5.8 and 5.9). All the data that follows refers to waking hours only. A total of 13 patients had spent no time alone. The maximum amount of time spent alone was 16½ hours (by a male respondent); 27 (15 males and 12 females) had spent between 4 and 8 hours alone; and another third (19 males and 11 females) had spent 8 hours or longer alone. The male respondents therefore appeared to have spent more time alone than did the females.

More than half the sample had spent less than 4 hours with relatives (Table 5.9): in fact, 39 respondents (43% of the sample) had spent no time with their relatives. A further 11 respondents (6 males and 5 females) had spent between 4 and 8 hours and 26 patients (7 males and 19 females) had spent more than 8 hours with their families. For 17 of this latter group, the amount of time exceeded 12 hours. The high number of females in this case was because of the higher number of married women in the sample.

Table 5.8

Time Spent Alone During The Previous Day

Number of Hours Spent Alone	Male	%	Female	%	Total	%
Under 4 hours	13	27	18	43	31	34.1
4 to under 8 hours	15	31	12	29	27	29.7
8 to under 12 hours	16	33	7	17	23	25.3
12 to under 16 hours	3	6	4	10	7	7.7
16 to under 20 hours	1	2	0	0	1	1.1
More than 20 hours	0	0	0	0	0	0
No Information	1	2	1	2	2	2.2
TOTALS	49	101	42	101	91	100.1

Many respondents had spent little time with other patients, or ex-patients (Table 5.9): 18 patients (15 males and 3 females) had spent between 4 and 8 hours with other patients and some of the patients in supervised lodgings or rest-homes had spent more than 12 hours in the company of other ex-patients. The high number of men in this group is because of the attendances to centres at St. James' Hospital.

On assessing the total number of waking hours spent with others, it was found that the majority (80%) had spent 4 hours or more in the company of others and, in fact, one-third of the sample had spent 12 hours or more with others. There were no particular differences between the sexes although, overall, it did appear that more males than females spent less time with relatives and more time with non-relatives, particularly other patients.

Two-thirds of the sample had spent some, or all of their time in the company of just one other: in fact, 15 respondents had spent in excess of 8 hours with one other, the majority of whom was another relative with whom the patient was living.

Two-thirds of the patients (64) had spent more than 8 of their waking hours in the home. Of those patients who had spent time out of the home, 8 had spent between 5 and 9½ hours at work; 19 had spent between 1½ and 10 hours at St. James' Hospital; and 5 had spent time at a community club (between 1½ and 2½ hours) or community day centre (6½ hours). A total of 12 patients had spent more than 4 hours out of the home in other structured activities, such as shopping and visiting friends or relatives. Time was spent by 3 patients in days out, for example, on a coach trip. Another patient had worked voluntarily for several hours in the National Schizophrenia Fellowship shop. A further 14 patients (10 males and 4 females) had spent time out of the home in unstructured activities, for example, walking the streets: 3 patients had spent between 3 and 5 hours and another had spent 7 hours in unstructured activity.

The activities in which the respondents participated were divided into passive activities (for example, watching television, listening to the radio, or reading) or active activities (for example, gardening, sewing or participation in a sport). Slightly more than a third of patients had spent more than 4 hours watching the television: of these, 2 males and 7 females had spent more than 8 hours and a further 2 female patients had spent more than 12 hours watching television.

Table 5.9

Amount of Time Spent With Others During the Previous Day

	Relatives						Patients or Ex-Patients						Total Time Spent With Others					
Number of Hours	Male	%	Female	%	Total	%	Male	%	Female	%	Total	%	Male	%	Female	%	Total	%
Less than 4	35	71	17	40	52	57	25	51	32	76	57	63	10	20	6	14	16	18
4 to less than 8	6	14	5	12	11	12	15	31	3	7	18	20	13	27	6	14	19	21
8 to less than 12	2	4	7	17	9	10	4	8	2	5	6	7	12	24	12	29	24	26
12 to less than 16	5	10	11	26	16	18	4	8	4	10	8	9	13	27	16	38	29	32
16 to less than 20	0	0	1	2	1	1	0	0	0	0	0	0	0	0	1	2	1	1
20 or more	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
No Information	1	2	1	2	2	2	1	2	1	2	2	2	1	2	1	2	2	2
TOTALS	49	101	42	99	91	100	49	100	42	100	91	101	49	100	42	99	91	100

However, only 15 patients (10 males and 5 females) had spent more than 4 hours listening to the radio or records: 3 of these had spent more than 8 hours and 1 respondent had spent more than 12 hours in this activity. Some of the respondents listened to the radio whilst engaged in other activity, for example, housework. Only 3 respondents spent more than 4 hours reading, although a third of the sample interviewed had read something during the day (in fact, several had spent between ½ hour and an hour looking at the newspaper).

Almost half the respondents (34 males and 19 females) had spent some time doing nothing: 15 (11 males and 4 females) had spent more than 4 hours doing nothing and 4 of these had spent more than 8 hours unoccupied. In this latter group, 2 were from supervised accommodation, 1 lived in a group home and 1 was a married man living with his family.

Some of the respondents had participated in an activity in which they took an active part, for example, domestic duties or a hobby such as gardening. Chatting with friends or relatives was classified as active and two-thirds of the sample interviewed had talked with others. The exact assessment of time spent in conversation with others was difficult in some instances, for example, if a patient had been in a sitting room with others and had been chatting for some of the time, but not all. In all cases, patients were prompted during the interview to give detailed information in these circumstances. It appeared that one-third (18 males and 13 females) of all the sample had not talked with others for at least half an hour; one-third (28) had talked between ½ hour and 4 hours; and one-third had chatted for more than 4 hours.

More males than females took no part in housework during the previous day (31 males and 17 females): another 38 respondents (16 males and 26 females) had done between ½ hour and 4 hours housework and 13 respondents had done more than 4 hours housework and all but one of these were females.

Active hobbies or interests such as gardening, sewing, going out to a sporting event were accounted for. Half the respondents (46) took no part in such an activity; 38 of the sample spent between ½ hour and 4 hours and 5 patients spent more than 4 hours in active recreation. One quarter of the sample interviewed had spent time visiting friends or relatives. There were no differences between the number of males and females who visited and only 5 respondents visited for 4 hours or more.

Overall, it appeared that the females in the sample had spent more time than the males in the company of others and had more structure to their day. The women had more contact with relatives and had taken far more of an active role within the home. The men in the sample seemed to be more dependent on the hospital than the women: there were major differences in the numbers attending day centres at St. James' Hospital and more contact with other patients was made by the men. The men also spent more time out of the home in unstructured activities, for example, walking the streets. Both the men and women spent a number of hours in passive activities: the women spent more hours than the men watching the television, yet the men had spent more time listening to the radio or records. There were major differences between the sexes in the amount of time spent doing nothing: the men spent many hours unoccupied. Again, this emphasises the fact that the majority of female respondents played more of an active role within the home, although not on every occasion.

(vi) Income

The sample were asked how much money they received each week: if married, the amount of joint income (Table 5.10). Nearly a third of the sample received between £41 and £60 per week. More than half the respondents had a personal income of £60 per week or less and there were more males (70% of males) than females (45% of females) in this group. Patients who received less than £20 (6 males and 4 females) were those who lived in accommodation with full board and had their rents paid directly by the DHSS. Of all the respondents, 19 had their rents paid in this way.

A total of 15 patients (7 males and 8 females) received more than £101 per week: these were 8 married women whose husbands were working, 4 working males, 2 unemployed married men whose wives were working, and 1 unemployed man in supervised lodgings who was responsible for paying his own rent.

The income for 80% of the sample came from public funds in the form of sickness, invalidity or social security benefits and state pensions. Overall, it was difficult to obtain exact figures on the amount of income received because some patients had rents paid directly to landladies. However, the impression gained was that the majority of patients lived below the 1985 estimate of average annual gross household income for the Portsmouth area of £11,623 (figures estimated by Brettell and Robinson, 1986).

Table 5.10

Distribution of Income

Amount Received Each Week	Males	%	Females	%	Total	%
£20 or less	4	8	6	14	10	11.0
£21 - £40	12	25	4	10	16	17.6
£41 - £60	18	37	9	21	27	29.7
£61 - £80	5	10	5	12	10	11.0
£81 - £100	2	4	5	12	7	7.7
£101 or more	7	14	8	19	15	16.5
Not Known	1	2	2	5	3	3.3
No Reply	0	0	3	7	3	3.3
TOTALS	49	100	42	100	91	100.1

(vii) Patterns of Expenditure

The research looked at how the patients managed their money and how much responsibility they took for their expenditure, for example, buying clothes.

Less than one-third of the sample took responsibility for the payment of rent or mortgage (18 males and 9 females). The patients' spouses took responsibility in 18 of the cases (5 males and 13 females) and the patients' parents or other relatives did so on 16 occasions (12 males and 4 females).

Three-quarters of the sample interviewed spent less than £1 per week on alcohol; 11 respondents spent between £1 and £5; 9 spent between £5 and £10 and 2 men spent in excess of £10 per week. The men in the sample spent more than the women, although the majority of respondents spent very little on alcohol.

However, less than a third of respondents spent under £1 per week on tobacco or cigarettes, and only 6 respondents spent between £1 and £5 per week. More than a third of patients spent between £5 and £10 and a further quarter spent more than £10 per week on tobacco. The habit was shared by both the men and women in the sample and it did appear that in some cases all pocket-money was being spent on cigarettes and tobacco.

Table 5.11

Amount of Income Spent on Alcohol and Tobacco

	Alcohol						Tobacco					
Amount Spent Each Week	Male	%	Female	%	Total	%	Male	%	Female	%	Total	%
Less than £1 per week	34	69	35	83	69	76	14	29	15	36	29	32
£1 - £5	7	14	4	10	11	12	4	8	2	5	6	7
More than £5, less than £10	6	12	3	7	9	10	19	39	13	31	32	35
£10 or more	2	4	0	0	2	2	12	24	11	26	23	25
Not Known	0	0	0	0	0	0	0	0	1	2	1	1
TOTALS	49	99	42	100	91	100	49	100	42	100	91	100

These dramatic figures probably reflect the fact that the majority of patients had spent considerable amounts of time in psychiatric hospitals where cigarettes and tobacco are used as a means of social control.

It appeared that the '30 to 45' age-group spent more money on tobacco than those patients under 30 or over 45 years of age (Table 5.12). More than two-thirds (69%) of this age group spent £5 or more per week on tobacco. The highest proportion of non-smokers (or those who spent under £1 per week on tobacco) were over 45 years of age.

Table 5.12

Distribution of Income Spent On Tobacco Across Age-Groups

Income Spent on Tobacco	Under 30 Yrs.	%	30-40 Yrs.	%	Over 45 Yrs.	%	Total	%
Under £1	3	33	9	25	17	36	29	31.9
£1 - £5	2	22	1	2	3	6	6	6.6
More than £5, less than £10	3	33	13	36	16	34	32	35.2
£10 or more	1	11	12	33	10	21	23	25.3
Not Known	0	0	1	2	0	0	1	1.1
TOTALS	9	99	36	98	46	97	91	100.0

Nearly one-third of the respondents (17 males and 9 females) said they never bought new clothes: they would either buy from jumble sales or be given clothing by relatives or landladies. The majority of this group (80%) spent £5 or more per week on tobacco. A further 21 respondents (10 males and 11 females) said they rarely bought clothing (i.e. once a year or less); 26 (13 males and 13 females) said they occasionally did (i.e. 2 to 4 times a year); and 15 patients (9 males and 6 females) frequently bought clothes. 78% of patients (34 males and 37 females) chose their own clothes and a further 7 (5 females and 2 males) took part in the choice of their clothing. But 10 males and 3 females had clothes chosen by others, for example, relatives, friends or landladies.

Half the sample said they ran out of money and there were twice as many males than females in this group: 19 (13 males and 6 females) said they ran out every week and, again, the majority of these (73%) spent £5 or more on tobacco. A further 10 patients (4 males and 6 females) ran out of money on numerous occasions but not every week; and 17 (13 males and 4 females) occasionally had no money. Some patients (12 males and only 2 females) borrowed money from friends or relatives when this occurred, 8 (5 males and 3 females) used their savings and 2 (1 male and 1 female) used a bank overdraft. The remainder managed somehow, usually going without cigarettes, tobacco or alcohol. One man said he went without food.

A total of 20 patients showed dissatisfaction with their income (Figure 5.1): all of these said simply that they did not have enough money. Another third (18 males and 11 females) said it was O.K. Only half the sample showed positive satisfaction with the level of their income.

Fig. 5.1

The poverty trap in which many of the patients were caught affected other areas of their lives, for example, few, if any, could ever buy their own homes (unless they inherited from parents). On a day-to-day basis, many could not afford bus-fares, a night out, or payment for club memberships or course fees. These restrictions affected the social lives and relationships of the patients. The following section looks at these areas of the patients' lives.

Chapter 6

Relationships

This section of the research, simply entitled 'Relationships', attempts to describe the amount of interaction and involvement with others the patients were having at the time of the interviews. The respondents' family structures and the contacts they had with their relatives are described, as well as their relationships outside the family environment. The respondents were also asked about their social lives during the previous week before the interview in order to gain an impression of their involvement with the community and activities with others.

A crucial aspect of this area of investigation was to gain an insight into how the patients were experiencing their relationships with others. All the respondents were asked for their comments during this part of the interview, and some of these are presented in the following pages. The research did not explore the situation from the relatives' point of view and, therefore, their views may well have differed from that of the patients.

(i) Family Structure and Contact with the Family

A Family Tree was devised (Appendix 2) in order to gain information about the structure of the respondents' families at the time of the interview. Martin and Webster (1971) had used a similar technique in their investigation of the social consequences of conviction. This method was partly used to add interest to the interview and thus aid the respondents' concentration, and partly to obtain accurate information about the structure of the family. The majority of respondents appeared to enjoy the exercise, which took part early in the interview, and the researcher felt it did, therefore, add interest. By using a structured diagram, the researcher was able to record the contact made with the close relatives in the family (this covered parents, children, brothers etc.), but did not include distant relatives. However, contact with distant family members was also taken into account (Table 6.1).

The purpose of this exercise was to see whether patients were in contact with some, or all of their relatives, or whether they had lost contact with family members. Table 6.1 summarises the comparison made between the numbers of existing family members and the numbers seen within the last year. Two of the women in the sample refused to give any information about the contact with their families.

Table 6.1:

Comparison Between The Numbers of Living Relatives And The Numbers Seen Within The Last Year

Number of Relatives	Relatives Seen										
	None	5 or less	6 - 10	11 - 15	16 - 20	21 - 25	26 or More	Not Known	No reply	Total	%
None	1	-	-	-	-	-	-	-	-	1	1.1
5 or less	1	-	-	-	-	-	-	-	-	1	1.1
6 - 10	4	8	6	-	-	-	-	-	-	18	19.8
11 - 15	-	2	5	3	-	-	-	-	-	10	11.0
16 - 20	1	-	7	3	3	-	-	-	-	14	15.4
21 - 25	-	1	1	1	-	-	-	-	-	3	3.3
26 or more	-	1	2	11	5	1	4	-	-	24	26.4
Not Known	2	4	5	5	-	-	-	2	-	18	19.8
No Reply	-	-	-	-	-	-	-	-	2	2	2.2
TOTALS	9 9.9	16 17.6	26 28.6	23 25.3	8 8.8	1 1.1	4 4.4	2 2.2	2 2.2	91 100.1	100.1

The majority of respondents (96%) had families of six or more members: only one respondent said he had no living relatives to his knowledge. In fact, more than a quarter of the respondents had large families of 26 or more relatives, although only 4 of this group had had contact with this number in the year before interview. On the whole, the sample appeared to have had reasonable contact with family members although 9 respondents had had no contact in the previous year.

Of the group who had had no contact, all but one were single and lived either in rest-homes or landlady accommodation. There were more females (6) than males (3) in this group. Of those patients who had seen 5 relatives or fewer (9 men and 7 women), 5 patients lived alone, 3 lived with their parents, another 3 lived in group homes, 4 lived in landlady accommodation or rest-homes and one patient was married and lived with her husband.

The married respondents were asked about the contact they had had with their partners' families (Table 6.2). These figures were not included in those previously given in Table 6.1. Two of the men were divorced but were in regular contact with members of their ex-wives' families. These have been included in the table.

Table 6.2

Number of Spouse's Relatives Seen Within The Last Year

Number of Spouse's Relatives	No. of Patients With Spouses					
	Male	%	Female	%	Total	%
None	1	11	8	40	9	31
5 or less	2	22	6	30	8	28
6 - 10	4	44	3	15	7	24
11 - 15	1	11	2	10	3	10
16 - 20	1	11	1	5	2	7
TOTALS	9	99	20	100	29	100

There was a tendency for male respondents to keep in contact with their wives' families: in fact, only one male had had no contact. However, 8 (40%) of the female respondents had had no contact with their partners' relatives during the previous year. This pattern of contact suggested that the females had more frequent contact with their families than the males, which in turn reflected the strength of the female social network.

(ii) Recent Contact with Relatives

An impression was gained of the amount of recent contact the patients had with their relatives by obtaining information about the week prior to the interview. It was found that more than half the respondents (54%) actually lived with relatives, the majority of whom were either in the marital or parental home (Table 6.3). More than half of the patients who did not live with relatives had had no contact with their families during the previous week. The younger respondents were more inclined to either live, or keep close contact with their families. Some of the patients had their family contact supplemented by letters or telephone calls.

Table 6.3

Contact With Relatives in the Week Prior to Interview

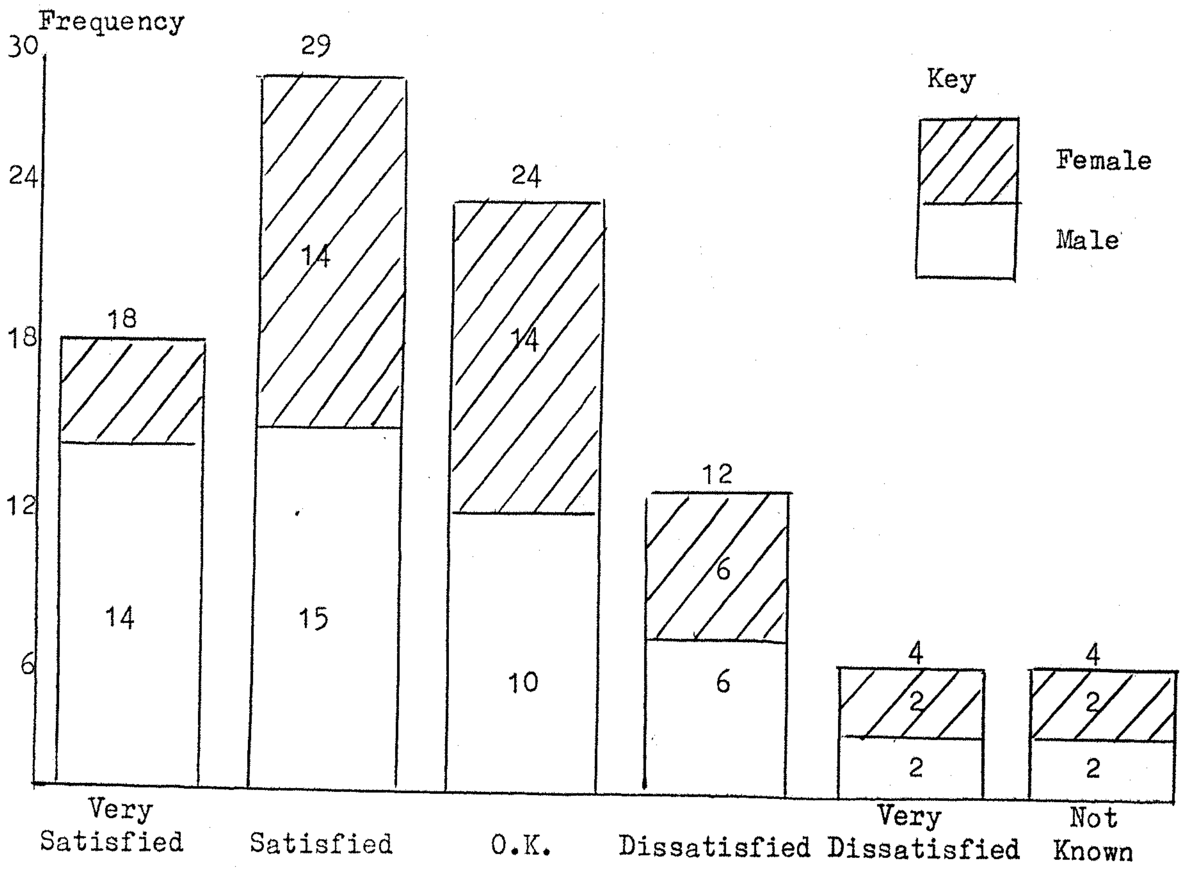
Number of Times Relatives Seen	Male	%	Female	%	Total	%
Living with Relatives	23	47	27	64	50	54.9
Daily	3	6	0	0	3	3.3
4 - 6 times	2	4	1	2	3	3.3
2 - 3 times	0	0	2	5	2	2.2
Once	7	14	4	10	11	12.1
Not seen relative	14	29	8	19	22	24.2
TOTALS	49	100	42	100	91	100.0

The patients were asked about their degree of satisfaction with the contact with their relatives. The results are illustrated in Figure 6.1

More than half the respondents said they were satisfied with the contact they had with their relatives (29 males and 18 females) and a further quarter said the contact was O.K. (10 males and 14 females). However, 16 of the respondents (8 males and 8 females) said they were dissatisfied with the contact. All eight men and four of the women were unmarried.

Fig. 6.1

Satisfaction With the Contact With Relatives



Of the patients who showed dissatisfaction, further comments were invited. On the whole, these respondents wanted more contact with their families:

Case 016, male, aged 53

'I would like to see my relatives more often, but I feel I would be a bother.'

Case 036, male, aged 45

'My daughter and son never write. I write to them and telephone.'

Case 056, male, aged 34

'I would like to know how they are all getting on. I would like to go and stay with them but my family are disappointed in me. I would like them to realise that I am sick.'

Case 024, female, aged 49

'I would like to see Mother more often with Father. When I see Dad alone he talks about sex and he hints about wanting to go to bed with me. He tries to kiss me.'

Case 078, female, aged 62

'Because I talk to myself my brother feels embarrassed. His wife doesn't like it.'

To summarise, the respondents had families of various sizes: a third of the sample had families of 15 members or below, and nearly a half had 15 or more relatives. Unfortunately, data was lost when 17 of the respondents did not give enough information.

This pattern changed when account was taken of the number of relatives seen within the last year: 83% of the sample had seen 15 relatives or less. Some married respondents (the males in particular) had kept contact with their spouses' families. More than half the sample lived with relatives: of the remainder, 21% had seen relatives within the last week and 24% had had no contact. More than half the sample were satisfied with the contact they had with their relatives, although 18% were dissatisfied. A further 4 respondents did not know. The main complaint of the dissatisfied was that they did not see enough of their relatives.

(iii) Friendships

The Chambers Twentieth Century Dictionary (1977) describes a friend as 'one loving or attached to another: an intimate acquaintance: a favourer, well-wiser....' The interviewer defined a friend as 'someone, other than a relative, with whom you share a common understanding or interest and who you have known for some time.' A distinction was made between the meaning of 'friend' and 'acquaintance': friendship involved a more trusting and intimate relationship than did acquaintanceship.

More than a third of the respondents (35%) said they had no friends (Table 6.4). Somewhat surprisingly, quite large proportions of both the married men and women said they had no friends. It could be that married respondents have less need to develop relationships outside the nuclear family. Again it appeared that the single men, in particular, were experiencing difficulties since 16 (38%) of the unmarried men but only 3 (14%) of the unmarried women lacked friendships.

Table 6.4

Number of Friends the Respondents Had

Number of Friends	Male	%	Female	%	Total	%
One	7	14	13	31	20	22.0
Two	4	8	2	5	6	6.6
A Few	10	20	4	10	14	15.4
Several	8	16	6	14	14	15.4
No friends	19	39	13	31	32	35.2
Other Residents	1	2	3	7	4	4.4
Not Known	0	0	1	2	1	1.1
TOTALS	49	99	42	100	91	100.1

The respondents were asked about the contact they had had with friends during the previous week (Table 6.5). More than half the sample (57%) had not met any friends: of these, 23 of the 27 males were unmarried and 13 of the 25 females were single. Several respondents had received letters or telephone calls from friends in the week before interview: 5 (2 males and 3 females) had done so two or three times and 9 (4 males and 5 females) had had contact on one occasion.

Table 6.5

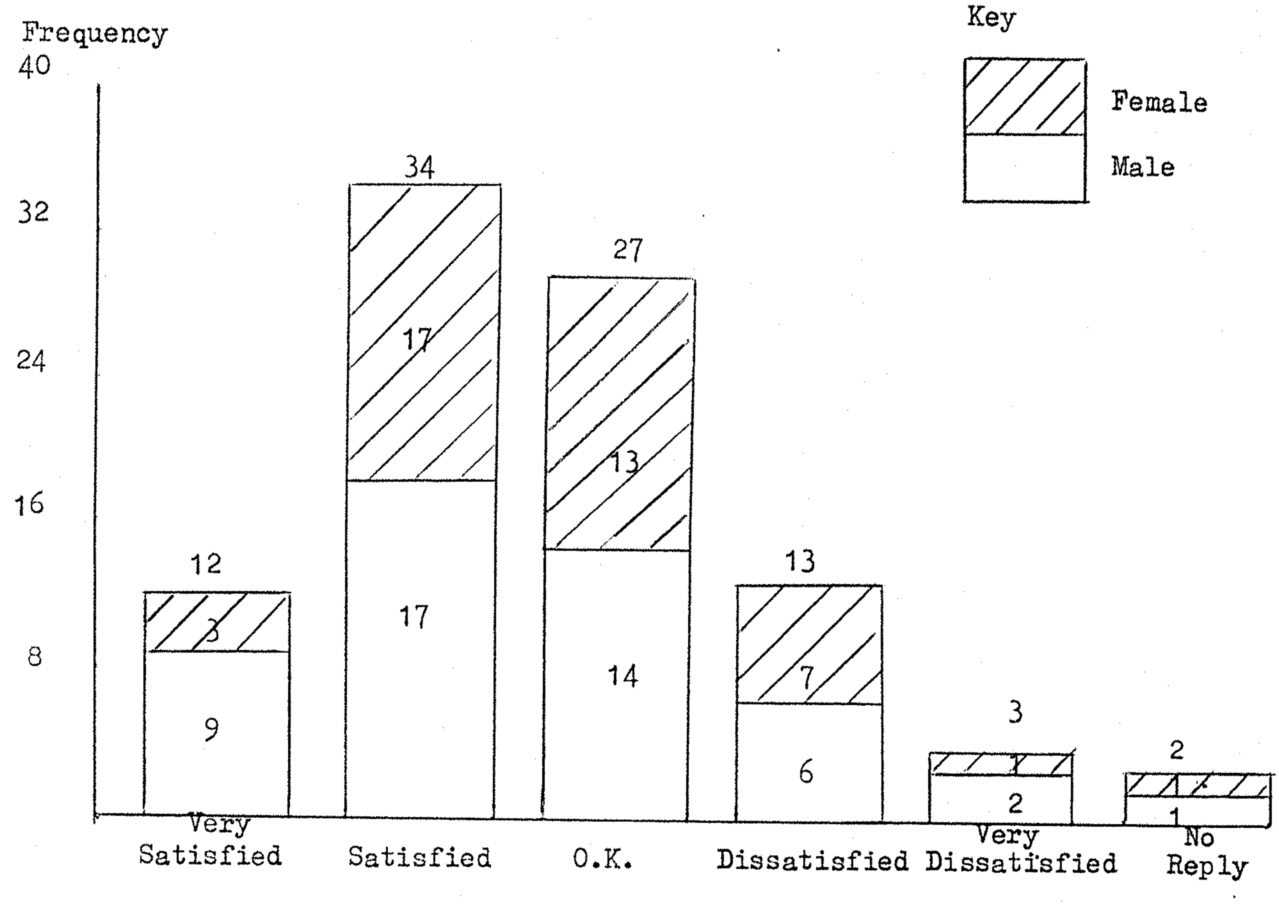
Contact With Friends in the Week Prior to Interview

Number of Times Met With Friends	Male	%	Female	%	Total	%
Daily	10	20	6	14	16	17.6
4 - 6 times	6	12	0	0	6	6.6
2 - 3 times	4	8	5	12	9	9.9
Once	1	2	5	12	6	6.6
Not met with friends	27	55	25	60	52	57.1
Not known	1	2	1	2	2	2.2
TOTALS	49	99	42	100	91	100.0

The respondents were asked about their degree of satisfaction with their friendships (Figure 6.2). It is interesting to note that, despite the high number of respondents who had no friends (35%), only 16 respondents (18%) showed any dissatisfaction with their friendships. Nine of the sixteen (56%) were in the 30 to 45 age-group, and this meant that a quarter of this age group showed dissatisfaction. All eight males in the dissatisfied group were unmarried. A further 27 respondents felt their friendships were O.K. and half the respondents (26 males and 20 females) showed no dissatisfaction with their friendships.

Figure 6.2

Satisfaction With Friendships



Those who were dissatisfied were invited to comment further. The main reason for their dissatisfaction was simply that they felt they lacked friendship, for example:

<u>Case 056, male, aged 34</u>

'I'm fed-up with talking to nutcases. All my friends are ex-psychiatric patients.'

Case 091, female, aged 45

'I'd like to have more friends but I don't know how to go about it.'

Case 099, male, aged 36

'I would like two or three friends outside the house.' (Rest-home)

Some of the men said they would like a girlfriend in particular, for example:

Case 038, male, aged 42

'I'd like a girlfriend. I'd also like a chum.'

Case 062, male, aged 30

'Sometimes I feel like a prisoner in the house. I would like to meet someone nice, but I couldn't provide for them adequately.'

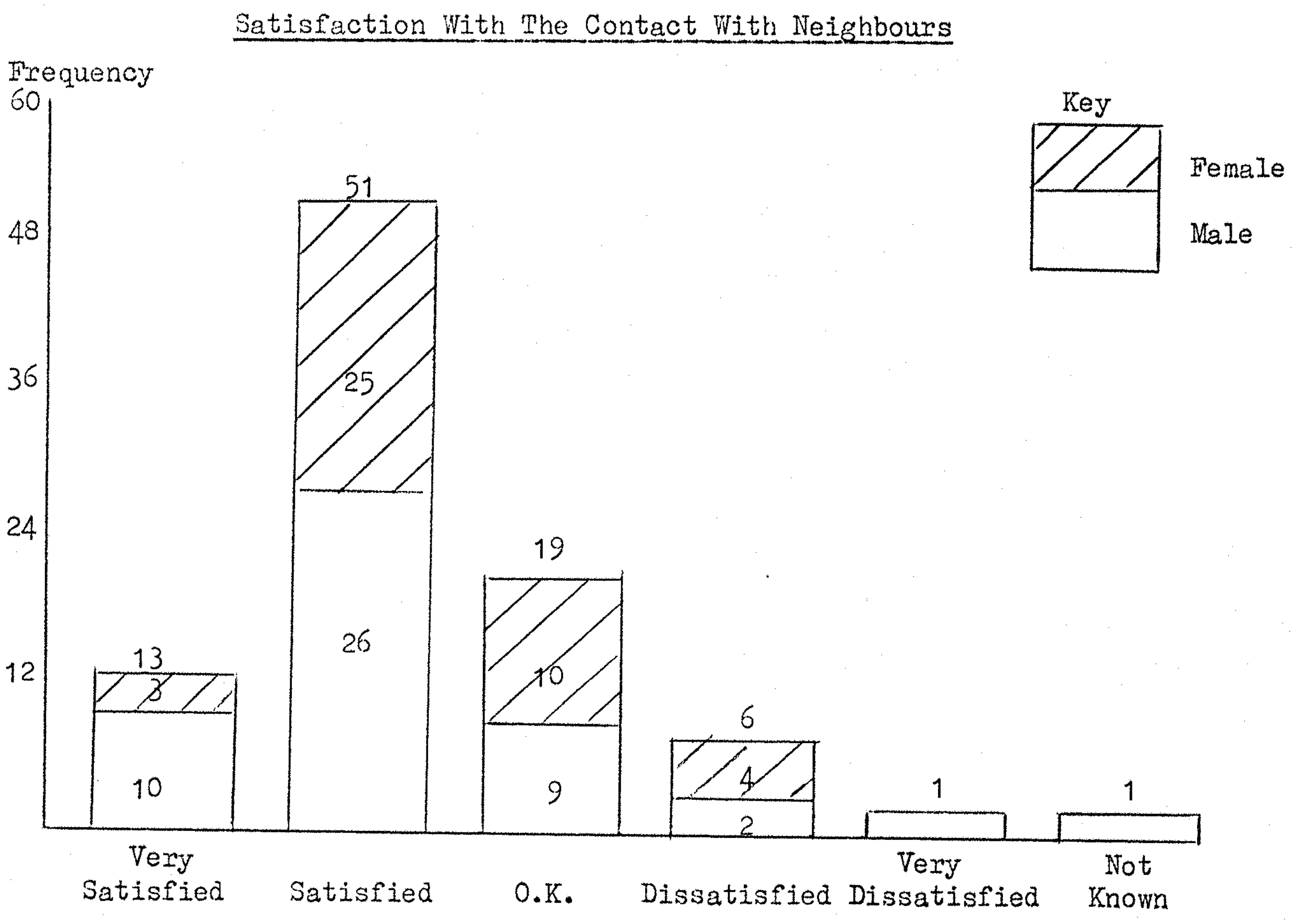
On the whole, many of the patients in the sample at the time of the interview (35%) appeared to live without friendship. A third of the respondents with friends had only one and a further 4 respondents had only the friendship of the other residents. More than half the respondents had not met with friends during the week before interview. However, despite this lack of contact, only 16 patients (18%) said, or admitted they were dissatisfied with their friendships.

(iv) Neighbours

The research looked at the contact the patients had with their neighbours. Overall, the relationships with neighbours appeared to be of little importance to the respondents. In fact, less than a quarter of the respondents (12 males and 10 females) had had contact with their neighbours during the previous week. 'Contact' was defined as having been engaged in conversation or, for example, having a cup of coffee with neighbours. If the contact had been very brief, such as a greeting, then it was not recorded.

Only 7 respondents showed any dissatisfaction with the contact they had with their neighbours (Figure 6.3). Again, the males were all unmarried at the time of interview.

Figure 6.3



Other than one female who said her neighbours were too noisy, the respondents would have liked more contact, for example:

Case 022, female, aged 50

'They could be more friendly. Everyone keeps themselves to themselves.'

Case 063, male, aged 29

'I'm not even on nodding terms with two of them. I don't know them.'

Case 088, female, aged 52

'I'd like to have them in for a cup of tea and a chat.'

(v) Social Life

The respondents were asked about their social activities during the week before interview, in order to gain an impression of the amount of social contact the patients had with others in their environments, or, in some cases, the degree of social isolation they were experiencing.

Three-quarters of the sample did not attend social clubs organised by the staff of St. James' Hospital, whether held in the community or in the hospital itself. Of the 24 respondents who did, 63% attended weekly or more often (Table 6.6). The men attended more regularly than the women in the sample. Only 5 of the patients relied on the community nurses or voluntary workers for transport to and from the clubs.

A higher proportion of patients attended other clubs, for example, church social clubs, community centres or further education centres. Of these, 21 respondents (64%) attended the centres weekly or more frequently (Table 6.6). Almost half the sample (47%) did not attend a club of any description and half of these were men. A small proportion (10%) attended both hospital and community clubs.

Table 6.6

Attendances at Clubs

Frequency	St. James' Hospital Clubs						Other Clubs					
	Male	%	Female	%	Total	%	Male	%	Female	%	Total	%
More than Weekly	1	2	0	0	1	1.1	4	8	3	7	7	7.7
Weekly	11	22	3	7	14	15.4	7	14	7	17	14	15.4
Once or Twice Monthly	0	0	1	2	1	1.1	5	10	1	2	6	6.6
For Injection Only	0	0	3	7	3	3.3	0	0	0	0	0	0
Occasionally	1	2	4	10	5	5.5	3	6	3	7	6	6.6
Never	36	73	31	74	67	73.6	30	61	28	67	58	63.7
TOTALS	49	99	42	100	91	100.0	49	99	42	100	91	100.0

The respondents who did not attend any organised clubs were invited to comment on why they did not. The replies showed either disinterest, a lack of money, or handicap because of the illness:

Case 001, female, aged 64

'We enjoy our own company and make our own entertainment.'

Case 055, male, aged 36

'I've seen enough of the hospital. I don't drink, so I can feel a bit left out in normal social circumstances.'

Case 089, female, aged 48

'It's the way I am. I don't want to be bothered with anyone. Familiarity breeds contempt.'

Case 020, female, aged 50

'Usually it means bus-fares. I'm restricted financially.'

Case 019, female, aged 51

'Every time we go outside the door it's money, isn't it?'

Case 091, female, aged 45

'I got upset at a coffee morning last year. People were horrible to me. They made me ill.'

Case 099, male, aged 36

'I won't go out in the evening as I'm not allowed - for my own good.'

The respondents were asked how many times they had been out on social outings in the previous week. 80% of patients had been out: almost a third of the sample (17 males and 10 females) had been out every day or evening; a further 30% of respondents (16 males and 11 females) had been out on between two and six occasions; and 21% (5 males and 14 females) had been out only once. A total of 18 respondents (20%) had not been out and, of the 11 men in this group, 10 were single.

The respondents had, for example, visited pubs, clubs, the cinema, friends' or relatives' houses, centres for further education, St. James' Hospital or had been out window-shopping or walking. The majority of patients had been accompanied on their outings: nearly a half (16 males and 28 females) had been with someone on every occasion and a further 24% (15 males and 7 females) had some of the time, but 7 single males had not been accompanied.

The respondents were asked if relatives or friends visited them at home and, if so, how often. Table 6.7 summarises the response. A total of 38 respondents (42%) rarely, or never received personal visitors and half of these were males. Similar proportions (45% of men and 41% of women) had daily or frequent visitors, The married respondents (particularly the women) were visited more frequently than the single patients.

Table 6.7

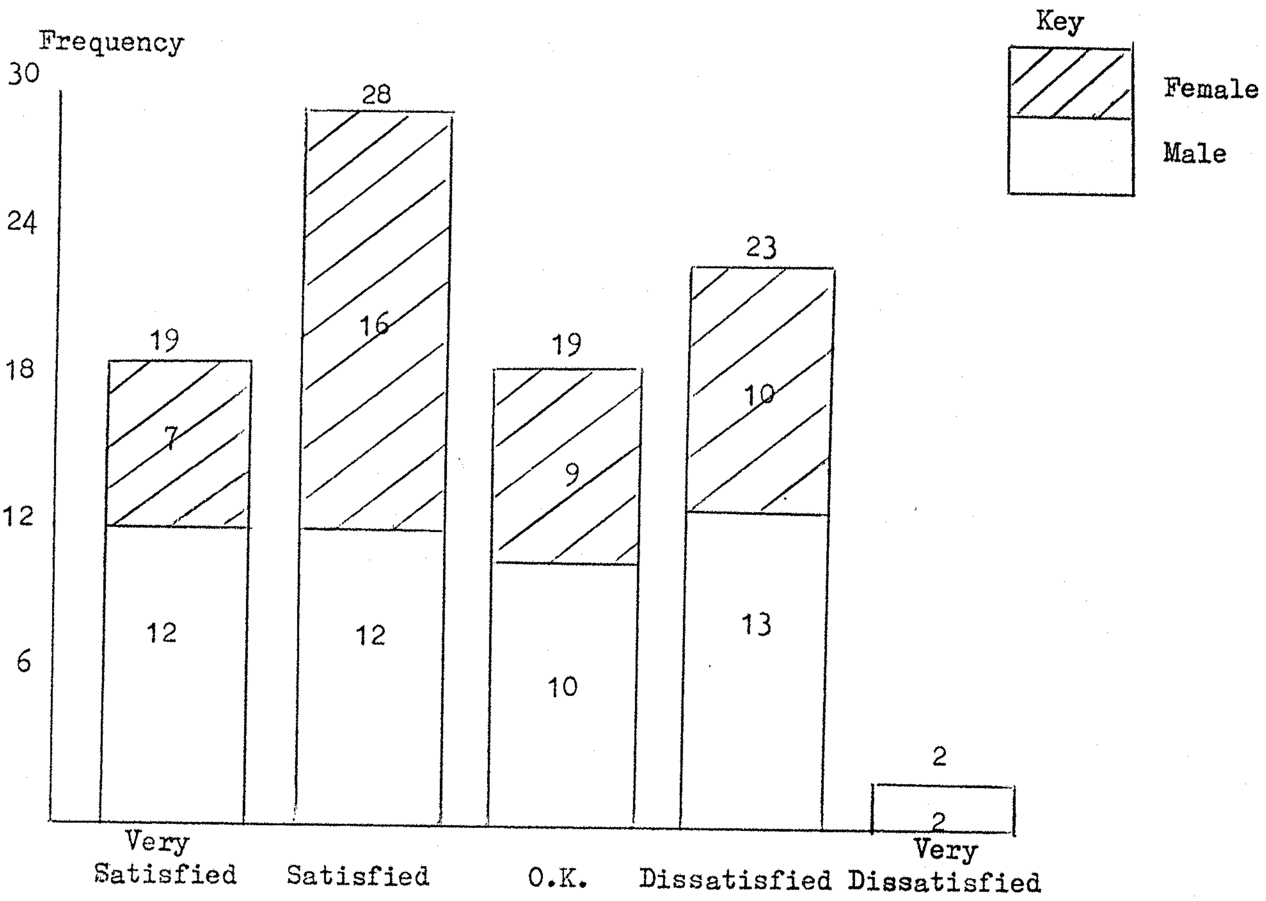
Visitors to the Homes of the Respondents

Frequency	Male	%	Female	%	Total	%
Daily, or almost daily	4	8	4	10	8	8.8
Frequently	18	37	13	31	31	34.1
Occasionally	6	12	7	17	13	14.3
Rarely	11	22	4	10	15	16.5
Never	6	12	13	31	19	20.9
Other*	4	8	0	0	4	4.4
No Reply	0	0	1	2	1	1.1
TOTALS	49	99	42	101	91	100.1

* These cases are all unmarried males, living with relatives, who felt the visitors came to see the relatives and not the respondent.

Respondents were asked if they felt satisfied with their social lives. Figure 6.4 illustrates their response.

Figure 6.4: Satisfaction With Social Life



More than a quarter of the respondents (15 males and 10 females) showed dissatisfaction with their social lives. All but one of the males and four of the females were single. The highest proportion of dissatisfied respondents (60%) were aged between 30 and 45 years. Another 19 respondents (10 males and 9 females) said it was O.K. Again, a high proportion of the males were single (80%). The respondents who showed dissatisfaction were invited to comment further: the reasons given were financial restrictions, symptoms of the illness or a lack of friendship:

Case 012, female, aged 56

'I just don't want to mix with people. I would like to, but find it difficult.

Case 034, male, aged 44

'My social life depends on my sisters. When I'm not with them I have no social life. I am lucky........the rest of them (in the rest-home) have nothing at all.'

Case 038, male, aged 42

'Not enough money.'

Case 041, male, aged 41

'I don't go out much, yet I would like to do so more often. I'm stopped by my depression.'

Case 052, male, aged 37

'I haven't any friends, apart from people in the flat.' (Cluster flat)

Case 056, male, aged 34

'I can't afford to take a girlfriend out. I would like a girlfriend and get married.'

Case 057, male, aged 32

'Once I get to the point of complete health I can mix more with people and take a part in helping others.'

Case 058, male, aged 32

'I have few friends around here, but I have friends in London.........'
'I've a lack of money. I've no girlfriend.'

Case 063, male, aged 29

'I used to have friends I could drink with, but no more. I've lost contact with my friends.'

Case 064, male, aged 28

'I've not enough money to spend.'

Case 069, male, aged 24

'All my friends have left college and Portsmouth. I'm a bit lonely.'

(vi) Someone To Turn To

The respondents were asked what relatives, if any, they would turn to if they needed help or advice. The majority of respondents (86%) thought they could turn to relatives for support: the largest group (48% of the sample) could approach 2 - 3 relatives. (Table 6.8). 65% of the males and 60% of females could have approached two or more relatives. All the patients under 30 years of age could approach two or more relatives.

Table 6.8

The Relatives Patients Could Turn To For Help And Advice

Relatives	Male	%	Female	%	Total	%
Spouse	1	2	4	10	5	5.5
Parents	4	8	1	2	5	5.5
Sibling	5	10	3	7	8	8.8
Other Relative	1	2	2	5	3	3.3
2 - 3 Relatives	21	43	23	55	44	48.4
4 or more Relatives	11	22	2	5	13	14.3
No Relatives	6	12	7	17	13	14.3
TOTALS	49	99	42	101	91	100.0

Of the married respondents, 5 said they could turn only to their spouses for help: the remainder could also turn to others in the family. Similarly, 5 unmarried patients living with their parents said they could turn only to their parents for support. A total of 13 respondents (14%) said they had no relative they could turn to; other than one female, all patients in this group were unmarried at the time of interview.

Of all the respondents, 40% (19 males and 18 females) said they would turn to no-one outside the family for help: 6 men and 11 women were married in this group. Another 5 patients (2 males and 3 females) said there was no-one they could turn to. Surprisingly, one of the females was married, but said she felt so isolated by her illness that she could approach no-one. The remaining respondents (54%) said they could approach such people as friends (a quarter of the sample said they could turn to friends for help), neighbours, landladies and hospital staff.

Of the married respondents, all but 5 females felt that their only close relationship was with their spouses (Table 6.9). More men than women felt closest to their parents: these were unmarried patients who still lived in their parents' homes. Others felt closest to another relative, or more than one relative (31%). 'Others' included friends, or other residents from rest-homes. However, 4 men and 5 women (10%) felt close to no-one and another 3 patients (2 males and 1 female) did not know if they felt close to anyone.

Table 6.9

Those Closest to the Respondents

Closest To	Male	%	Female	%	Total	%
Spouse only	7	14	15	36	22	24.2
Parents	12	24	4	10	16	17.6
Other Relative	10	20	6	14	16	17.6
More Than One Relative	5	10	7	17	12	13.2
Priest	1	2	0	0	1	1.1
Landlady	2	4	0	0	2	2.2
Other	6	12	4	10	10	11.0
No-One	4	8	5	12	9	9.9
Not Known	2	4	1	2	3	3.3
TOTALS	49	98	42	101	91	100.1

(vii) Respondents Who Felt Close to No-One

The four men in this group were aged between 32 and 42 years and the 5 females between 45 and 62 years. Other than one married female, all the patients in this group were unmarried at the time of the interviews and either lived in rest-homes (1 male and 4 females), unsupervised lodgings (2 males) or a group home (1 male). All the patients were unemployed at the time of interview, except one of the men who had casual employment. Two of the men attended Industrial Therapy at the hospital.

Only one of the men attended a club run by staff from the hospital and one woman attended occasionally. Another two women occasionally attended other clubs in the community. Of these 9 patients, 3 had not been out socially during the previous week and a further 2 had been out on one occasion only. Two-thirds of the group (1 male and 5 females) never had any visitors, 2 men did on rare occasions only and 1 man had frequent visitors. However, despite the apparently high degree of isolation experienced by these patients, only 3 (1 male and 2 females) showed any dissatisfaction with their social lives.

Again, despite the fact that only 2 of the men had met with friends during the previous week, only 2 (1 male and 1 female) said they had no friends. However, four of the group (2 males and 2 females) said they were dissatisfied with their friendships.

The majority of these isolated patients (3 males and 4 females) had seen no relatives in the previous week: in fact, 4 (1 male and 3 females) had seen no relatives within the last year. Only 2 females said they were satisfied with the contact they had with their relatives, 2 males said the contact was O.K. and the remainder showed dissatisfaction with this situation. Two-thirds (2 males and 4 females) said they could not turn to a relative for help and 3 (1 male and 2 females) said they could turn to no-one for help. Another 3 (1 male and 2 females) said they would turn to their landlady for help.

All of these respondents, other than 2 men who did not know the answer, said there was something missing from their personal relationships. They commented on this, saying it was because of a lack of contact with relatives, not having girlfriends (males), the effects of the illness and loneliness.

(viii) Factors Missing From Personal Relationships

The sample were asked if they felt anything was missing from their personal relationships and, if so, what they thought it was. More than half the sample (28 males and 20 females) said there was something missing: all but 2 of the males were single, yet 10 of the females were married. Another 4 respondents (3 males and 1 female) did not know and 1 female refused to answer the question. A total of 18 men and 20 women felt there was nothing missing from their relationships.

The answers from those who felt something missing are presented below and it is these that provide the most poignant commentary. One is left with the impression that, for many patients, life is experienced in isolation and yet the loneliness is not welcomed. They allow the reader to experience the devastation schizophrenia has on the lives of it's victims. Generally, patients talked of difficulties they had experienced within relationships and the ways in which their illnesses had affected their relationships. Eleven respondents specified problems with relatives; 10 said they missed a partner and/or marriage; 8 said they missed friendship and felt lonely; 5 said the effects of their illnesses had caused problems and the remainder said it was their relationships in general. The remaining respondents who felt something was missing were not sure what it was. Some of the replies are presented below.

Case 002, male, aged 63

'I feel my sister could invite me to her bungalow more often for a meal. My sister tends to come here more often than me go there.'

Case 012, female, aged 56

'I miss my children.'

Case 027, male, aged 47

'On a good day I am quite happy, or, "on a good day I can see forever". On a bad day I just hope the next day will be better.'

Case 031, male, aged 46

'Only perhaps love and kindness.'

Case 033, male, aged 43

'I miss my wife and boys. I feel isolated and lonely at times.'

Case 034, male, aged 44

'The Bible says "The greater the sacrifice, the richer the reward." I am therefore happy that I will be rewarded when I get to heaven.'

INTERVIEWER: 'Do you know what that reward will be?'

'My father used to say that there is no marriage in heaven. I hope there is. I will be more able to cope with that then.'

Case 044, female, aged 40

'I've lost rapport. I've lost the closeness I once felt for people. It's largely because I've lost my imagination. It's most distressing - it sometimes makes me feel life isn't worth living. It makes me feel quite depressed.'

Case 045, female, aged 39

'I'd like more close friends. I've got Barry and Sheila, but they're tied up with each other. I'd like to get married, but I wouldn't rush into it this time.'

Case 048, male, aged 37

'I want a girlfriend.'

Case 056, male, aged 34

'I would like a girlfriend. A man of my age should be married. Not a girlfriend from St. James'. I am fed up with masturbation..........
'A lot of my friendships leave a lot to be desired but there's nothing I can do about it..........
'Society doesn't like people from St. James': like a pack of wolves with a weak one - they will turn round and kill it.........
'Most of the time I feel lost.'

Case 057, male, aged 32

'The loving part of me has been affected by my illness. I can't radiate enough love to my fellow man.'

Case 058, male, aged 32

'I don't see friends often enough. I think they're a bit frightened of the fact that I had a nervous breakdown. Really, I've led a very lonely life since I had a breakdown and haven't made any new friends.'

Case 060, male, aged 32; Case 066, male, aged 27; Case 070, male, aged 23

'A steady relationship with a girlfriend.'

It is in the area of relationships and social contact with others that the majority of problems were encountered by the sample. One is left with the impression that some of the patients were living their lives in isolation, yet were not happy with this situation. Some patients were not only having to live with debilitating effects of the illness itself, but also with the social effects of that illness. So far, the research has explored the social environment in which these patients were living and it has become apparent that some of the patients were coping and were happy with specific areas of their lives. But for others, living with schizophrenia meant living in varying degrees of isolation, and having problems with employment, income or relationships, in particular.

Support in the community must be available for these patients: if it is not, it is probable that they will deteriorate and break down again, or at least be forced to live 'second-rate' lives and will never be able to reach their full potential. The following chapter identifies local support services available in the community and the use made of them by the sample.

Chapter 7

Community Services and Facilities in Portsmouth And The Use Made of Them by the Respondents

Part 1: Service Provision by NHS

Since the interviews took place, the psychiatric services have undergone changes in both managerial and service structure. This chapter attempts to describe the services available at the time of interview together with an indication of current major changes.

(i) St. James' Hospital

St. James' Hospital was built a little more than a century ago, and is typical in architectural design of asylums built in that era. The hospital is situated in the south-eastern sector of the city in a built-up, residential area. It provides services for general, acute psychiatry; the long-stay patient; psychogeriatrics; and a number of specialist services including a Child and Family Unit, an Alcoholic Unit and community service, and an expanding Drugs Advice and Treatment Centre.

The hospital has been following the national policy of reducing it's number of beds, particularly for the long-stay population, and the number of beds available in January, 1986 was 418 for the District. At the time of the interviews the services were being managed centrally, although, at the present time, the services are in the process of being de-centralised. 'Patch Teams' have now been created in each area of the District; each team being responsible for identifying the needs of it's own area and the subsequent development of services within that area. Portsmouth City (excluding the psychogeriatric service) is now divided into three patches: Southsea, Portsmouth Central and Cosham. At the time of interview, these identical divisions existed, each area having its own Consultant Psychiatrist and multi-disciplinary team, for example C.P.N.'s and Social Workers. The main difference from the previous arrangement is that each area now has it's own manager who is responsible for the multi-disciplinary team in his or her own 'Patch'. Eventually these teams will operate from Community Health Centres to be set up in each patch. These will operate as day-centres and will provide all facilities for patients living in that area (other than specialist services, such as drug addiction or alcohol addiction). The Unit General Manager is now responsible for all the psychiatric services.

(ii) Day Hospitals

The District has two day hospitals for acutely ill psychiatric patients: Havant Day Hospital and, for the City, Solent Day Hospital. The latter can accommodate forty patients at any one time and in January, 1986, had 60 patients registered with it. Length of stay is usually short-term only, although 23 of the 60 registered patients attended Industrial Therapy on a longer term basis. These patients attended the day hospital for meals and therefore the day unit had responsibility for them.

A range of activities is provided by the day hospital and includes occupational, group and relaxation therapies. The out-of-city area is also served by a Travelling Day Hospital, which is held for two days at Petersfield and two days at Wecock Farm, Cowplain. The psychogeriatric area has separate day hospital facilities.

(iii) Industrial and Occupational Therapy

The Occupational Therapy Department at St. James' Hospital is, at the time of writing, being de-centralised along with the other psychiatric services. At the time of the interviews, however, the Occupational Therapy Department was situated in the hospital grounds and offered such activities as woodwork, art therapy and creative skills for both in-patients and out-patients.

The Industrial Therapy Unit is situated in the grounds of St. James' Hospital, although it is planned eventually to move the unit out into the community. In-patients and out-patients are accepted in the unit: until 1979/80, 85% of the attenders were in-patients, but now with the emphasis on community care, the majority of patients are out-patients. At the time of writing, there were only seven in-patients attending this 75-placement unit. There are normally 70 attenders at any one time, a few places being kept for emergency referrals.

The unit consists of a sheltered workshop, which caters for the majority of the patients attending, an assessment unit and a long-day workshop. The latter two stages are for potential workers. The long-day workshop provides a realistic working environment in which the patients are assessed for their technical and social skills, general behaviour, time-keeping and understanding of instructions. Close liaison with the Disablement Resettlement Officer of the Department of Employment continues throughout the process of assessment. If the patient is considered to be ready for employment, then referral is made to the Employment Rehabilitation Centre for full assessment. This service is described later in this chapter. (Part 2, section (iii) (b)).

(iv) The 'Modecate' Clinics

Two main clinics are held in the day hospitals - one is at Havant, and the other at St. James' Hospital in the Solent Day Hospital. Patients attend the clinics at specified times in order to receive their injections and to discuss any problems with the nurses.

Other clinics have been developed by the community nurses - one is held on a weekly basis in the surgery at Petersfield, and a further four operate from Health Centres within the city. The city clinics are now the responsibility of one CPN and have been set up since the interviews took place. Other CPN's, as well as giving injections at home, also give injections at the Contact Clubs. At the time of interview this was common practice and many patients who attended for injection joined in with the social activities as well.

(v) The Community Psychiatric Nursing Service

The Community Psychiatric Nursing Service (CPN service) has been in existence at St. James' Hospital for about thirteen years. It has now grown to be one of the largest services in the country with 37 full - time equivalent CPN's. The service covers the whole district and includes services for the elderly; acute psychiatric care and supervision; child and family psychiatry, addiction services for alcohol and drugs; involvement in travelling day hospitals for the elderly, long-term and acute psychiatric patients; a specialist nurse who administers long-acting phenothiazine injections; and 'Special Projects' nurses, who are responsible for the care of the long-term, chronic psychiatric patients, together with an involvement in the group homes and Portsmouth Contact Club. At present, two CPN's work in the 'Special Projects' team in the city and carry a joint caseload of 168 patients. The aim is eventually to appoint one specialist nurse for each patch.

Other than some of the specialist CPN services, for example drug addiction, referrals are accepted from the Consultant Psychiatrist only. At the time of the interviews, the service was managed centrally by one Clinical Nurse Manager, although the Community Psychiatric Nurses are now managed by the appropriate Patch Team Manager.

The post-graduate nursing course in community psychiatric nursing also has it's base in Portsmouth and at present operates from the St. James' School of Nursing (ENB 805 and 810).

(vi) Contact Clubs

It has been established practice, during the last decade, for the CPN service to be responsible for the setting up, and supervision of 'Contact Clubs' in the community. Volunteers help in the organisation of activities and refreshments. The aim of the clubs is to give social contact to patients in the community, who experience isolation in one form or another. The clubs provide a social environment that is comfortable and relaxed - particularly important for schizophrenic patients who cannot tolerate over-stimulation.

The patients are normally selected for attendance by the CPN's, and are often patients on their caseloads. The clubs also enable the nurses to keep regular contact with their patients and assess their progress or deterioration.

At the time of the interviews, there were four contact clubs held on a weekly basis across the city: one in Paulsgrove, another in Cosham and two in Portsmouth itself. A further three clubs were operating outside the city in Petersfield, Hayling Island and Leigh Park.

(vii) Accommodation

St. James' Hospital has close involvement with seven established group homes - six within the city and one outside. They accommodate a total of approximately 35 residents. A further house has been developed on the perimeter of the hospital grounds as part of the rehabilitation facilities. The six city homes are all situated in Southsea. One of the houses is supervised on a part-time basis. A housekeeper cooks one main meal a day and does general domestic work, including helping with patients' problems, such as enquiring about D.H.S.S. benefits. This service is provided by the Portsmouth Housing Association, which also manages all the homes, as well as providing 5 of the homes. The other two are Portsmouth City Council properties.

The Half-Way House Steering Group is responsible for the homes. This group is a formal liaison between representatives from St. James' Hospital, Social Services, Portsmouth Housing Association, Portsmouth and Havant Housing Departments, the local benefits' office and the voluntary sector.

(viii) Recent Developments

As was stated earlier, the psychiatric services are undergoing major changes, both in management and service structure.

Since the interviews took place early in 1985, further community services have been developed, and, although they were not available for use at that time, it is important to describe these new services and to include them in the later discussion.

(a) Dickens Villa

This villa is located in the grounds of St. James' Hospital. It is an activity centre for patients during the day, and serves as a community centre in the evening, both for patients in the hospital and those living in the community. A wide variety of facilities is available, including a Social Recreational Room, refreshment facilities and sports equipment. The villa is open at weekends as well as during the week.

The centre is run by paid activity co-ordinators and voluntary workers. The aim of the villa is to provide social activities in a non-institutional environment and the Committee of Members help to decide the programme of activities and hours of opening.

(b) Radnor House

Radnor House is a recent development in the community and offers a dual role for residential and out-patients. It is located in Southsea in a residential area and is near the shops and sea-front.

The upper floors of Radnor House constitute a residential rehabilitation unit of 14 beds, formerly within the grounds of St. James' Hospital. The aim of the unit is to rehabilitate handicapped patients within a therapeutic community to enable them eventually to live in the community.

Referrals are taken from any area of the psychiatric service. The treatment is offered on a long-term basis - no limit is set on the length of stay. The unit offers a relaxed atmosphere that operates on democratic lines. Great efforts have been made to develop the unit as far away from institutional practices as possible. The accommodation offered is six single and four double rooms. Activities include shopping, cooking, budgeting and general self-awareness programmes. The patients receive one week's supply of medication and are responsible for it. The staff intervene only if necessary.

The residential unit also offers places for eight day-patients, so, as people are discharged, they can return to the unit for support. This support is intended to be offered on a very informal, flexible basis. Contact with relatives is encouraged.

The ground floor of Radnor House has recently been developed as a separate day centre for the unoccupied patients who live in the community. Referrals are accepted from any professional source, and an open, drop-in centre operates on three afternoons a week. The project is joint-funded for the first three years, that is, financial responsibility is shared by both the Health and Social Services for this period. During this initial stage, an evaluation of the use of the service will be carried out.

The age group catered for is between 18 and 65 years. At the time of writing, it is mostly men in their 30's and men of the older age group who are using the centre. 'Basically, they are the people that nobody else wants' said one of the staff. The activities available include social skills training, art, creative writing, cooking (patients may bring their own food and use the kitchen, if they wish), shopping, outings and games. Staffing consists of a nursing sister from St. James' Hospital (Day Centre Organiser), a staff nurse (Deputy Day Centre Organiser), and three care assistants (one full-time and two part-time).

(c) Relatives' Support Group

A Relatives' Support Group is supervised by the Special Projects CPN's on a monthly basis. The aim of the group is to offer support for those relatives who have a long-term, chronically ill patient in the family. Many of the members of the group also attend the monthly meetings of the National Schizophrenia Fellowship and the group, therefore, complements the support received at those meetings by making available professional help and advice.

Part 2: Community Provision by non-NHS Resources

(i) Social Service Provision

A team of Social Workers work within the hospital itself and have close liaison with the area offices. In the city, the three areas, or 'patches' as they are now called, each have their own area office for the residents of that area.

Joint funding has been provided for some community projects, for example, the Radnor Day Centre earlier described. Social Services have also made provision for the Contact Clubs and, in fact, pay the total rental for one of the city clubs.

The Hampshire Adult Placement Scheme was launched in 1979: six Adult Placement Officers have divisional responsibility for advertising, recruitment of carers, matching of client/carer and giving on-going support once a placement has been completed. In Hampshire there are six Adult Placement Officers and two of these work within the South-East Hants area. In addition to the officers, there is an Adult Placement Social Worker in each area office, whose role it is to offer support before, during and after placement. The clients who are found homes are, in the main, mentally handicapped, although physically handicapped, elderly and mentally ill clients have been placed. In April, 1980, fifteen mentally ill clients were currently in placement (not including short-stay placement); this number had increased to 44 in April, 1986. One Adult Placement Officer commented that the mentally ill are particularly difficult to place because of inappropriate referrals and a lack of day-care, particularly drop-in centres.

(ii) Special Provision for Accommodation

(a) Portsmouth Housing Association

Portsmouth Housing Association was founded in 1973 by the local Shelter group and the Portsmouth Council of Churches. The Association is involved with the management of the seven group homes in the Portsmouth area (one of these is situated outside the city). One of the houses is partly supervised by a housekeeper funded by the Association, which provided five of the homes. The other two houses are City Council properties, leased to the Association. The PHA is also involved in the Health Authority's Half-Way House Steering Group, a multidisciplinary group that meets regularly to discuss and make decisions on all matters concerning group homes.

(b) Charitable Organisations

St. Petroc's Community Trust

St. Petroc's is a well established organisation in Portsmouth that provides accommodation for males only. It has three stages: Stage 1, Mill House in Milton has accommodation for 36 men and provides full board and supervision; Stage 2 is The Talbot, a former public house near Fratton Bridge, which offers accommodation for 15 men; Stage 3 consists of four bedsits in Gladys Avenue, North End. The second and third stage dwellings are owned by the Portsmouth Housing Association and leased to St. Petroc's.

The progress of residents through the stages is decided jointly by staff in discussion with the resident concerned, and there is no limit as to the length of stay, although the resident could be reviewed in the latter two stages.

The Harbour Community

The Harbour Community provides hostel accommodation for 25 homeless men and is situated near the City centre in Portsea. The dwelling is owned by the Portsmouth Housing Association and leased to the above.

The Salvation Army

Although the Salvation Army do provide housing facilities for families, no special provision is made in the area for single persons, of specific groups like the mentally ill.

(c) The Private Sector

The recent, fairly rapid shift from the institution to the community of the care of the long-term, chronically ill psychiatric patients has been made possible, particularly in Portsmouth, by the massive expansion of the private sector. This expansion has filled the gap that existed in community services serious lack of suitable accommodation for those patients in hospital that were capable of living outside hospital with supervision.

It is difficult to assess exactly how many psychiatric patients live in private lodgings or nursing homes: if homes accommodate three people or fewer, there is no requirement to register as a nursing or rest home. There also appears to be homes that cater for more than three residents, yet remain unregistered.

When a home accommodates four or more residents the owners are obliged to register the home with the Social Services Department if they are offering board and personal care. The 1984 Registration of Homes Act was an attempt to achieve a tighter control over the standards of care that homes offered. The registered homes are inspected in detail - the facilities, fire precautions, level of care and whether or not the owner is a fit and proper person to run the home. Inspections must take place annually, although Hampshire Social Services attempt to see the homes twice a year. Once a home is registered, then the owner will receive an average of £130 per patient (at the time of writing) from DHSS benefits. This amount is allocated for the provision of full board, services and supervision.

The types of private accommodation vary tremendously. The registered homes appear to offer full board and lodgings, care and supervision, and a comfortable social environment. At the other end of the scale, provision is a room only and no supervision at all. Between these extremes is a wide range of private care, varying in degree of care, support and living standards.

(iii) Employment Opportunities for the Disabled

The Disabled Persons (Employment) Acts 1944 and 1958 require that a register of disabled people is kept by the Manpower Services Commission. It should include people who have difficulties in obtaining work because of their particular handicaps, whether physical or psychiatric. The Acts also require that employers who employ 20 or more workers are to include 3% registered disabled people in the work-force. Permits may be issued to the employers, enabling them to employ non-disabled people in these positions if no suitable disabled person is available. However, the employers have to inform the Disablement Resettlement Officer (D.R.O.) of any vacancies as they arise, as he may be in contact with a disabled person suitable for interview. Certain occupations are reserved for disabled people, for example, lift attendants and car park attendants. The Acts also introduced the creation of sheltered working environments known as Remploy factories.

(a) The Disablement Resettlement Officer

The D.R.O. is an official of the Department of Employment whose role it is to help the disabled person back into training and/or employment, if possible. He is 'the key person who can provide access to further industrial rehabilitation, to vocational guidance and training, and to such sheltered employment as is yet available.' (Morgan, 1983, p 161)

The D.R.O. in Portsmouth is based at the Job Centre and visits St. James' Hospital on a weekly basis. The purpose of his visits is to monitor the progress of patients in Industrial and Occupational Therapy and to receive referrals from the staff. Following referral, two or three interviews are conducted by the D.R.O. in order to assess whether or not the patient would be suitable for attendance at the Rehabilitation Centre at Hilsea.

(b) Employment Rehabilitation Centres

One of Britain's 27 Employment Rehabilitation Centres (E.R.C.'s) is situated at Hilsea in Portsmouth. It is funded by the Manpower Services Commission and runs courses for disabled people. The courses, lasting about 8 weeks, 'are provided for men and women who after illness or accident need physical toning up, an opportunity to adjust themselves gradually to normal working conditions and a skilled assessment to determine the type of work for which they are best suited.' (Employment Service Agency, 1975, p 13)

The minimum age for entry is school leaving age and all attenders are paid a maintenance allowance. The assessment looks at such aspects as the person's capabilities and understanding of instructions; how the person gets on with his/her working colleagues and those in authority; attitudes to work; confidence, both at work and socially; and time-keeping and appearance. The assessment involves performance in a wide range of tasks, for example, commercial work, gardening, engineering and woodwork.

(c) Vocational Training

Vocational training courses are made available under the Training Opportunities Scheme (TOPS) or other training schemes for disabled people by the Training Services Agency. The Skill Centre at Hilsea runs courses under this scheme in, for example, engineering, vehicle and body maintenance, radio and television repair, and the building trades. Courses are also run at Highbury Technical College, Portsmouth Polytechnic and with employers. Residential courses are available for the disabled in residential training centres, for example, Queen Elizabeth's Training College in Leatherhead, Surrey.

(d) Remploy

Remploy provides sheltered employment for registered disabled men and women who are unable to compete on the open market with other disabled people because of their disability. Remploy is funded by MSC and has a nationwide network of factories that produce a wide range of goods and services. The Portsmouth factory manufactures cardboard cartons: It is labour intensive and the work requires a certain amount of physical stamina. The factory employs about 77 workers, some of whom are schizophrenic. All the employees of Remploy have been referred via the D.R.O.

(iv) Community Facilities Available to the Public

(a) Portsmouth City Council Provision

The City Council has involvement with approximately sixteen Community Associations. These associations are managed by Voluntary Organisations and the premises are provided by the City Council. The Council contribute towards their running costs and provide professional and support staff for the five largest. Most of the remainder have no City Council staff. All the associations are Registered Charities. The department responsible for this area is the Community Provision Section of the Community Services Department, the latter being responsible for the play, youth and community provision of the city. These three areas make up the Neighbourhood Services Department which, at the time of writing, has a budget of about half a million pounds per annum.

The role of the section is to offer on-going help and support to existing associations and also to work with new and emerging groups, responding to neighbourhoods with limited or non-existent youth and community facilities. The officers work with statutory and voluntary organisations, and with tenants and residents' groups (for example, of General Improvement Areas, of which there are about 28 in the City).

Existing community, or neighbourhood centres can be found throughout the city. They are listed in Appendix 5. The local residents identify the particular needs of their area and, as a result, decide the appropriate programme of activities. New developments include the development of the old Southern Electricity Board site in Southsea into housing for young people with a neighbourhood centre and a new community school in Buckland, an inner-city area.

Sports facilities are provided by the Parks and Recreation Department of the city and include a £3½ million Mountbatten Centre which is used for local, national and international sporting events, Wimbledon Sports Centre in Southsea, three swimming pools, tennis courts, bowling greens and playing fields.

There is a sports scheme for the unemployed and a 'Young Blues' scheme - a community football scheme - which consists of two full-time workers who organise football activities for young people in the City.

(b) Hampshire County Council Provision

The County Council fund three large community centres in the city: Paulsgrove Youth and Community Centre, Portsmouth Community Centre and Southsea Community Centre. The County provide staff for these centres and are involved in provision for a number of other Youth and Community Associations, for example, St. Saviour's Youth and Community Centre in Stamshaw and the Hillside Centre in Paulsgrove.

The County Council are also responsible for the provision of Adult Education programmes, and these include a large number of day and evening classes for adult students in vocational and non-vocational studies. These services, provided by the County, are managed by the Portsmouth Institute Management Committee.

(c) The Voluntary Sector

Other community facilities are provided by the Church: provision is made for a wide variety of social activities, clubs, outings and luncheon clubs. Churches have also provided the rooms for the majority of the Contact Clubs in the city and have taken a special interest in them.

The National Schizophrenia Fellowship has a branch in Portsmouth. It meets on a monthly basis in St. George's Church Hall in Portsea and provides help and support for the relatives of schizophrenic sufferers as well as for the victims themselves. The Fellowship frequently organise social activities and outings. The volunteers run a shop in Portsmouth and raise substantial sums of money from their efforts.

Part 3: The Respondents' Use of Facilities in the Community

This section summarises the contact the patients in the sample had with the services described in Part 1 and Part 2 of the chapter.

(i) Contact with National Health and Social Services

One-third of the sample had been admitted to hospital within the last two years, the majority having only one admission. Most patients had a fairly long psychiatric history and all but one respondent had had at least one admission to a psychiatric hospital.

All but three of the patients had seen either their General Practitioner, Psychiatrist or both within the year before interview. In fact, other than two patients who could not remember, all the respondents were in contact with one or more professionals. More than two-thirds of the sample had seen the Consultant within the last year and another 40% were in recent contact with a CPN. Only 15 (16%) had had contact with a Social Worker during the year before interview. The majority of patients had been receiving their injections for more than two years: two-thirds attended the 'Modecate Clinic' in the Solent Day Hospital and the other third of the sample were supervised by the CPN's.

Although 87% of the sample were unemployed, only 17 patients attended St. James' Hospital during the day for industrial or occupational therapy and the majority of these were men (88%). At the time of interview, the social clubs supervised by the hospital and available to the patients were either the Tuesday Club at the Solent Day Hospital or the Contact Clubs. Almost three-quarters of the respondents (74%) did not attend any of these clubs. Of the 24 respondents who did, 16 attended frequently, 5 attended occasionally and 3 only went in order to have their injections.

(ii) Accommodation

A total of 6 men (7%) lived in group homes in the Southsea area of the city, another lived in Mill House (St. Petroc 's), and a further man lived in the Harbour Community. The total number of respondents living in private lodgings was 18 (20%): 4 (3 men and 1 woman) lived in unsupervised lodgings where only bed and breakfast was provided and the other 14 (6 men and 8 women) were in fully supervised accommodation. The majority of patients in this latter group lived in rest-home accommodation where 24-hour cover was provided together with full board and services. The remainder of the sample either lived in their own accommodation or with their relatives.

(iii) Non—NHS Centres and Clubs

No patients attended the Employment Rehabilitation Centre or Skill Centre at Hilsea, even though there was such a high level of unemployment in this sample. Similarly, none of the respondents worked within a sheltered environment such as Remploy. However, more than a third of all respondents attended a centre or club in the community (19 males and 14 females). The centres included social clubs, church clubs, community centres and the National Schizophrenia Fellowship. The majority of those who attended did so on a regular basis.

(iv) A Comparison Between the Patches

The change in the structure of psychiatric services had resulted in the creation of three separate areas, or 'patches'. Each 'patch' is responsible for the identification of needs and the subsequent development of services within it's own area. Therefore, it was decided to make a further analysis of the data in order to identify any major differences between the three areas in services available and the use made of the facilities. This section looks at accommodation, levels of employment, attendances at day centres and the place of administration of injections.

The Cosham Patch is the northern sector of the city and includes the large council housing estates of Paulsgrove, Wymering and Portsdown Park as well as areas of private housing. At the time of writing, Portsdown Park had been run down and the residents rehoused because of deteriorating conditions within the flats and maisonettes. However, at the time of the interviews, this re-housing programme was not underway. Portsmouth Central Patch again has a mixture of privately owned and council housing. The areas of council housing tend to be concentrated near the city centre. The Southsea Patch is the southern sector and has private housing, council housing and larger, Victorian houses that are often let as bedsits or flats. There is also a concentration of privately run rest-homes and lodging houses in this area. The distribution of the types of accommodation in which the respondents were living is shown in Table 7.1.

The majority of home owners lived in the central area of the city and the least number in the southern sector. The largest number of patients living in council accommodation lived in the northern sector where the large council housing estates of Paulsgrove and Wymering are situated. All but one patient living in rented accommodation lived in the southern patch and the majority of patients living in supervised lodgings also lived in this area. The one patient in

Table 7.1

Distribution of the Types of Accommodation Within the Patches

ACCOMMODATION	COSHAM			PORTSMOUTH CENTRAL			SOUTHSEA		
	Male	Female	Total	Male	Female	Total	Male	Female	Total
Own Property	2	6	8	4	8	12	1	3	4
Council Rent	5	6	11	1	3	4	2	0	2
Private Rent	0	0	0	0	0	0	3	2	5
Rented Bedsit	0	1	1	0	0	0	2	1	3
Living with Relatives	7	0	7	0	3	3	5	0	5
Supervised Lodgings or Nursing Homes	0	0	0	1	0	1	5	8	12
Unsupervised Lodgings	0	0	0	1	0	1	2	1	3
Reception Centre	0	0	0	1	0	1	1	0	1
Group Home	0	0	0	0	0	0	6	0	6
TOTALS	14	13	27	8	14	22	27	15	42

Table 7.2

Distribution of Employment Levels Within the Patches

EMPLOYMENT STATUS	COSHAM			PORTSMOUTH CENTRAL			SOUTHSEA		
	Male	Female	Total	Male	Female	Total	Male	Female	Total
Employed - full time	1	2	3	3	0	3	1	0	1
Employed - part-time	0	0	0	0	2	2	1	0	1
Casual Labour	0	0	0	1	0	1	0	0	0
Awaiting early retirement	0	0	0	1	0	1	0	0	0
Unemployed	13	11	24	3	12	15	25	15	40
TOTALS	14	13	27	8	14	22	27	15	42

Table 7.3

The Place of Treatment Within the Patches

PLACE OF TREATMENT	COSHAM			PORTSMOUTH CENTRAL			SOUTHSEA		
	Male	Female	Total	Male	Female	Total	Male	Female	Total
Clinic	11	6	17	6	8	14	23	4	27
CPN at home	2	4	6	1	5	6	4	10	14
CPN & Clinic	0	1	1	1	0	1	0	0	0
Contact Club	1	2	3	0	0	0	0	1	1
Contact Club & CPN at home	0	0	0	0	1	1	0	0	0
TOTALS	14	13	27	8	14	22	27	15	42

supervised lodgings who lived out of that area lived in the central patch in a small, end-of-terrace house with only three other lodgers. Other lodging houses in Southsea tended to be much larger and therefore catered for more residents.

No patients living in lodgings lived in the Cosham Patch, although seven of the men living with their relatives lived in this area and the other five men living with relatives lived in the southern patch. All three females living with relatives lived in the central sector.

Unemployment levels varied from area to area as Table 7.2 shows.
Even though fewer patients lived in the Portsmouth Central Patch, the highest number of employed patients lived in this area. However, in all areas the numbers of employed respondents were small. The area with the least number of patients attending a day centre was the northern patch where only three patients were attending St. James' Hospital. The reason for this low proportion is probably the difficulties patients would have in travelling to the hospital from the outskirts of the city, for example, to travel from Paulsgrove to the hospital would involve catching at least two buses each way and would cost a considerable amount of money.

It was of interest to look at the distribution across the three area of where the patients attended for injection: whether, for instance, there was a higher concentration of home visits in the northern sector because of the geographical distance from the Solent Day Hospital. However, it became apparent that this was not the case. (Table 7.3).

To summarise there appeared to be a wide range of social centres and activities available in the City of Portsmouth: many of these had been provided by the City and County Councils as well as the voluntary sector, and included community centres and associations, provision for the young and sports facilities. The County Council was also responsible for the wide range of adult education classes available in the area. The psychiatric services provided sheltered social environments for the long-term patients in the community, as well as sheltered working and occupational environments. The Portsmouth Housing Association helped to provide group homes and, with the help of other voluntary organisations, provided additional supervised accommodation in the city.

On the whole, members of the sample appeared to have had regular support from professionals. The following chapter looks at the length of time the patients had been receiving their injections, the side-effects (if any) and why the patients felt the injections had been prescribed. Detailed analysis of the recent contact the patients had had with professionals and a brief psychiatric history is also presented.

Chapter 8

Psychiatric Histories, The Injections, Contacts With Professionals and Postscripts

(i) Psychiatric History

The research examined the social situation of the sample and did not include a psychiatric assessment of the patients. However, a brief psychiatric history was taken at the end of the interview in order to gain an impression of previous use made of the psychiatric services. All the patients interviewed had been in contact with the psychiatric services for more than two years. The duration of contact with the services is summarised in Table 8.1.

Table 8.1

The Duration of Contact With Psychiatric Services

Duration of Contact	Male	%	Female	%	Total	%
Longer than 2 years, less than 5 years	7	14	4	10	11	12.1
5 - 10 years	11	22	6	14	17	18.7
Longer than 10 years, less than 15 years	9	18	5	12	14	15.4
Longer than 15 years	21	43	25	60	46	50.5
Not Known	1	2	2	5	3	3.3
TOTALS	49	99	42	101	91	100.0

Half the sample had been in contact with the psychiatric services for fifteen years or longer, more women (60%) than men (43%) had been in contact with the psychiatric services for this length of time. This meant that for many patients their illnesses were long-term, even though they were now living out of hospital in the community. Only one female had never been admitted to a psychiatric hospital. Table 8.2 illustrates the number of times the patients had been admitted to a psychiatric hospital.

Table 8.2: The Number of Past Admissions to a Psychiatric Hospital

Number of Admissions	Male	%	Female	%	Total	%
None	0	0	1	2	1	1.1
One	8	16	7	17	15	16.5
Two	13	27	9	21	22	24.2
3 - 5	16	33	14	33	30	33.0
6 - 10	5	10	7	17	12	13.2
More than 10 times	5	10	1	2	6	6.6
Not Known	2	4	3	6	5	5.5
TOTALS	49	100	42	98	91	100.1

More than half the sample (53%) had been in hospital on 3 or more occasions and there was an even distribution between the sexes (53% of men and 52% of women). However, 5 of the 6 patients who had been admitted more than 10 times were male.

The majority of patients had been in hospital for a stay of longer than a month at any one time (Table 8.3). Of the men, 49% had admissions of 6 months duration or longer, and, although this figure was lower for the women, almost a third of females had had admissions of this same length of time.

Table 8.3

The Longest Period of Time Spent in Hospital

By The Respondents At Any One Time

Length of Time	Male	%	Female	%	Total	%
Less than a week	1	2	0	0	1	1.1
Longer than 2 weeks, less than a month	3	6	5	12	8	8.8
1 - 3 months	12	24	17	40	29	31.9
Longer than 3 months, less than 6 months	6	12	4	10	10	11.0
6 months - 1 year	9	18	4	10	13	14.3
Longer than a year	15	31	9	21	24	26.4
Not Known	3	6	2	5	5	5.5
Not Applicable	0	0	1	2	1	1.1
TOTALS	49	99	42	100	91	100.1

Even though the majority of patients had been admitted to hospital on one or more occasions and for considerable lengths of time, two-thirds of the sample interviewed had not been admitted to a psychiatric hospital within the previous two years (Table 8.4).

Table 8.4

The Number of Admissions Within the Previous Two Years

Number of Admissions	Male	%	Female	%	Total	%
None	28	57	31	74	59	64.8
One	14	29	9	21	23	25.3
2 - 3	4	8	0	0	4	4.4
7 - 10	1	2	0	0	1	1.1
From a long-stay ward	1	2	1	2	2	2.2
No Reply	0	0	1	2	1	1.1
Not Known	1	2	0	0	1	1.1
TOTALS	49	100	42	99	91	100.0

Of those who had been admitted within the previous two years, 90% had no more than one admission. Interestingly, all those admitted more than once were males, and, overall, more men than women had been admitted. Because of the long psychiatric histories of the majority of patients, these results were promising and perhaps illustrated that the community care received by these respondents did help to reduce the number of admissions to a psychiatric hospital.

To summarise, it did appear that the majority of patients had spent a considerable amount of time as in-patients in a psychiatric hospital and had been suffering from their illnesses for a long time. However, a large number of patients had not recently been admitted to hospital: this is probably a result, not only of the positive effects of long-acting medication but also of changing practices in psychiatry, that is, preference being given to caring for patients in the community rather than admission to hospital.

(ii) The Injections

Table 8.5

The Length of Time the Respondents Had Been Receiving Injections

Length of Time Receiving Injections	Male	%	Female	%	Total	%
6 months - 1 year	1	2	0	0	1	1.1
Longer than 1 year, less than 2 years	4	8	4	10	8	8.8
2 - 5 years	17	35	12	29	29	31.9
Longer than 5 years, less than 10 years	9	18	9	21	18	19.8
Longer than 10 years	15	31	16	38	31	34.1
Not Known	3	6	1	2	4	4.4
TOTALS	49	100	42	100	91	100.1

The injections were usually given between two and four weekly, although a small number received them less frequently. Only one patient had been receiving his injection for less than a year: in fact, the majority of patients had been having their injections for longer than two years. More than half the sample (54%) had been receiving injections for more than 5 years.

Again, this confirmed the fact that, for most patients, their illnesses were long-standing, although it is true to say that few were suffering from acute, or primary symptoms of their illnesses because of the long-acting neuroleptics. As we have seen, the majority of patients had not recently been admitted to hospital for treatment, that is, within the two years before interview, and, among those who had been admitted, only 5 men had on more than one occasion.

Two-thirds of the sample interviewed attended the clinic at St. James' Hospital. The remainder (38%) all had their injections given by the Community Psychiatric Nurses: 26 had their injections at home and 5 attended Contact Clubs or attended a Health Centre. Interestingly, the majority of men (80%) attended the clinic for injection, whereas only 40% of the women did so. One of the major factors involved in the selection of the place of treatment appeared to be the home and family environment.

Two-thirds of the patients living alone and with landladies and 86% of patients living with their parents attended the clinic for injection. Those who attended the hospital during the day (and the majority of those were men) also attended the clinic. On the other hand, three-quarters of the patients supervised by the Community Psychiatric Nurses were women, and half the married respondents were supervised at home. Of the married patients, the majority either did all, or shared the household chores and appeared to play a major role within the home. In these cases, the CPN provided valuable support within the home environment. However, it was normal practice to provide CPN supervision for those patients who were poorly motivated and handicapped by their illness: in fact almost half the patients in the CPN group appeared to have spent time doing nothing during the day before interview and 3 men and 1 woman had spent most of their day doing nothing.

The respondents were asked if they knew why it was necessary to receive regular injections. A total of 13 patients had no idea why they had injections and, even when prompted by the researcher, could give no answer. The remaining 78 respondents gave various reasons why. (Table 8.6)

Table 8.6

Reasons Given By The Respondents
As To Why The Injections Were Necessary

Reason Given	Male	%	Female	%	Total	%
To Stay well, or similar	10	20	17	40	27	29.7
To calm down, or similar	13	27	5	12	18	19.8
Bad nerves, or similar	7	14	5	12	12	13.2
Schizophrenia	6	12	4	10	10	11.0
Because the doctor says so	3	6	1	2	4	4.4
Physical well-being	2	4	1	2	3	3.3
Depression	2	4	1	2	3	3.3
To stop the voices	0	0	1	2	1	1.1
Not known	6	12	7	17	13	14.3
TOTALS	49	99	42	99	91	100.1

The largest single group (27%) simply said the injections helped them to stay well: in fact, 40% of women gave this reason. Another 18% (27% of the men) said the injections helped them to stay calm and steady; 12% said they were for their bad nerves. Only 10 patients mentioned schizophrenia in their replies. Other answers given are illustrated in the table.

A selection of replies was made in order to illustrate the different reasons given, and these are presented below.

Case 007, Male, Aged 60

'Heart trouble.'

Case 012, Female, Aged 56

'I don't know. They just give it to me.'

Case 014, Male, Aged 55

'I don't feel I need them any more, but Dr. ------- said I had to. It's up to him, you see.'

Case 019, Female, Aged 51

'What goes on in my head is like a fester that breaks out and all the bad thoughts run down my head. The injection makes me stop this - it makes it lie dormant.'

Case 025, Female, Aged 49

'There are strange voices and thoughts in my head. The injection tries to stop them.'

Case 039, Male, Aged 42

'The injections are for my physical well-being, that is, for my body. It's like a correction drug. I feel more alive, that I can cope.'

Case 044, Female, Aged 40

'Now they don't help me. When I was ill they enabled me to have some peace..........I think I must have had a schizophrenic episode mixed with depression. I just don't know.'

Case 045, Female, Aged 39

'The injections are an anti-depressant for schizophrenia. I don't ask my consultant; I trust him; he's smashing.'

Case 055, Male, Aged 36

'The injections stop my mind from going haywire. They keep me steady, tranquillised and calmish.'

Case 057, Male, Aged 32

'I experienced an impact from within and I experienced a lot of negativity from within. It is being released. The injection helps me take the impact.'

Two-thirds of the sample (67%) said they had no unpleasant side-effects or problems with the injections. However, the others said they did suffer such symptoms as shakiness, trembling, difficulty in keeping legs still, heaviness, discomfort in the limbs and tiredness. (Table 8.7)

The most common side-effect experienced by the respondents was tiredness: 13 patients complained of this effect, that is, 43% of all those who suffered side-effects.

Overall, then, the majority of patients had been receiving their injections for more than two years: in fact, more than half the sample had had injections for more than five years. Most patients had them on a regular basis between two-weekly and monthly. The largest number of patients (62%) attended the clinic, the remainder being supervised by the Community Psychiatric Nurses.

Table 8.7

The Side-Effects of the Injections

Side-Effect	Male	%	Female	%	Total	%
Tiredness	6	12	7	17	13	14.3
Shaky, trembling	2	4	2	5	4	4.4
Psychological effects	1	2	2	5	3	3.3
Unable to keep legs still	2	4	0	0	2	2.2
Heaviness, discomfort in limbs	2	4	0	0	2	2.2
Increased weight	1	2	1	2	2	2.2
Depression	1	2	1	2	2	2.2
Dizziness	1	2	0	0	1	1.1
Vomiting	1	2	0	0	1	1.1
No Side-effects	32	65	29	69	61	67.1
TOTALS	49	99	42	100	91	100.1

A large number of patients (67%) suffered no side-effects: of those who did, 43% complained of tiredness. Others experienced both physical and psychological effects.

(iii) Recent Contact With Professionals

Since all the patients in the sample were in touch with psychiatric services at the time of the interviews, the amount of recent contact with professionals was looked at, including the contact with the General Practitioner (Table 8.8). This was partly to see whether, in fact, patients were being seen by statutory services and partly to identify who the supportive services were.

None of the respondents were in contact with other members of the Primary Health Care Team, for example, the Health Visiting service. In addition to the above contact, those patients attending the clinic at the hospital had support from the nursing staff at the clinic at the time of their injections.

Table 8.8

Recent Contact With Professionals

Last Seen	G.P.	%	Psychiatrist	%	CPN	%	Social Worker	%
Less than a week ago	3	3.3	3	3.3	13	14.3	1	1.1
1 - 2 weeks ago	7	7.7	6	6.6	14	15.4	1	1.1
More than 2 weeks, less than 6 weeks ago	14	15.4	14	15.4	8	8.8	8	8.8
6 - 12 weeks ago	17	18.7	19	20.9	1	1.1	1	1.1
More than 12 weeks, less than 6 months ago	9	9.9	11	12.1	0	0	1	1.1
6 months - 1 year ago	12	13.2	9	9.9	0	0	3	3.3
More than a year ago	28	30.8	25	27.5	0	0	6	6.6
Not Applicable	0	0	0	0	54	59.3	68	74.7
Not Known	1	1.1	4	4.4	1	1.1	2	2.2
TOTALS	91	100.1	91	100.1	91	100.0	91	100.0

A quarter of the respondents had seen their General Practitioner and another quarter had seen their Psychiatrist within the 6 weeks before interview. More than half the sample had seen their G.P. within the previous 6 months and, similarly, half had seen their Consultant Psychiatrist within the same period. However, for nearly a third of the sample (31%) a G.P. had not been seen for more than a year, and 28% had not seen a Psychiatrist. About half the patients in the latter group were in regular contact with a CPN. It could be said that this group of patients saw the CPN instead of the Psychiatrist in many instances. The half that had no contact with a CPN received regular support from the nurses at the clinic.

In 36 cases, a Community Psychiatric Nurse had been seen within the previous 3 months, but for 54 patients, a CPN had no involvement. It is evident that in 30 of the 36 cases (83%) the contact involved the administration of the injections as well as general support. This meant, therefore, that only 6 of the patients who attended the clinic had the additional support of a CPN. Interestingly, there were major differences between the sexes in that 62% of women regularly saw a CPN, yet only 20% of the men did. This was because of the greater number of females who had their injections at home.

Only 15 of the 91 respondents had seen the Social Worker within the year before interview: 10 of these had seen the Social Worker within the previous six weeks. Six of the patients had not seen the Social Worker for more than a year and another 2 patients did not know whether they still had one.

Overall, the majority of patients had support from one or more professionals: only 2 patients were not in touch with a CPN or Social Worker and could not remember the last time they saw a doctor, although this is not to say they had not seen either the GP or Psychiatrist. Those patients who had not seen a doctor within the 12 months before interview were either seeing a Community Nurse or Social Worker (3 patients only). The majority of patients had seen either a GP or Psychiatrist or both. Most patients who attended the hospital clinic did not have contact with a CPN, although, for those patients who did (40% of the sample) contact had been made within the two weeks before interview in 27 of the cases (75%). All the patients had seen their CPN at least once in the 3 months before interview.

(iv) Postscripts

At the end of the interview, the respondents were asked whether or not they wished to add anything they felt was important. Table 8.9 summarises their response.

Table 8.9

Postscripts

Area Referred To	Male	%	Female	%	Total	%
Type of Care	5	10	5	12	10	11.0
Effects of Medication	3	6	5	12	8	8.8
More contact with services	3	6	2	5	5	5.5
Isolation and Loneliness	3	6	2	5	5	5.5
Settled	4	8	1	2	5	5.5
Effects of Illness	2	4	1	2	3	3.3
Employment	2	4	0	0	2	2.2
Accommodation	1	2	1	2	2	2.2
Fear about the future	2	4	0	0	2	2.2
Income	0	0	1	2	1	1.1
More contact with relatives	0	0	1	1	1	1.1
No additional comments	24	49	23	55	47	51.7
TOTALS	49	99	42	98	91	100.1

Half the patients said they felt the interview covered the important areas and therefore did not wish to add anything. However, 44 respondents (48%) did wish to comment further: of this group, 25 (57%) were males and 19 (43%) were females. Their comments were analysed for content and then grouped into the broad areas shown in Table 8.9. The largest single group (23% of those who made further comment) talked about care, for example:

Case 043, female, aged 40

'I feel too much importance is attached to drugs. Doctors should be more easily accessible. We need more group therapy. If time was given, then we wouldn't need so many drugs.'

Case 045, female, aged 45

'My consultant said I can call on him any time I want. That has helped me.'

Case 046, male, aged 39

'I could tell the doctors about therapy. People don't want to throw balls about - talking is much more important............

'I think a day-room to function after hours would be a good idea. I know it's a lot to ask in these times of cuts..........

'It's terrible here for housing. I stayed in a lodging house for ten people in a two-up and two-down. I was admitted to hospital and then sent back. It was like a three-year sentence. I was in a twilight state and couldn't do anything about it.'

Case 069, male, aged 24

'I protested when I came here. I was admitted under duress. I feel I shouldn't have injections when there is nothing wrong with me.'

A further 8 patients commented on the effects of their medication, for example:

Case 025, female, aged 49

'I would like to emphasise that I feel so tired all the time. I can sleep at any time. I have put a lot of weight on.'

Case 027, male, aged 47

'I'm not really as well as I'd like to be, but I have a lot of support around me. I'm fairly happy with the drugs - I don't want to go back to how I was in my teens. I had a happy childhood but a wretched youth.'

Case 083, male, aged 55

'My injections give me that extra confidence.'

Case 090, female, aged 46

'The hospital has done all it can for me and the injections do me good. What I've got to do is to get out and socialise more to gain my confidence.'

Case 098, female, aged 37

'If I could lose weight I would feel much better.'

The following commentary is a wide selection to illustrate the other areas talked about by the respondents:

Case 002, male, aged 63

'My time attending the hospital has been reduced - I would like to do more hours (at the hospital). The days at home are unoccupied and I have to find my own meals.'

Case012, female, aged 56

'My accommodation is most important. I want to move out. I get aggravation from the other residents.'

Case 015, female, aged 54

'There is nobody to turn to if I'm in need.'

Case 020, male, aged 51

'There is not enough after-care, treatment and follow up. For out-patients there is not enough community nursing care, which is important.'

Case 064, male, aged 28

'A lot of employers stigmatise against people who have suffered mental illness.'

Case 032, female, aged 45

'I feel a bit shut out of everything, out of everyday living. I feel quite alone.'

Case 033, male, aged 43

'I don't know if I'll meet anyone and get married again. Perhaps it will be too much pressure.'

Case 038, male, aged 42

'I went for a job this week. I'm actively looking for a job - it's very important.'

Case 052, male, aged 37

'One idea of the cluster flat is to allow independence. But it doesn't work. What we need is support. I am so lonely. I don't know what is going on in the hospital, for example, social clubs. Also, I need support to find a job. There is a lot of stigma attached to mental illness.'

Case 054, male, aged 36

'I'm worried about the world situation - violence, wars and the nuclear deterrant.'

Case 073, female, aged 65

'I'd like £20 a week please, so I can go to the Wimpy Bar more often.'
(From supervised, private rest home)

This study has described the social situation of 91 schizophrenic patients who lived in the community in Portsmouth. It has looked at various aspects of their lives and has attempted to identify areas of need. The following chapter discusses the results and implications of the research and conclusions have been drawn based on this discussion.

Chapter 9

Conclusions

The Background of the Study

Primary, or 'first-rank' symptoms of schizophrenia are now well controlled by phenothiazines (Leff and Wing, 1971) and other long-acting neuroleptics, and the development of these depot injections has ensured the continuation of medication and therefore improved recovery rates (Hirsch et al, 1973; Crawford and Forrest, 1974). This has enabled many patients to lead a life outside hospital in the community. All the patients in this study received long-acting neuroleptics and lived in the community in the City of Portsmouth.

However, long-term schizophrenic illness can prove to be severely debilitating as secondary or 'negative' symptoms are often present, for example, social withdrawal, flatness of effect, poverty of speech and slowness (Wing, 1978b). Research has shown that the social environment can influence such factors and that poverty of, or an under-stimulating environment can negatively effect the onset and course of a schizophrenic illness (Brown et al, 1966; Wing and Brown, 1970).

A review of the literature has shown that schizophrenic patients living in the community are often subjected to such environments: many are unemployed or unoccupied during the day (Korer et al, 1978; Gibbons et al, 1984), and many play only a limited part in household care and management (Creer and Wing, 1974). Many expect to sit, sleep or do nothing during the day (McCowen and Wilder, 1975). Large numbers of patients are isolated and lonely and many who do not complain of isolation appear subjected to it (Cheadle et al, 1978). They suffer self-consciousness and a lack of self-esteem, and complain of an inability to make friends and form meaningful relationships (Korer et al, 1978). A large number of patients return to their families who often bear the greatest burden and a number of relatives are dissatisfied with the services provided (Creer and Wing, 1974).

However, many families have been found to be accepting and tolerant and tend to understate their problems (Brown et al, 1966; Creer and Wing, 1974). Some family situations are known to be harmful to the schizophrenic patient, for example, where there is a large amount of 'expressed emotion' (EE) from the key relative. Research has shown that this proves to be the best single indicator of a symptomatic relapse (Brown et al, 1972; Vaughn and Leff, 1976). Yet there is a recognised lack of suitable alternative accommodation (DHSS, 1975; Hewett et al, 1975; Ritchie and Keegan, 1983). The lack of suitable sheltered accommodation contributes towards the numbers of 'new' long-stay patients in psychiatric hospitals (Mann and Cree, 1973).

The principles of community care are widely accepted in the light of the evidence presented concerning the harmful effects of the institution, especially on those individuals suffering from chronic mental illnesses. But the literature has also shown that the reduction of available beds has been encouraged before services in the community have been developed and that many chronically mentally ill people and their families cope in the community with little or no support (Social Services Committee, 1985; Mind, 1985). In 1975, the government said:

'There is an urgent need for more research into the overall size of the problem.........little is known about the chronically disabled in the community whose needs are unmet or are being met only at the price of near intolerable strains on their families, or who are perhaps living with elderly relatives who will be unable to cope with them for much longer.' (DHSS, 1975, p 42)

It was felt there was a need for a local study in community care, particularly of this very vulnerable and often neglected patient group. There was a dearth of available information on the effectiveness of local community services for the mentally ill, even though the psychiatric services were undergoing major changes in management and structure. Available beds at St. James' Hospital were being drastically reduced without, it seemed, an adequate expansion of resources in the community. Chapter 1 has discussed the need for a balance, for example, between integration and segregation, intervention and interference, and dependence and independence. Was this balance being achieved by the local services, or was there simply a transfer of institutional care from within the walls of the hospital to the community outside? Were we offering the patients a second-rate, inflexible service, in which little or no choice was available to the patient? Were we, in fact, trying to achieve a cheaper option?

The Limitations of the Study

The study looked only at the social situation of a particular group of patients - those who had been diagnosed as schizophrenic and who were being treated with long-acting neuroleptics. The results apply, therefore, only to those patients, or to others in a similar position in Portsmouth, that is, people suffering from chronic, handicapping mental illnesses. It could be said that these were the lucky ones - they were being treated, and therefore remained in touch with the psychiatric services. It must be remembered that many others are not so fortunate: 'As things are, most of them are returned to their "families", if any. The rest are on park benches, in prisons, doss houses or seedy and rapacious lodgings.' (National Schizophrenia Fellowship, 1985, p 209)

For many discharged psychiatric patients in Portsmouth, accommodation is found in the lodging-houses or rest-homes of Southsea. In our sample, 20 per cent lived in such accommodation. But not all residents remain in contact with the psychiatric services. This situation has been acknowledged by the Social Services Committee (1985):

'Many others referred to the plight of former hospital patients living in boarding houses. There appears to be lamentably little follow-up of discharged patients. A PRA survey found that of long-stay patients discharged from hospital in one year, as many as 40 per cent of the sample had no contact with the hospital or formal social services. Evidence received suggested that such inappropriately discharged patients may end up taking their own lives, if not other people's.'

It must be remembered, therefore, that many patients do slip through the net of care, and that these patients may well be experiencing severe difficulties which are not accounted for in this study. It is also interesting to note that the majority of the respondents in this project (96%) were of British nationality. It could well be that in other cities a higher proportion of ethnic groups would be represented and this might affect their situations, for example, in the amount of family contact.

However, the data provided valuable information about the situations in which these patients were living and the contact they had with the statutory services. The data has been described in detail in Chapters 4 to 8, from which several interesting patterns emerged, for example, differences between the sexes, a high unemployment level and subsequently tragic waste of human potential and the differing characteristics of the three 'patches'.

The Major Differences Between the Males and Females in the Sample

During the data analysis it became apparent that major differences existed between the men and women in the sample: the men, for example, tended to experience more difficulties with relationships. In fact, significantly more women than men were married - only 14% of the men were married at the time of interview, compared with 45% of the women. The women were more likely to have married: 74% of women but only 28% of men had been married at some time in their lives. Gibbons et al (1984) had found similar patterns in their study of schizophrenic patients in Southampton. These differences could well be due to difficulties experienced by the handicapped male in taking the leading role in courtship. A further factor could be that, because of the low levels of income received due to the high level of unemployment, the men in the sample simply could not afford to go out socially. It would have proved even more difficult to take a young lady out as one of the men, aged 34, said: 'I can't afford to take a girlfriend out. I would like a girlfriend and get married.'

This conclusion is also supported by the fact that more men than women were single and lived with their parents. It could well be that the majority of these men had never left the parental home as all but one of them had lived there for ten years or longer. One reason for this high proportion could be that the parents supported the patient financially, whether directly or indirectly. Certainly living at home would normally prove cheaper than living in a bedsit or flat. Another reason for living in the parental home may simply have been because of the difficulties in making relationships, particularly romantic ones.

Of the men who had married at some time, half were divorced or separated at the time of interview, compared with 17% of the married women. This higher divorce rate among the men may have been caused by symptoms of the illness that had proved to be too stressful for the partner. A further reason may have been because of the patient's inability to hold down a job and play a supportive role within the home.

The women in the sample seemed more able to occupy themselves during the day and many felt they had a useful role to play within the home. Responsibility for activities within the home was looked at, including housework, shopping, laundry and cooking. Overall, the women took more responsibility for these tasks than the men, although a considerable number of men did undertake some, or all of these tasks. The women, on the whole, had a role to play within the home and this was also evident in their accounts of activities taken from the time-budgets. The general impression gained was that the women were more able to structure their days and were more motivated than the men in engaging in activities which interested them. This was particularly important because of the high incidence of unemployment in the sample. The women, it seemed, were more able to look after others and, therefore, themselves.

The women also appeared, in general, to manage their money better than the men: fewer women ran out of money regularly and a higher proportion of the men could never afford to buy new clothes. However, despite these differences, an equal number of men and women showed dissatisfaction with their financial situation. The difficulties some of the men had with managing their income may well have contributed to the problems they encountered in their social lives.

More single men than women said they lacked friendship and that they were dissatisfied with their social lives. For the respondents who had no money to spend on social outings, there was little opportunity to meet people and make new friends. A higher number of males regularly attended the hospital social clubs, although it was unlikely that new acquaintances, particularly romantic ones, would be made at these social events. However, it is likely that the social environment at these clubs provided a safe and comfortable situation in which the handicapped patient could mix with others and socialise at his or her own level. For, without a doubt, the handicaps caused by the illness were a major contributing factor in the difficulties encountered by the patients in forming and maintaining friendships and romantic attachments.

These handicaps, such as slowness and apathy, would also make the possibility of finding employment an unlikely prospect. We know that the women in the sample were more able to occupy themselves during the day and this, in turn, provided a certain amount of stimulation and therefore helped to minimise the secondary handicaps of the illness. But for many of the single men in the sample, the opposite was true: they lived in understimulating environments which would undoubtedly lead to an exacerbation of their secondary handicaps.

It appeared that the men were more dependent on the hospital for support than were the women. However, a higher proportion of women (60%) than men (20%) had their injections at home and therefore had the support of a Community Psychiatric Nurse.

It must be remembered that the majority of cases lost from the original sample were single males. These men may well have been experiencing similar difficulties to those included in the study. Therefore, it is probably true to say that the differences between the sexes would have been even greater if all cases had been interviewed.

Employment

'Disabled people have long experience of unemployment and what began as a doubt of their own ability ever to face the challenge of work again, changes eventually into a resigned conviction that the demands would be too great and had better be avoided.' (Morgan and Cheadle, 1981, p 36)

Without a doubt this attitude of hopelessness and resignation was felt by many of the patients in the sample. Out of the total sample of 91 patients, 12 were employed and a further 12 were housewives who were not really in the employment market. However, of the 67 who might have been eligible for work, only 17 (25%) were looking for employment. The majority who were not looking for employment said it was because of their illness and their inability to cope with work, for example: 'I'm schizophrenic and can't cope with work... people would notice I'm a bit odd. Once you've mentioned this place (St. James' Hospital) you've had it.'

Jacky Korer (1977) had found in her study of schizophrenic patients in the community that the stigma of having had a mental illness was a major problem when searching for employment. 'This would affect the employment record so preference in a competitive situation like applying for jobs, would be given to the man with the "clean" record.' (p 13). However, Michael Floyd and his colleagues (1981) in their study of schizophrenia and employment did not feel this was the most important factor, although they acknowledged that

'Our research suggests that anyone, who has been unemployed for substantial amounts of time during the period immediately prior to their applying for a job - whatever the reason - will be regarded as a poor prospect. Thus a vicious circle whereby unemployment leads to further unemployment, is a very important aspect of the problems experienced by our subjects.' (p 7)

The researchers found that the main problem was not actually finding employment, but that 'increased unemployment may well be related to the shorter times subjects tend to remain in jobs during the "post-illness" period, and that this is "the problem", rather than their difficulties in finding employment in the first place.' (p 7)

They found that only a few of their subjects were actually dismissed from their jobs: in fact, most of their subjects left voluntarily. The researchers felt that most professionals would put this down to a 'lack in motivation' and say that 'a central aim of rehabilitation is to restore motivation.' (p 8). However, they felt that 'A more likely explanation is that they were withdrawing from a situation that they were finding too "stressful". (p 8)

The findings of the present study are consistent with this conclusion because it is clear that, even after the initial onset of their illness, many of the respondents had held responsible jobs which they had held down for considerable lengths of time.

Floyd and his colleagues identified aspects of the working environment in which their subjects were more likely to stay, for example, good supervision and working within a fairly small work-group. This would provide feedback and enable the comparison of the patient's work with that of a colleague.

'One reason for an "isolate" role being undesireable - contrary to much conventional wisdom with regard to appropriate work situations for people with schizophrenia - may well be that it rules out the possibility of such a comparison. Where such feedback is lacking it is likely that......subjects will find it difficult to go for long periods without some reassurance that they are performing adequately; in other words, too great a "time-span of discretion" will be found to be stressful.' (pp 10/11)

Agnes Miles (1971, 1972) found that, in her study of schizophrenic patients working in a hospital's industrial unit, the patients' motivation and ability to work improved in the unit, more so than in the Occupational Therapy unit. An important aspect of the work was the contact with, and cooperation between patients and the good social climate which existed in the work-group.

It is interesting to note that, in our study, three of the men who had successfully obtained first degrees, failed whilst pursuing their Master's degrees. It was during this time that they first experienced a mental illness. It could well be that the isolation and lack of group support in this situation proved too stressful and subsequently led to the breakdown, whereas some group support was present whilst studying for their first degree.

Floyd and his colleagues concluded that there is a need for 'a radical assessment of current practice with regard to the rehabilitation, resettlement and employment of people with schizophrenia...' (p 12). The first step is to help people find the right job, although they acknowledge that in today's economic climate patients may have little choice. However, they make the point that they had 'found little evidence for the assumption that a diagnosis of schizophrenia should be equated with an inability to do more skilled types of work' and that 'Few of our subjects have ever received any form of counselling about appropriate work situations. To the extent that any of them have been steered into particular kinds of work situation, it is as likely to have been in the direction of "bad" environments as of "good" ones.' (p 12)

One is left with the impression that, for many patients in the present study, apathy and resignation had taken over from ability and a willingness to reach their full potential. The illness was responsible for only part of this situation - the fact that many of the patients had experienced long terms of unemployment also contributed to this downward spiral to permanent unemployment. 'Unemployment is debilitating and may lead to further breakdown. It reduces an individual to a state of dependency which is an insult to his dignity and a constant reminder of his failure.' (Brown et al, 1966, p 72)

Unfortunately, one aspect not taken sufficiently into account during the interviews was the ability and creativity of the patients. However, the researcher observed that an abundance of creative ability had been present among the patients, for example, a professional actress, two professional musicians, several highly competent, amateur musicians, artists and academics were represented in the sample.

What we have is a tragic waste of human potential. As Roger Morgan (1983) commented

'During illness it is accepted that people are temporarily excused by society from the obligation to work. This element of the "sick role" is entirely appropriate to a patient's needs during short-term, recoverable illness but not so appropriate in chronic illness or permanent disability, if what began as a humane and sensible exemption turns later into a demoralizing deprivation.' (p 151)

Relationships

'A lot of my friendships leave a lot to be desired but there's nothing I can do about it........society doesn't like people from St. James' - like a pack of wolves with a weak one - they will turn round and kill it ...... Most of the time I feel lost.'

- Graham, aged 34

The feelings of apathy and resignation experienced by many of the patients in relation to their employment situation, turned to feelings of despair and pathetic isolation regarding their relationships. It could be argued that this lack of contact with others may have been through choice - that withdrawal acted as protection and therefore avoided further breakdown. However, the impression gained was that many of the patients were not happy with this situation, and, in fact, had said so: more than a quarter of the sample had shown dissatisfaction with their social lives and more than half the sample said there was something missing from their relationships. The single men and those aged between 30 and 45 seemed to experience these problems particularly acutely.

Nearly all the respondents had reasonable contact with their relatives: only 9 patients seemed to have lost contact with their family. Indeed, in many cases, the family appeared to maintain a high degree of contact with the patients and offered companionship and support. More than half the sample (54%) actually lived with their families, while as many as 86% claimed they could turn to relatives if they needed help or advice.

The unmarried patients in the sample, and the majority of these were men, did appear, on the whole, to experience problems in their relationships with others. At the time of the interviews, a third of the respondents lived without friendship, although only 16 patients admitted they were unhappy with this situation. However, more than half the sample admitted that something was missing from their relationships; for example, ten respondents said they missed a partner and/or marriage and another eight said they missed friendship and felt lonely.

Despite the isolation felt by some of the patients, only a quarter of the sample attended clubs organised by the hospital. It could well be that the respondents did not wish to form relationships and make contact with others in the same position as themselves: as one young man said 'I would like a girlfriend. A man of my age should be married. Not a girlfriend from St. James'.'

He had earlier explained that he was 'fed-up talking to nutcases. All my friends are ex-psychiatric patients.' Another patient living in a rest-home said that she would like to make friends outside the home.

But, for the majority of the respondents, it did seem that the probability of forming new relationships outside the hospital or family environment was minimal. The impression gained at the interviews was that existing friendships were long-standing and that few, if any, respondents had made new friends since the onset of their illness. Often, to live with schizophrenia meant a sacrifice of what there had been before the illness. Again it seemed that schizophrenia had destroyed the potential of its victims.

The Role of the Family

The impression gained by the researcher was that, for a large number of patients, their families provided the majority of support in the community. As we have seen, more than half the respondents lived with their families and the great majority claimed that they could turn to one or more of their relatives for support. Only 9 of the respondents had lost contact with their families, all patients in the older age groups. The younger patients appeared to have kept contact: the most probable reason for this is the shorter period of time in which the patients and their relatives had experienced the effects of living with a schizophrenic illness.

Gibbons et al, in their Southampton study, found that among the patients living with supporters, the predominant patterns were of sons living with mothers and wives with their husbands. The pattern in the present study was similar. The Southampton project studied this in more detail and found that in their sample, a quarter of all primary supporters were of retirement age (65 years or over) and, in fact, 11% were over 75 and these were nearly all mothers. They also discovered that

'About 30% of the primary supporters were living alone with the patient: this proportion increased with the supporters' age, so that 38 per cent of supporters over 65 were alone with the patient, and 45 per cent of supporters over 75. In such circumstances the patient was often an important prop to the parent.' (Gibbons et al, 1984, p 73)

Research has shown that the experience of caring for schizophrenic relatives has aroused very different reactions among families.

Some have found it highly stressful, particularly if the patient had displayed offensive or violent behaviour (Brown et al, 1966; Creer and Wing, 1974; Gibbons et al, 1984). On the other hand many, particuarly parents, expressed few complaints (Creer and Wing, 1974). Although the present study did not look at the experiences of the patients' relatives, it was apparent that problems were encountered in some of the cases. An account of a mother's experiences is presented in Appendix 6. She says:

'At first I was filled with pity for his plight: then, after a while, I became very resentful that we, as a family, had this enormous problem thrust upon us.......At this time my daughter would not visit the house because she was, I think, very frightened at X's apparent loss of control over his mind... I became very introverted myself: not going out or having friends to visit because of X's unpredictable behaviour.'

Nevertheless, despite the difficulties experienced by some of the relatives of the respondents, many kept in regular contact with the patients: during the week before interview, three-quarters of the sample had met with relatives. More than half the sample were happy with the contact they had with their relatives, a quarter said the contact was O.K. and 16 patients were dissatisfied. Three-quarters of this group were unmarried.

The major role that relatives play in the community care of the mentally ill must be acknowledged. The stress experienced by both patients and their families because of schizophrenia must be recognised. If the statutory services offer adequate resources and support, then no doubt families will be more willing and more able to continue with the care they offer. Without that support, many will not be able to cope.

Accommodation

Overall, the majority of patients said they were satisfied with their accommodation, but it is possible that many of the patients did not complain simply because they had not experienced any alternatives. Also, the situation in which many mentally ill patients find themselves is one of dependence, whether on family or statutory services, and poverty: these together result in a loss of choice on the part of the individual. The patient often ends up being 'grateful' for whatever comforts he or she has. It is this situation that Terry Hammond (Portsmouth Housing Association), in interview, called 'The Colditz Syndrome' - a survival at whatever level.

Surprisingly, the length of time in accommodation presented a stable picture: many respondents had been living in their accommodation for considerable periods (Gibbons and colleagues had found similar results in Southampton). Almost three-quarters of the sample had been in the same accommodation for more than two years. They may have enjoyed this security because they were supported by friends, relatives or community services.

Concern has recently been expressed about the numbers of psychiatric patients who are discharged into boarding houses (Social Services Committee, 1985). Eighteen (20%) of the sample lived in either supervised or unsupervised lodgings. The majority of the patients who lived in rest-homes shared their bedrooms and other facilities, although it must be said that the homes visited offered pleasant rooms, each resident having his or her own wardrobe and drawers.

The problem was that the rest-homes were, in the main, converted hotels or large Victorian houses and therefore had large rooms. In order to make a profit out of running a home, the owners had to support as many residents as possible and this meant requiring residents to share rooms. Most of the homes visited appeared to have only minimum restrictions, although none of the residents did any cooking and the majority had their cleaning and washing done for them. In several cases, the patients undertook tasks in the home and received extra pocket-money for doing so.

Hewett and her colleagues (1975) found in their study of non-hospital residential care in London, that the hostels they looked at tended to be 'permissive', although certain restrictive practices were retained. These practices, however, were intended to be caring and not restrictive. Nevertheless, they did find that criteria for admission to the units included employability and acceptable behaviour.

In Portsmouth, many of the rest-homes are now run by psychiatric nurses. It has been said that the nurses select the most attractive patients for their homes and that those patients with behaviour problems are rejected. Of Southsea, in particular, Marjorie Wallace reported in The Times, December 17th, 1985:

'The money is so attractive that some psychiatric nurses have left the demoralized atmosphere of the hospital to set up lodging houses. They have the advantage that they can select the least troublesome patients, even making arrangements with them before leaving the wards.'

At present, a draft document has been drawn up for a District Code of Practice on the referral of patients to rest-homes owned by staff currently working in the National Health Service. It says that 'The code primarily aims to protect patients from potential exploitation. It also aims to protect staff who may be falsely accused of exploitation of patients.' (p 1). However, at the time of writing the Code of Practice is in draft form only. It sets out a firm referral policy and says: 'It could be considered inacceptable for a person to be named as an employed member of staff in a nursing/rest home within the application document if they are simultaneously an employee in the NHS.' (p 3)

Unfortunately, all those patients living in bed and breakfast accommodation chose to be interviewed at the hospital because they felt there would have been a lack of privacy within their accommodation. Therefore, no assessment could be made of these lodgings. However, several patients who lived with relatives were interviewed at home and the majority of these environments appeared to be comfortable and with little or no restrictions placed upon the respondent.

Portsmouth City has only six group homes and another is situated outside the city. These houses, or flats, provide accommodation for about 35 residents. All the residents in the group homes in the sample were men, although accommodation is provided for men and women. Some houses are now supported by part-time housekeepers, who cook and offer supervision to the residents. However, at the time of interview, some concern was felt by the researcher because of the situation found in the cluster flat. One of the residents said he felt unhappy and isolated in the flat:

'One idea of the cluster flat is to allow independence. But it doesn't work. What we need is support. I am so lonely. I don't know what is going on in the hospital, for example, social clubs. Also, I need support to find a job. There is a lot of stigma attached to mental illness.'

Had Balance Been Achieved

In the first chapter, the question of balance was discussed - in order to plan, develop and implement a comprehensive community service for the schizophrenic, and often chronically handicapped patients, there needs to be an acute awareness of the need to create the right balance.

From the evidence presented in this study it did appear that, for some of the patients, the balance was just right - that they were in contact with their families, settled in their relationships and accommodation, were occupied during the day and, on the whole, were satisfied with their situation.

However, for others the story was not such a happy one. In particular, the single men in the sample seemed to be experiencing difficulties in their relationships, social life and could not find suitable employment or occupation during the day. Many, it seemed, were unhappy with this situation - they were feeling lost, lonely and yet were unable to do anything about their plight. Therefore, they had slipped into a state of apathy and resignation. Although it appeared that the women, on the whole, were more able to look after themselves and manage their lives, some expressed dissatisfaction with their situation. The impression gained by the researcher was that, although they experienced fewer difficulties with their relationships, management of income and were able to occupy themselves during the day, a number were unhappy with these areas of their lives. A higher proportion of the women were married and this group seemed to be more settled in their relationships, regularly saw their families and had a role to play within the home.

It can, therefore, be concluded that some patients in the sample lived in under-stimulating environments, which, in turn, led to an exacerbation of secondary symptoms of their illnesses: these symptoms included apathy, a loss of motivation and a subsequent loss of self-confidence. It was unlikely that most of those who were unemployed would be able to find suitable jobs, particularly because of the lack of sheltered employment in the area.

It seemed that most patients preferred living in the community and would not have welcomed a return to an institutional setting. However, the majority of respondents gave the impression that they viewed the hospital in a positive way and, for some, it provided valuable support in the day, for example, at Industrial Therapy, Occupational Therapy and in the Canteen. Unfortunately, even though many of the patients were unoccupied during the day, the number of places at Industrial and Occupational Therapy was restricted. Additionally, it seemed unlikely that any members of the sample would be accepted by the Disablement Resettlement Officer for referral to the Employment Rehabilitation Centre or Remploy: again, places were restricted and a certain standard of performance was required of those people fortunate enough to gain places. Many of the patients in our sample, particularly those who had been unemployed for a long time, would probably have had great difficulty in reaching the standards required, for example, of punctuality.

This, coupled with the fact that the majority of unemployed patients had resigned themselves to the fact that their illness made them 'unfit' to work, made the prospect of referral extremely unlikely. There is, therefore, evidence of the need for further provision of special industrial and occupational facilities for the chronically handicapped person in the community.

Some patients appeared to experience isolation and loneliness, even though, in many cases, they were living with their relatives or others. Of course, the isolation may have been self-inflicted, that is, the patients may have withdrawn from stimulation and the company of others as a protective measure. However, many of these respondents had expressed their unhappiness about their feelings of loneliness and their inability to form meaningful relationships. Living in the community, for these patients, did not mean living in harmony with others - it often meant feeling rejected by, and segregated from other people.

Because of this, the impression gained by the researcher was that a number of patients remained dependent on the support of either the hospital or the Community Psychiatric Nursing Service. Several of the patients relied solely on the other patients or the hospital staff for their contact with others outside the family. It has been acknowledged that many patients do need asylum (Social Services Committee, 1985) and it appears that, for some of the respondents, the hospital offered just that, yet allowed them to retain their independence.

An important factor was that the patients had choice - they could choose when to make contact and how much contact to have. A comprehensive community service should provide that choice, within reason, in all aspects of care: this would help even the most dependent patients to have some degree of independence. But, unfortunately, all too often the opportunity to choose was removed from the patient because of a lack of suitable resources in the community. Once that choice had been removed, the concept of providing individual care was made impossible. The Social Services Committee (1985) recommended that

> 'the Department lay an obligation on authorities to ascertain so far as is practicable, and give due consideration to, the wishes and feelings of mentally disabled individuals for whom a service is provided, and in particular where closure of a long-stay facility is contemplated.' (p cxiv)

But, it could be argued that, for many of the patients in our sample, there was little choice of alternative accommodation and that meant being grateful for the comforts available in their present environment. For many discharged psychiatric patients or those with chronic illnesses, owner occupation is merely a dream and Local Authority housing means a long wait. Terry Hammond said that

> 'if we discount owner occupation and if we forget Local Authority for the time being, that is nearly 90% of the housing stock out of reach to you. That leaves you with a little over 10%, that 10% being the private market and for anyone of you who have ever tried to look for a decent private rented accommodation, that is all but impossible, unless you are prepared to pay very high rents or considerable sums in key money.' (Hammond, 1984, pp4,5)

Other than the group homes, no special housing was provided for the psychiatric patients in the area by the statutory services, even though it is recognised that a wide range of accommodation is needed to suit individuals' requirements (DHSS, 1975; Peter Ryan, 1979; Social Services Committee, 1985). Provision for those patients requiring high levels of support was left to the private sector and, despite the fact that the homes visited were, on the whole, comfortable and well-run, it must be remembered that the proprietors need to make a profit out of caring. To leave the sole responsibility of caring for the homeless, chronically ill to the private sector must be short-sighted, for if the owners' circumstances change and there is a need to sell property, what would happen to those patients? The lack of hostel accommodation in the community in the Portsmouth area is a gaping hole in the net of care.

The Adult Placement Officer, although he had successfully placed several mentally ill people into suitable, supportive homes, commented that his job was made particularly difficult because of the lack of available day-care facilities in the city. This lack of day-care has been the complaint of many relatives, together with the need for more help, advice and easier access to the services (National Schizophrenia Fellowship, 1985).

The patients in the sample were supported by either members of the medical or nursing teams, or both. Those patients who were not in contact with their General Practitioner or Consultant Psychiatrist received regular support from either a Community Psychiatric Nurse or the nursing staff of the Modecate Clinic.

However, only 36 respondents were in contact with the CPN service, even though the value of CPN support for patients and relatives is widely recognised (DHSS, 1975; Hunter, 1978; Morris, 1981; Social Services Committee, 1985). Why some patients were referred to the CPN service and others not was not examined in this study, although it did seem that the home environment, for example, whether or not the patient had responsibilities within the home, and the degree of motivation were important factors. Those who had responsibilities, such as married women, and those who lacked the motivation to attend the clinic were referred to the CPN's. The patients, it seemed, were not normally involved in the decision for referral to the CPN Service. This was left to the staff.

The remaining patients received the support of the clinic staff when they attended for injection, or more often if required. The impression gained by the researcher was that the clinic nurses were very supportive to the patients and that, for many of the clinic patients, their visit to the hospital was an enjoyable one from which they benefited. However, it was likely that the relatives or landladies of the clinic patients received little in the way of support from nursing staff, unless a CPN was also involved.

Despite this need for support, intervention by the statutory services must never become interference - what there needs to be is a close liaison between the formal and informal carer. Bayley (1982) acknowledged 'that there is a danger of the formal system taking over and/or destroying the informal system.' (p 185). However, often the opposite appears to be true - that the families of patients largely take the responsibility for their schizophrenic relatives. It is the responsibility of the statutory services to ensure that the correct balance of accountability is obtained.

Overall, it could be said that community care for this particular group of patients had been achieved to a certain extent, although serious gaps in the services have been found. The service mainly falls short in it's provision of special accommodation, employment and occupational facilities. It has been widely acknowledged that CPN involvement is highly beneficial, yet only 40% of the sample had this support. A high proportion of patients were experiencing difficulties in their relationships and social contacts with others and it is probable that these patients would have been assisted by CPN involvement and support. This support would also have been available to the relatives - it appeared that, in many cases, community care was being provided by families who, in turn, received very little in the way of support and advice.

It must be acknowledged that, for the majority of our sample, the seriousness of, and chronic disabilities caused by their illnesses required the on-going support of a fully comprehensive community service. Many other mentally ill people are treated successfully by the acute psychiatric services and, often, may never need them again, or, at least, require only minimal support thereafter. But, as Peter Ryan (1979) had said, the 'acid test' of a service in the community lies in whether or not the needs of the severely mentally disabled are met and that 'An effective service must be able to cope with their needs without giving rise to intolerable burdens on families or on the community at large and without allowing a drift into destitution.' (p 60)

Chapter 10

Policy Implications

The study has explored the social environment in which 91 schizophrenic patients were living in Portsmouth between January and August 1985. Identification has been made of the patients' recent family and social contacts, together with the types of accommodation in which they were living, employment levels, income and the availability and use made of the local community services. The exploration of previous research provided information from which conclusions could be drawn about the needs of this particular group of patients, for example, the balance between under-stimulation and over-stimulation (Wing et al, 1964). The gaps in existing services have been highlighted by those needs of the patients in the sample that remained unmet, or where it was believed that patients had not achieved their maximum potential.

It has been widely agreed that there needs to be a balance between institutional and community care. Hospital provision should not continue to be reduced without adequate provision in the community for the mentally ill and, in particular, the chronically ill. They are often unable to articulate their needs and very rarely complain about their situation. As the Social Services Committee (1985) put it:

'It is only now that many people are waking up to the legacy of a policy of hospital rundown which began over 20 years ago. Many of the horror stories of mentally ill people living on the streets or miserably in board and lodgings are the results of an earlier era. Whatever the weaknesses of present policies and practice, everybody must be aware of the need for appropriate community services to be in place before the process of hospital rundown races ahead yet further........' (p xviii)

The government had maintained that its real aims had not been 'the closure or rundown of the mental illness hospital as such; but rather to replace them with a local and better range of facilities.' (DHSS, 1975, p 84)

However, it is unrealistic to attempt to develop services for the mentally ill in the community if the community is unable, or unwilling, to receive them. The Social Services Committee acknowledged that we 'cannot close our eyes to the degree of community resistance to having mentally handicapped or, even more so, mentally ill people living in close proximity.' (p lxvi)

The Committee recommended that 'the Government promote a positive programme designed to procure a greater degree of community acceptance of community care policies, both by a national initiative and through specific guidance to authorities......' (p 1xviii).

There is a need for a long-term education programme to promote community care, the aim of which must be to develop an understanding and awareness of the needs of the mentally ill. But public anxieties will continue to exist if community resources are not provided: only with a comprehensive service supporting patients outside hospital can we hope to begin to reduce the prejudice and stigma against the mentally ill. Without adequate services, life in the community for many patients would prove difficult and crises would occur. This not only would reinforce prejudice and stigma, but would probably increase it.

A major criticism of the institution was the lack of individual care. To avoid this situation re-occurring in the community, there needs to be a wide range of services available to cater for the differing needs of individual patients. The system needs to be flexible, so as to allow movement within it, according to the changing needs of the patients. If individual care is to be developed, the patients must be able to exercise choice, wherever possible. The Social Services Committee commented that there is a fundamental point at issue

'which professionals may prefer to ignore: the right of mentally disabled people to have a say in how and where they are cared for. All involved must realise that there can be no absolute right for mentally disabled people to choose how their wishes are to be met, any more than any individual has that right. But we do consider that the wishes of individuals should be given more explicit attention.' (p 1xxvii)

It did appear that, in some cases, our study showed a loss of choice, particularly in relation to accommodation, employment or occupational opportunities. The main reason for this was simply that there was not the variety or amount of facilities necessary to cater for all the differing needs of the individuals in the sample. Unmarried respondents, in particular, would no doubt have benefited from additional services, for example, drop-in centres, which would also have provided support to those caring for these patients.

There needs to be close liaison between the patients, formal and informal carers in order to allow accessibility to asylum or supporting community services whenever necessary. It has been widely claimed that informal carers, in particular, have experienced difficulties in gaining access to the psychiatric services. If informal carers are not provided with support from, and access to these services, they cannot be expected to continue caring for mentally ill relatives who often have special needs and problems with behaviour.

Although this study has not been concerned with financial aspects of community care, to believe that the development of a comprehensive service for the mentally ill would be a cheaper option is both unreasonable and unrealistic. The Social Services Committee acknowledged that a 'decent community-based service for mentally ill or mentally handicapped cannot be provided at the same overall cost as present services.' (p xiv).
They continued 'We are at the moment providing a mental disability service which is under-financed and understaffed both in its health and social aspects' and they recommended that 'The Government now accept that genuine community care policies are achievable only in the context of some real increase over a period of years in expenditure on services for mentally handicapped and mentally ill people.'

Of course, the cost to families of caring for a schizophrenic relative is enormous. In this study we have seen patients living on very low incomes, who were, in fact, living 'on the bread line'. Some of these patients had no alternative but to live with this situation. Others were more fortunate - often parents and other family members make financial sacrifices in order to help the disabled person. As a mother said:

'From the beginning he never made much effort to fend for himself. Personally, I had a great deal of sympathy over this as, even to ask a fit and well person to live on (at that time) £29 per week seems to be asking a lot. But for a sick person it is virtually impossible. It meant, in effect, that I was, and still am, helping him in practical ways - by doing his washing, giving him at least one hot meal every day, helping him to pay his bills and buying his clothes etc.' (A Mother, 1985)

It is, at the very least, morally doubtful that society should expect some of the weakest members of the community to be kept going at minimal financial, but great personal cost, by so many relatives not far removed from poverty themselves.

It is probably true to say that community care in Portsmouth corresponds to national situation, although the data has described certain rather specific aspects of care that will be discussed separately.

Accommodation

A very real danger is that, as soon as comfortable accommodation has been found for out-patients, professional support and intervention is reduced, or at least kept to a minimum. This is an 'out of sight, out of mind' policy. A wide range of accommodation must exist with various degrees of support both for the patients and their carers, in order to provide individual care in the community. As mentioned previously, it is also crucial that patients are given a choice, within reason, of where they live. A comment by a 39 year old man in this study illustrates the misery caused when that choice was removed:

'It's terrible here for housing. I stayed in a lodging house for ten people in a two-up and two-down. I was admitted to hospital and then sent back. It was like a three-year sentence. I was in a twilight state and couldn't do anything about it.'

The impression gained in this study was that the majority of respondents were happy with their accommodation - indeed, the patients' responses to questions about their accommodation confirmed this. But often there was no choice and it is therefore possible that the patients' responses may well have reflected this situation - that they felt grateful for whatever they had.

It appeared from the evidence presented that there was a serious lack of supervised accommodation provided by the statutory services. At present, other than the group homes, private rest-homes or lodgings provide the only alternative to living with relatives or in hospital for patients requiring supportive environments. The private sector is vulnerable to the general financial climate and there is also a danger that rest-home proprieters or landladies could run into personal difficulties, such as divorce or ill-health, which might result in the closure of the home. If services continue to be run down without provision of sheltered accommodation by the statutory services, then problems could arise in the future - that is, there will be too few places for too many patients.

A further problem that could arise is that these units of supportive accommodation, whether run privately or by the statutory services, may become mini-institutions in the community, particularly if staff lack formal training in community care and are unaware of the special, individual needs of this patient group. The need for special training for nurses is discussed later in the chapter.

Since the interviews took place the residents of one group home have acquired the support of a part-time housekeeper who cooks a daily meal for the patients and deals with any day-to-day problems that may occur. This service for the dependent, and often chronically handicapped patients may well provide enough support so as to avoid crises and subsequent re-admission to hospital. Patients, too, often need additional support if one particular resident is experiencing difficulties or problems with behaviour and the housekeeper can offer this support.

More than half the respondents in this study lived with their families. Relatives often provide the care and support required to enable their schizophrenic relative to live outside hospital and, as a result, often themselves require the help and support of community services. Although this particular aspect was not examined in this study, the impression gained by the researcher was that many relatives would have welcomed additional contact with, and support from the statutory services. A way to provide that support is to ensure that patients are occupied during the day.

Employment

The majority of patients had, in the past, held responsible positions in open employment while others had been creative, for example, musically and artistically. Despite this fact, the majority of respondents were unemployed at the time of interview. It is probably true to say that, for many of these patients, holding down a job in open employment or continuing their education would prove to be too stressful and would lead to further breakdown. The majority of unemployed patients, however, would have benefited from attending a centre providing an informal social setting.

Nevertheless, it did seem that some patients were under-achieving and that within supported, sheltered environments they could probably have had some form of occupation. A minority of patients (8%) in this study attended the Industrial Therapy Unit at St. James' Hospital on a daily basis. These respondents gave the impression that they enjoyed their attendances because it offered them occupation and stimulation and the company of others. Some of these patients said that without this support they would have little else and that they would be lost without it.

One of the difficulties schizophrenic patients seem to experience is the inability to keep regular hours - and punctuality is a requirement of I.T. Units. This factor, coupled with secondary symptoms, such as poor concentration, slowness and apathy, means that many chronically handicapped patients are considered to be unsuitable for I.T. attendance. An additional local problem that made the situation worse was the requirement for lunch to be provided by the hospital for all attenders to I.T. and O.T. Units: because lunch provision was limited, so, too, were places within the units.

Outside the hospital, there appeared to be a serious lack of places in sheltered employment and this lack of provision made it difficult for patients to move out of the hospital environment into jobs elsewhere. None of the patients in the sample held a position in sheltered employment and the likelihood of them doing so in the future appeared remote. Although facilities existed in Portsmouth for work rehabilitation at the Employment Rehabilitation Centre and the Skill Centre, there seemed to be a reluctance on the part of the Disablement Rehabilitation Officer to refer schizophrenic patients to these units because of previous difficulties experienced with such disabled patients. Many mentally ill people who had been accepted for training have had difficulties in coping with the pressures of courses and have left during training. A further problem, claimed the D.R.O., was that many schizophrenic patients do not show ability and training potential and, because they have to compete for training places with other disabled people, they simply are not selected by the panel.

This situation, together with secondary handicaps of the illness itself, accounts for the high percentage of unemployed in the sample. The truth of the matter is that the majority of these patients will never be able to hold down a job in open or sheltered employment. However, this does not mean that they should be offered no other form of occupation: under-stimulating environments will lead to an exacerbation of secondary symptoms and the individuals subjected to them become progressively more disabled. What it does mean is that day-care facilities must be provided in order to provide occupation, which in turn will enable the schizophrenic patient to explore his potential and develop his skills to the best of his ability.

Day Care

An expansion of day-care facilities would provide, not only stimulation for the unoccupied patients in the community, but would also help to support relatives and landladies by giving them some time away from the patients. The Adult Placement Officer in Portsmouth had experienced difficulties in placing patients with suitable families because of the lack of day-care facilities in the city.

Previous research has shown that patients who live in environments with a high amount of Expressed Emotion benefit from a reduction in face-to-face contact with their relatives. Patients in such environments would benefit from having time away from the family and home environment. Since the interviews took place Radnor Day Centre has been developed as a 'drop-in' centre and Dickens Villa as a social centre and these projects must be applauded. Portsmouth City has a wealth of community centres and it may be possible to provide similar day-centres within these existing facilities.

We know that in this study a minority of respondents appeared to experience difficulty in integrating with others in their communities and therefore appeared to be isolated. It is difficult for many patients with a schizophrenic illness to mix with others in existing public facilities - many lack the social skills necessary to form and maintain relationships outside familiar environments, for example, the family home. Others may have difficulties in being punctual and would be unable to attend functions or club activities at specific times.

Therefore it is important to provide sheltered social environments run by experienced staff and volunteers who understand and appreciate the special needs of these handicapped patients. However, such environments could encourage under-stimulating and sometimes rather institutional practices - a young man in the sample had remarked 'I could tell the doctors about therapy. People don't want to throw balls about - talking is much more important.....' On the other hand, too much stimulation could force the patient to withdraw from the situation: it is therefore important that sheltered social environments allow individuals to integrate and socialise at a level that suits them, enabling them to feel more comfortable with others and motivated to attend regularly. At present, the contact clubs provide sheltered environments for the handicapped patients and experience has shown that many members have become more self-confident and more skilled socially because of their attendances. These clubs were set up and are run by the Community Psychiatric Nurses, who saw the need for this type of informal support for the chronically handicapped patients in the community.

Community Psychiatric Nurses

As well as support offered to patients by Community Psychiatric Nurses, the majority of support for informal carers in this study appeared to be offered by the CPN's. However, the study showed that only a minority of patients and their supporters were in touch with this service. It has been widely acknowledged that the CPN's are the key professionals involved with moving care of the mentally ill out into the community (Social Services Committee, 1985) and the value of CPN support for patients and relatives is fully recognised.(Mangen and Griffith, 1982; Morris, 1981). The Community Psychiatric Nursing service should continue to be expanded as hospital beds are reduced in order to make available these specialist nursing skills to a greater population of patients and relatives.

However, this does not simply mean the instant development of hospital nurses into the community: many nurses have worked within the institution for many years and have, inevitably, become somewhat institutionalised themselves. There should be training for all nurses moving into the community. The Social Services Committee stated that

'there is not general agreement as to how far training should be mandatory, nor as to its integration with other nurse training. There must however be general assent that some training is better than none, and that nurse training funds must be used to this end.' (p c). They recommended that 'funds be earmarked by health authorities and the ENB for the future training of CPN's and that the Government undertake to find the funds necessary to provide training over a period of years.' (p c)

The English National Board for Nursing (ENB), the body responsible for nurse training in England and Wales, provides an outline curriculum for CPN training, although there are diverse interpretations of this curriculum by the individual training institutions across the country. Generally, CPN courses put forward a more holistic approach to patient care as opposed to the approach adopted by the old-style RMN training which was one of removing the individual from his familiar environment and treating him within the institution, which often resulted in a loss of identity and individuality.

In Portsmouth, the CPN course concentrated on developing specific psychiatric nursing skills, with the aim of enabling the nurse to become an independent practitioner in the community. Emphasis was placed on the effects of the social environment upon the individual's psyche and the appropriate approaches to nursing patients within their particular environments were considered. The course required students to undertake a small research project and, throughout the course, encouraged nurses to understand and appreciate past research. A critical approach towards psychiatry and psychiatric care was also encouraged, for example, looking at anti-psychiatric models such as Laing's philosophy.

In addition to the specialist nursing skills required for community nursing, the care and rehabilitation of chronically disabled patients, and in particular those suffering from schizophrenia, requires special interest and skills on the part of the staff working within the area and should be recognised as a nursing speciality. For too long the care of the chronically ill patient has been regarded by many as unattractive and unstimulating. However, others acknowledge that the work is challenging, stimulating and requires the acquisition of special skills and knowledge. To develop community services without highly trained and skilled staff would only lead to the development of a second-rate service; Institutional practices may continue to exist and apathy and negative attitudes may develop. This, in turn, would effect the care of these patients and their families and may not only lead to a deterioration in their mental condition, but would also result in a serious reduction in their level of achievement.

The Differences Between the Patches

The data showed differences in the distribution of the sample across the three areas, or patches. Perhaps the most obvious difference was the distribution of patients who lived in either rest-homes, bed and breakfast accommodation or lodgings. The majority of these patients lived in the Southsea patch, where the most suitable housing was available for these purposes.

The reorganisation of services that has occurred since the interviews took place, that is, the de-centralisation of the services into patch teams, has enabled the managers of each geographical area to identify the needs within their patches and plan services around these needs. This means that suitable resources, for example, supportive day-care or contact clubs, can be made available where required, that is, within easy reach of those patients who require support.

Finally, an important aspect of the move out into the community is an understanding that individuals respond to their environment and other people within it. We have seen that relatives, and the support they offer, play a major part within the environments of many patients. If services are developed and planned at a local level the needs of relatives and other primary carers must also be considered. It is probably true to say that without the support that relatives give, community care could not exist, nor even be considered. Therefore, local services must make themselves accessible to supporters so that they, too, may receive the help and support they require to care for their mentally ill relatives.

APPENDICES

Appendix 1 - Letter of Introduction

Appendix 2 - The Family Tree

Appendix 3 - The Interview Schedule

Appendix 4 - The Method Used for the Assessment of the Diets

Appendix 5 - The Portsmouth Community Centres

Appendix 6 - A Mother's Story

Appendix 1

PORTSMOUTH AND SOUTH EAST

HAMPSHIRE HEALTH AUTHORITY

Community Nursing Dept.,
St. James' Hospital
Locksway Road,
Portsmouth PO4 8LD

Portsmouth (0705) 822331
Extension 4220

Please ask for Annie Coulson

Dear

I am writing to ask if you will be kind enough to help me in some research I am undertaking. I am trying to understand more about the circumstances of patients in the community who are receiving long-acting injections. I hope that this will enable the services to be improved where this seems necessary.

I should be grateful if I could come and talk to you for about an hour on a strictly confidential basis. I am a trained psychiatric nurse and your consultant has agreed that I can approach you. Naturally I hope you will be able to help, but if you would prefer not to see me you are under no obligation to do so. If you do not wish to see me please complete the slip below and return it to me. If I do not hear from you I shall call to arrange a suitable time for us to talk and to explain the research more fully to you if you wish.

I must stress that anything told to me will be treated in the strictest confidence.

Hoping you will be able to help me,

Yours sincerely,

Annie Coulson
RMN CPN (cert)

Cut Here --

I do not wish to take part in the project described above.

NAME ....

ADDRESS ....

....

Appendix 2

The Family Tree

Where appropriate, fill in SEX of relative in box: M for male relatives, F for female relatives. Thus: $\boxed{M}$ $\boxed{F}$

If the relative is no longer living, fill in as above, placing a diagonal line across the box. Thus $\cancel{\boxed{M}}$

Seen in Year: A relative seen during the last twelve months for at least one hour at any one time.

Living in Household: Indicate whether child is living in the same household as respondent at present time. Answer YES, NO or TA (Temporarily Away, e.g. at college)

SPOUSE Sheet only:

Record all spouse's relatives seen within the last year only.

Record details of present spouse OR last spouse (if present marital status is widowed or divorced).

The interviewer may help, or if necessary, complete the Family Tree for the respondent.

FAMILY TREE - SELF

	FATHER	MOTHER
Alive/D	......	......
Seen in Year	......	......

...... No. of Father's Former Marriages
...... No. of Children from Unions
...... No. of Above Seen in Year

No. of Mother's Former Marriages ......
No. of Children from Unions ......
No. of Above Seen in Year ......

BROTHERS & SISTERS										
Alive/D	.....	.....	.....	.....	.....	.....	.....	.....	.....	.....
M/S/D/C-Habiting	.....	.....	.....	.....	.....	.....	.....	.....	.....	.....
Seen in Year	.....	.....	.....	.....	.....	.....	.....	.....	.....	.....

Nos. of Aunts & Uncles .....
Nos. of Cousins .....
Nos. of Nephews & Nieces .....
Nos. of above seen in Last year .....

Nos. of Bros/Srs-in-Law .....
Nos. Seen in Year .....

FORMER MARRIAGES				
DIV/WID	.....	.....	.....	.....
Seen in Year	.....	.....	.....	.....

SELF

Age ......
Nationality ......
M/S ......

CHILDREN										
Age/Yr.D.	.....	.....	.....	.....	.....	.....	.....	.....	.....	.....
Seen in Year	.....	.....	.....	.....	.....	.....	.....	.....	.....	.....
Living in Household	.....	.....	.....	.....	.....	.....	.....	.....	.....	.....
Specify Union	.....	.....	.....	.....	.....	.....	.....	.....	.....	.....

No. of Grandchildren .....
No. Seen in Year .....

FAMILY TREE - SPOUSE

.... No. of Father's Former Marriages
.... No. of Children from Unions
.... No. of Above Seen in Year

	FATHER	=	MOTHER
Alive/D	......		......
Seen in Year	......		......

No. of Mother's Former Marriages ....
No. of Children from Unions ....
No. of Above Seen in Year ....

										BROTHERS & SISTERS
.....	.....	.....	.....	.....	.....	.....	.....	.....	.....	Alive/D
.....	.....	.....	.....	.....	.....	.....	.....	.....	.....	M/S/D/C-Habiting
.....	.....	.....	.....	.....	.....	.....	.....	.....	.....	Seen in Year

Nos. of Bros/Srs-in-Law .....
Nos. Seen in Year .....

Nos. of Aunts & Uncles ....
Nos. of Cousins ....
Nos. of Nephews & Nieces ....
Nos. of Above Seen in Last Year ....

SPOUSE

.... Age
.... Nationality
.... M/S

FORMER MARRIAGES				
DIV/WID	.....	.....	.....	.....
Seen in Year	.....	.....	.....	.....

										CHILDREN
.....	.....	.....	.....	.....	.....	.....	.....	.....	.....	Age/Yr.D.
.....	.....	.....	.....	.....	.....	.....	.....	.....	.....	Seen in Year
.....	.....	.....	.....	.....	.....	.....	.....	.....	.....	Living in Household
.....	.....	.....	.....	.....	.....	.....	.....	.....	.....	Specify Union

No. of Grandchildren .....
No. Seen in Year .....

APPENDIX 3

CONFIDENTIAL QUESTIONNAIRE

V001. Serial Number ☐☐☐

V002. Date of Interview ☐☐☐☐☐☐

V003. Place of Interview ☐

0	Home
1	Clinic
2	Other Hospital Area Specify ____________________
7	Other Specify ____________________
8	Not applicable
9	Not known

V004. Sex ☐

0	Male
1	Female

Explain Family Tree. Interviewer to help patient complete the Tree.

V005. How old are you? ☐☐

6	No reply
7	Other Specify ____________________
8	Not applicable
9	Not known

V006. What Country do you come from? ☐

Specify ____________________

0	U.K.
1	Eire
2	Europe
3	Africa
4	Asia
5	West Indies
6	No reply
7	Other Specify ____________________
8	Not applicable
9	Not known

V007. What is your present marital status? ☐

0	Single
1	Married
2	Co-habiting (for a minimum of three months)
3	Separated
4	Divorced
5	Widowed
6	No reply
7	Other Specify ____________________
8	Not Applicable
9	Not Known

V008. How many times have you been married? ☐
(Include present marriage)

0	Never married
1	Once
2	Twice
3	Three times
4	Four times
5	Five times
6	Six times
7	Other Specify ____________________
8	Not Applicable
9	Not Known

V009. How many children are you the parent of? ☐

0	No children
1	One child
2	Two children
3	Three children
4	Four children
5	Five children
6	Six children
7	Other Specify ____________________
8	Not Applicable
9	Not Known

V010. How many children are living in your household? ☐

0	No children
1	One child
2	Two children
3	Three children
4	Four children
5	Five children
6	Six children
7	Other Specify ____________________
8	Not Applicable
9	Not Known

V011. How many children are living in your household aged 16 years or under? ☐

0	No children
1	One child
2	Two children
3	Three children
4	Four children
5	Five children
6	Six children
7	Other Specify ____________________
8	Not Applicable
9	Not Known

<u>Continue with Family Tree</u> On Completion:

V012. How many relatives have you seen during the past year (for at least one hour at any one time) that have not been included in your Family Tree? ☐

0	No other relative
1	1 - 3
2	4 - 6
3	7 - 9
4	10 - 12
5	13 - 15
6	16 or more
7	Other Specify ____________________
8	Not Applicable
9	Not Known

V013. Number of living relatives (to your knowledge) ☐

0	5 or less
1	6 - 10
2	11 - 15
3	16 - 20
4	21 - 25
5	26 or more
6	No relatives
7	Other Specify ____________________
8	Not Applicable
9	Not known

V014. Number of living relatives you have seen during the past year (for at least one hour at any one time) ☐

0	5 or less
1	6 - 10
2	11 - 15
3	16 - 20
4	21 - 25
5	26 or more
6	No relatives
7	Other Specify ____________________
8	Not Applicable
9	Not known

ACCOMMODATION

V015. What area of Portsmouth do you live in? ☐☐

0	Portsea
1	Old Portsmouth
2	Southsea
3	Eastney
4	Milton
5	Langstone
6	Copnor (Area 2)
10	Fratton
11	Landport
12	Buckland
13	North End (Area 2)
14	Stamshaw
15	Tipnor
16	North End (Area 1)
17	Copnor (Area 1)
18	Hilsea
19	Cosham
20	Portsdown Park
21	Wymering
22	Paulsgrove
23	East Cosham
24	Drayton
25	Farlington
26	No Fixed Abode
7	Other Specify ____________________
8	Not Applicable
9	Not Known

V016. Specify Consultant Area ☐

0	No Fixed Abode
1	Area 1
2	Area 2
3	Area 3
7	Other Specify ____________________
8	Not Applicable
9	Not Known

V017. What type of accommodation do you live in? Who owns it? ☐☐

Pt's description ____________________

____

0	Own house/flat/maisonette/bungalow
1	Own caravan
2	Privately rented house/flat/maisonette/bungalow
3	Privately rented caravan
4	Council-owned flat/house/maisonette/bungalow
5	Rented bedsit
6	Supervised lodgings/guest-house
10	Unsupervised lodgings/guest-house
11	Group home, cluster flat
12	Reception centre
13	No fixed abode
7	Other
	Specify ____________________
8	Not applicable
9	Not known

V018. How long have you lived in your present accommodation? ☐

0	Less than 6 months
1	More than 6 months, less than a year
2	One year - two years
3	More than two years, less than five years
4	5 - 10 years
5	More than 10 years
7	Other
	Specify ____________________
8	Not applicable
9	Not known

V019. How many rooms do you have free access to? (That is, without supervision) Exclude bath/toilet and hall. ☐

0	One room only
1	Two rooms
2	Three rooms
3	Four rooms
4	Five rooms
5	Six rooms or more
6	No rooms accessible without supervision
7	Other
	Specify ____________________
8	Not applicable
9	Not known

V020. How many rooms do you have access to under supervision only ☐

0	One room only
1	Two rooms
2	Three roome
3	Four rooms
4	Five rooms
5	Six rooms or more
7	Other
	Specify ____________________
8	Not Applicable
9	Not Known

V021. Do you have a bedroom to yourself? ☐

0	Own room
1	Share with spouse (co-habitee)
2	Share with one relative (not spouse)
3	Share with more than one relative
4	Share with one non-relative
5	Share with more than one non-relative
6	Have no bedroom
	Specify ____________________
7	Other
	Specify ____________________
8	Not Applicable
9	Not Known

V022. What cooking facilities do you have access to? ☐

Pts. description ________________________________

____

0	Kitchen in family home
1	Kitchen in group home, cluster flat
2	Kitchen in unsupervised lodgings/guest-house
3	Kitchen in supervised lodgings/guest-house
4	Kitchenette attached to bedsit/flat
5	Cooker ring only
6	No cooking facilities
7	Other
	Specify ____________________
8	Not Applicable
9	Not Known

V023. Who do you share your cooking facilities with? ☐

0	Own facilities
1	Shared with relative(s)
2	Shared with non-relative(s)
3	Shared with relatives and non-relatives
4	No facilities
7	Other
	Specify ____________________
8	Not Applicable
9	Not Known

V024. Do you have a sitting room?
If so, who do you share it with? ☐

0	Own room
1	Shared with one other relative
2	Shared with more than one relative
3	Shared with one non-relative
4	Shared with more than one non-relative
5	Shared with relative(s) and non-relative(s)
6	No sitting room
7	Other
	Specify ____________________
8	Not Applicable
9	Not Known

V025. Do you have access to a garden at your accommodation? ☐

0	Yes
1	No
7	Other
	Specify ____________________
8	Not Applicable
9	Not Known

V026. Do you feel satisfied with your accommodation? ☐

0	Very satisfied
1	Satisfied
2	O.K.
3	Dissatisfied
4	Very dissatisfied
6	No reply
7	Other
	Specify ____________________
8	Not Applicable
9	Not Known

HOUSEHOLD COMPOSITION

V027. Who is the primary person you live with? By this I mean the person who is the central, or key person. ☐

0	Lives alone
1	Parent (s)
2	Spouse
3	Co-habitee (of three months or more)
4	Other relative
	Specify ____________________
5	Landlady/landlord
6	Cluster flat/group home
7	Other
	Specify ____________________
8	Not Applicable
9	Not Known

V028. How many people live in the household? Do not include temporary guests on holiday. ☐

0	Lives alone
1	One other
2	2 - 4 others
3	5 - 7 others
4	8 - 10 others
5	11 - 15 others
6	16 or more others
7	Other
	Specify ____________________
8	Not Applicable
9	Not known

V029. Does the accommodation you live in cater for temporary guests (for example, holiday-makers or tourists) and if so, how many? ☐

0	No temporary guests accommodated
1	1 - 5 throughout the year
2	6 - 10 throughout the year
3	More than 10 throughout the year
4	1 - 5 in summer season only
5	6 - 10 in summer season only
6	More than 10 in summer season only
7	Other
	Specify ____________________
8	Not Applicable
9	Not Known

V030. Do you have any pets? Specify. ☐
Who do they belong to?

Pts. description ______________________________
____
____
____

0 Yes, own
1 Yes, family
2 Own plus family pet(s)
3 Household pets (non-family)
4 Own and household pets (non-family)
5 No pets
7 Other
Specify ____________________
8 Not Applicable
9 Not Known

HOUSEHOLD RESPONSIBILITIES

V031. At home, who mainly cleans and tidies the house? ☐

0 Self
1 Spouse
2 Other relative or friend
Specify ____________________
3 Home help
4 Landlady's responsibility
5 Joint self/spouse
6 Joint self/relative or other (not spouse)
7 Other
Specify ____________________
8 Not Applicable
9 Not Known

V032. At home, who mainly does the shopping? ☐

0 Self
1 Spouse
2 Other relative or friend
Specify ____________________
3 Home help
4 Landlady's responsibility
5 Joint self/spouse
6 Joint self/relative or other (not spouse)
7 Other
Specify ____________________
8 Not Applicable
9 Not Known

V033. At home, who mainly does the laundry? ☐

0	Self
1	Spouse
2	Other relative or friend
	Specify ________
3	Home help
4	Landlady's responsibility
5	Joint self/spouse
6	Joint self/relative or other (not spouse)
7	Other
	Specify ________
8	Not Applicable
9	Not Known

V034. At home, who normally does the cooking? ☐

0	Self
1	Spouse
2	Other relative or friend ________
3	Meals-on-wheels
4	Landlady's responsibility
5	Joint self/other
	Specify ________
6	No cooking done
	Explain ________
	________
	________
7	Other
	Specify ________
8	Not Applicable
9	Not Known

V035. Do you find your domestic arrangements satisfactory? ☐

0	Very satisfactory
1	Satisfactory
2	O.K.
3	Unsatisfactory
4	Very unsatisfactory
6	No reply
7	Other
	Specify ________
8	Not Applicable
9	Not Known

V036. If you find them at all unsatisfactory, could you tell me why? ☐

0	Definite quote
1	Possible quote
2	No quote
6	No reply
7	Other
	Specify ____________________
8	Not Applicable
9	Not Known

MENU PLAN

Now I would like to ask you if you could tell me what meals you ate yesterday and who with. I would also like to know if you ate them at home or not, and if not, where you were (for example, at the Solent Clinic, in a cafe etc.etc.)

Interviewer - please complete menu plan overleaf. Beverages drunk throughout the day to be entered under snacks.

MENU PLAN

MEAL	MENU	PARTICIPANTS	PLACE
BREAKFAST			
LUNCH			
EVENING MEAL			
SUPPER			
SNACKS & BEVERAGES			

V037. Diet in general for the previous day: ☐

0 Good
1 Moderate
2 Poor
6 No information obtained
7 Other
Specify ____________________
8 Not Applicable
9 Not Known

CODING FROM MENU PLAN

V038. Breakfast: ☐

0 Alone at home
1 Alone out of home
2 Accompanied at home
3 Accompanied out of home
4 No breakfast eaten
6 No information given
7 Other
Specify ____________________
8 Not Applicable
9 Not Known

V039. Lunch: ☐

0 Alone at home
1 Alone out of home
2 Accompanied at home
3 Accompanied out of home
4 No lunch eaten
6 No information given
7 Other
Specify ____________________
8 Not Applicable
9 Not Known

V040. Evening Meal: ☐

0 Alone at home
1 Alone out of home
2 Accompanied at home
3 Accompanied out of home
4 No evening meal eaten
6 No information given
7 Other
Specify ____________________
8 Not Applicable
9 Not Known

V041. Supper: ☐

0 Alone at home
1 Alone out of home
2 Accompanied at home
3 Accompanied out of home
4 No supper eaten
6 No information given
7 Other
Specify ____________________
8 Not Applicable
9 Not Known

V042. Snacks and beverages ☐

0	Taken
1	Not taken
6	No information given
7	Other
	Specify ____________________
8	Not Applicable
9	Not Known

V043. How many meals a day do you usually have?
What are they? ☐

0	Breakfast, lunch, evening meal and/or supper
1	Breakfast, evening meal and/or supper
2	Lunch, evening meal and/or supper
3	Evening meal and/or supper
4	Breakfast, lunch
5	Lunch only
6	Breakfast only
7	Other
	Specify ____________________
8	Not Applicable
9	Not Known

V044. Do you eat at set times? ☐

0	Always
1	Usually
2	Sometimes
3	Never
7	Other
	Specify ____________________
8	Not Applicable
9	Not Known

V045. On the whole, do you feel satisfied with your
meal arrangements? ☐

0	Very satisfied
1	Satisfied
2	O.K.
3	Dissatisfied
4	Very dissatisfied
6	No reply
7	Other
	Specify ____________________
8	Not Applicable
9	Not Known

EDUCATION AND EMPLOYMENT

V046. At what age did you leave school? ☐

0	14 years or under
1	15 years
2	16 years
3	17 years
4	18 years
5	No education
7	Other
	Specify ____________________
8	Not Applicable
9	Not Known

V047. Did you obtain any examinations or certificates at school? ☐

0	School Certificate
1	O Levels
2	A Levels
3	O and A Levels
4	C.S.E.
5	Combination
6	None obtained
7	Other
	Specify ____________________
8	Not Applicable
9	Not Known

V048. Have you undertaken any examinations or taken any training since leaving school? (Not including ERC) ☐

0	Degree
1	HNC, HND or equivalent
2	Professional course
3	Apprenticeship
4	Combination
5	No training taken
7	Other
	Specify ____________________
8	Not Applicable
9	Not Known

V049. Did you complete this training? ☐

0	Yes
1	No
2	If more than one training taken, completed one or more, but not all
7	Other
	Specify ____________________
8	Not Applicable
9	Not Known

V050. If training was taken and not completed, could you tell me why? ☐

0	Definite quote
1	Possible quote
2	No quote
6	No reply
7	Other
	Specify ____________________
8	Not Applicable
9	Not Known

V051. Have you a job at present? That is, are you in paid employment? ☐

0	Full-time employment
1	Part-time employment
2	Casual employment (e.g. seasonal)
3	Not employed
7	Other
	Specify ____________________
8	Not Applicable
9	Not Known

V052. What job do you do? Describe your job, in your own words. ☐

Pts. description ________________________________

____

____

____

0	Professional
1	Managerial/executive
2	Skilled non-manual
3	Skilled manual
4	Semi-skilled manual
5	Unskilled manual
6	Not employed
7	Other
	Specify ____________________
8	Not Applicable
9	Not Known

V053. How long have you been in your present job? ☐

0	Less than a month
1	1 - 6 months
2	More than 6 months, less than a year
3	1 - 3 years
4	More than 3 years, less than 5 years
5	5 years or more
6	Not employed
7	Other Specify ______________________
8	Not Applicable
9	Not Known

V054. Do you feel satisfied with your job? ☐

0	Very satisfied
1	Satisfied
2	O.K.
3	Dissatisfied
4	Very dissatisfied
6	No reply
7	Other Specify ______________________
8	Not applicable
9	Not known

V055. If dissatisfied, can you tell me why? ☐

0	Definite quote
1	Possible quote
2	No quote
6	No reply
7	Other Specify ______________________
8	Not Applicable
9	Not Known

V056. If you are unemployed, when did you last have a job? (i.e. paid employment) ☐

0	Less than 6 months ago
1	6 months - a year ago
2	Longer than a year, less than two years
3	Two years or longer
4	Never had a job
7	Other Specify ______________________
8	Not Applicable
9	Not Known

V057. What is the longest length of time you have had any one job? ☐

0	Less than a month
1	More than a month, less than 6 months
2	6 months - 1 year
3	More than 1 year, less than 3 years
4	More than 3 years, less than 5 years
5	5 years or longer
6	Never had a job
7	Other
	Specify ________________
8	Not Applicable
9	Not Known

V058. How many jobs have you had in the last two years? ☐

0	None
1	Present occupation only
2	One (not currently employed)
3	2 - 5 jobs
4	6 - 9 jobs
5	10 jobs or more
7	Others
	Specify ________________
8	Not Applicable
9	Not Known

V059. Was this job/these jobs casual or seasonal employment? ☐

0	Yes, casual
1	No, not casual
2	Casual and non-casual
3	No job(s)
7	Others
	Specify ________________
8	Not Applicable
9	Not Known

V060. What is the best, or most responsible job (that is, paid employment) you have had? Describe this job. ☐

Pts. description __________________________

____

____

0	Professional
1	Managerial/executive
2	Skilled non-manual
3	Skilled manual
4	Semi-skilled manual
5	Unskilled manual
6	Not employed
7	Other
	Specify ________________
8	Not Applicable
9	Not Known

V061. Do you attend any of the centres at St. James Hospital? ☐

0 Industrial Therapy
1 Solent Day Hospital (as a day patient)
2 Occupational Therapy only
3 Gardening
4 None of these
7 Other
Specify ____________________
8 Not Applicable
9 Not Known

V062. How many days a week do you attend? ☐

0 For a specific group only
1 1 day
2 2 days
3 3 days
4 4 days
5 5 days
7 Other
Specify ____________________
8 Not Applicable
9 Not Known

V063. How long have you been attending for? ☐

0 Less than a month
1 1 month - 3 months
2 More than 3 months, less than 6 months
3 6 months - 1 year
4 More than 1 year, less than 2 years
5 2 years or longer
7 Other
Specify ____________________
8 Not Applicable
9 Not Known

V064. Are you attending any of the following centres? ☐

0 Employment Rehabilitation Centre at Hilsea
1 Local Authority Day Centre
2 Day Centre run by voluntary organisation
3 None of these
7 Other
Specify ____________________
8 Not Applicable
9 Not Known

V065. How many days a week do you attend? ☐

0	Less than one full day
1	1 day
2	2 days
3	3 days
4	4 days
5	5 days
7	Other
	Specify ____________________
8	Not Applicable
9	Not Known

V066. How long have you been attending for? ☐

0	Less than 1 month
1	1 month - 3 months
2	More than 3 months, less than 6 months
3	6 months - 1 year
4	More than 1 year, less than 2 years
5	Two years or longer
7	Other
	Specify ____________________
8	Not Applicable
9	Not Known

V067. If not employed or attending a centre, are you currently looking for a job? ☐

0	Yes, looking for a job
1	No, looking after house and/or family
2	No, retired
3	Not looking for a job and not included in 1 and 2 above
6	No reply
7	Other
	Specify ____________________
8	Not Applicable
9	Not Known

V068. If not looking for a job, (and not looking after house and/or family or retired) could you tell me the reasons why? ☐

0	Definite quote
1	Possible quote
2	No quote
6	No reply
7	Other
	Specify ____________________
8	Not Applicable
9	Not Known

INCOME

V069. Would you mind telling me how much money you receive each week? If you are employed, the amount of your actual take home pay. If you are married and living together, your joint income (or spouse's income if you do not work) ☐

Pt.'s own words ______________________________

____

____

0	£20 or less
1	£21 - £40
2	£41 - £60
3	£61 - £80
4	£81 - £100
5	£101 or more
6	No reply
7	Other
	Specify ____________________
8	Not Applicable
9	Not Known

V070. Do you take responsibility for seeing that mortgage/ rent and/or rates are paid? ☐

0	Yes
1	No - paid direct by DHSS
2	No - spouse takes responsibility
3	No - mother/father takes responsibility
4	No - other relative or friend takes responsibility
5	No - landlady takes responsibility
6	Joint self/other responsibility
	Specify other ____________________
7	Other
	Specify ____________________
8	Not Applicable
9	Not Known

V071. How much do you spend on alcohol each week? ☐

0	Less than £1
1	£1 - £5
2	More than £5, less than £10
3	£10 or more
6	No reply
7	Other
	Specify ____________________
8	Not Applicable
9	Not Known

V072. How much do you spend on cigarettes or tobacco each week? ☐

0 Less than £1
1 £1 - £5
2 More than £5, less than £10
3 £10 or more
6 No reply
7 Other
Specify ____________________
8 Not Applicable
9 Not Known

V073. How often do you buy new items of clothing? ☐

0 Very frequently (at least once a month)
1 Frequently (less than 0, more than 2)
2 Occasionally (2 - 4 times a year)
3 Rarely (once a year or less)
4 Never - Why?
Specify (e.g. Jumble Sale)
____
____
6 No reply
7 Other
Specify ____________________
8 Not Applicable
9 Not Known

V074. Who normally chooses your clothing? ☐

0 Self
1 Self and parent(s)
2 Self and other
Specify ____________________
3 Parent(s)
4 Relative (other than parent)
6 No reply
7 Other
Specify ____________________
8 Not Applicable
9 Not Known

V075. Do you ever run out of money? ☐

0 Every week
1 Often
2 Occasionally
3 Never
6 No reply
7 Other
Specify ____________________
8 Not Applicable
9 Not Known

V076. What do you do if you run out of money? ☐

0 Borrow from a friend or relative
1 Borrow from the bank
2 Go without food
3 Go without cigarettes and/or alcohol
4 Use savings
5 No problem caused when money runs out
6 No reply
7 Other
Specify ____________________
8 Not Applicable
9 Not Known

V077. How do you see your financial situation? ☐

0 Very satisfactory
1 Satisfactory
2 O.K.
3 Unsatisfactory
4 Very unsatisfactory
6 No reply
7 Other
Specify ____________________
8 Not Applicable
9 Not Known

PERSONAL LIFE

V078. Do you attend any of the hospital community social clubs or hospital social clubs? ☐

0 More than once a week
1 Usually once a week
2 For injection only
3 Occasionally
4 Never
7 Other
Specify ____________________
8 Not Applicable
9 Not Known

V079. How do you normally get there? ☐

0 Picked up by voluntary worker or Community Nurse
1 Own, or public transport
2 Walk
7 Other
Specify ____________________
8 Not Applicable
9 Not Known

V080. **Do you attend any other clubs?** (for example, church social clubs, community centre, Further Education centre) ☐

Specify ______________________________

____

0	More than once a week
1	Usually once a week
2	Once or twice a month
3	Occasionally
4	Never
7	Other Specify ______________
8	Not Applicable
9	Not Known

V081. If you do not attend any organised club, could you tell me why? ☐

0	Definite quote
1	Possible quote
2	No quote
6	No reply
7	Other Specify ______________
8	Not Applicable
9	Not Known

TIME BUDGET

I would now like to ask you about yesterday (day 1985) and how your day was structured.

Interviewer to fill in details on Time Budget sheet overleaf. When completing ACTIVITY column, if it is not clear where activity is taking place, please provide particulars.

TIME	ACTIVITY	PARTICIPANTS
0000 - 0600		
0600 - 0630		
0630 - 0700		
0700 - 0730		
0730 - 0800		
0800 - 0830		
0830 - 0900		
0900 - 0930		
0930 - 1000		
1000 - 1030		
1030 - 1100		
1100 - 1130		
1130 - 1200		
1200 - 1230		
1230 - 1300		
1300 - 1330		
1330 - 1400		
1400 - 1430		
1430 - 1500		
1500 - 1530		

TIME	ACTIVITY	PARTICIPANTS
1530 - 1600		
1600 - 1630		
1630 - 1700		
1700 - 1730		
1730 - 1800		
1800 - 1830		
1830 - 1900		
1900 - 1930		
1930 - 2000		
2000 - 2030		
2030 - 2100		
2100 - 2130		
2130 - 2200		
2200 - 2230		
2230 - 2300		
2300 - 2330		
2330 - 2400		

V082. ☐

0 Time Budget completed
1 Time Budget Not Completed
Specify ______________________
____
6 No Reply
7 Other
Specify ______________
8 Not Applicable
9 Not Known

Interviewer to code from the Time Budget estimate: (in numbers of half-hours)
(Items V084 - V103 refer to waking hours)

V083. Total number of waking hours

V084. Total number of sleeping hours

V085. Total number of hours spent alone

V086. Time spent with relatives

V087. Time spent with patients/ex-patients

V088. Total number of hours spent with others

V089. Specify amount of time spent in the company of one other

V090. Time spent at home

V091. Time spent at work

V092. Time spent at St. James Hospital (e.g. at I.T.)

V093. Time spent at day centre, community club etc. (i.e. involved in structured activity away from St. James Hospital in a group of others)

Specify ____________________

V094. Time spent in unstructured activity away from home (such as walking the streets)

Specify ____________________

V095. Time spent away from home in activity other than above

Specify ____________________

Number of hours spent in following activities:

Passive:

V096. Watching television

V097. Listening to records or radio

V098. Reading

V099. Doing nothing

Active:

V100. Chatting

V101. Domestic duties

V102. Hobbies or interests (e.g. gardening, fishing, sewing). Include such activities as being a spectator at a sporting event, going to the cinema - i.e. when respondent leaves home in order to participate. Specify ____________________

V103. Visiting friends/relatives

V104. Other Activity. Specify ____________________

V105. During the last week have you been out socially? (For an hour or more) ☐

0 Every day/evening
1 4 - 6 times
2 2 - 3 times
3 Once
4 Have not been out
6 No reply
7 Other
Specify ____________________
8 Not Applicable
9 Not Known

V106. Where did you go? ☐

Pt's description ______________________________

____

____

0 Pub/club or equivalent
1 Further Education Centre
2 Visiting friends/relatives
3 Cinema, theatre, dancing, bingo or equivalent
4 Out walking
5 St. James Hospital
6 Combination of above
Specify ______________________________
7 Other
Specify ____________________
8 Not Applicable
9 Not Known

V107. Were you accompanied? (That is, the social/recreational activity was shared with another or others. Casual conversations are excluded e.g. in pubs) ☐

0 Yes, every time
1 Yes, some of the time
2 No
6 No reply
7 Other
Specify ____________________
8 Not Applicable
9 Not Known

V108. Do relatives or friends visit you at home, and if so, how often? ☐

0	Every day/nearly every day
1	Frequently
2	Occasionally (about once every 4 - 8 weeks
3	Rarely (less frequently than 2)
4	Never
6	No reply
7	Other Specify ____________
8	Not Applicable
9	Not Known

V109. During the past week have you been involved in any regular hobbies or pastimes? What are they? ☐

Pt's description ____________________

____

____

____

0	Passive pastimes only
1	Active pastimes only
2	Mostly passive, some active pastimes
3	Mostly active, some passive pastimes
4	Equal number of passive and active pastimes
5	No pastimes
6	No reply
7	Other Specify ____________
8	Not Applicable
9	Not Known

Notes on coding:

Active pastimes include:

Gardening, needlework, art, sporting activities, playing board games or cards, going out to pubs, clubs, dances, bingo, visiting friends and relatives etc.etc.

Passive pastimes include:

Sitting doing nothing or in a group and not joining in conversation, watching television, listening to the radio or records, reading books or newspapers etc.etc.

V110. How satisfied do you feel with your social life? ☐

0	Very satisfied
1	Satisfied
2	O.K.
3	Dissatisfied
4	Very dissatisfied
6	No reply
7	Other
	Specify ____________
8	Not Applicable
9	Not Known

V111. If dissatisfied at all, could you tell me why you think that is? ☐

0	Definite quote
1	Possible quote
2	No quote
6	No reply
7	Other
	Specify ____________
8	Not Applicable
9	Not Known

V112. During the past week how often have you met with friends? (For at least an hour. Social clubs recorded previously not to be included) ☐

0	Every day
1	4 - 6 times
2	2 - 3 times
3	Once
4	Not met with friends
6	No reply
7	Other
	Specify ____________
8	Not Applicable
9	Not Known

V113. How many friends do you have? (A "friend" is someone other than a relative with whom you share a common understanding/interest and who you have known for some time) ☐

0	One
1	Two
2	A few
3	Several
4	No friends
6	No reply
7	Other - Specify ____________
8	Not Applicable
9	Not Known

V114. During the past week how often have you had contact with friends by letter or telephone? ☐

0	Every day
1	4 - 6 times
2	2 - 3 times
3	Once
4	No contact
6	No reply
7	Other
	Specify ____________________
8	Not Applicable
9	Not Known

V115. Do you feel satisfied with your friendships? ☐

0	Very satisfied
1	Satisfied
2	O.K.
3	Dissatisfied
4	Very dissatisfied
6	No reply
7	Other
	Specify ____________________
8	Not Applicable
9	Not Known

V116. If you are at all dissatisfied, could you tell me why? ☐

0	Definite quote
1	Possible quote
2	No quote
6	No reply
7	Other
	Specify ____________________
8	Not Applicable
9	Not Known

V117. During the past week how often have you seen a neighbour? (For at least half an hour) ☐

0	Every day
1	4 - 6 times
2	2 - 3 times
3	Once
4	Not seen neighbour
6	No reply
7	Other
	Specify ____________________
8	Not Applicable
9	Not Known

V118. How satisfied do you feel with the contact you have with your neighbours? ☐

0	Very satisfied
1	Satisfied
2	O.K.
3	Dissatisfied
4	Very dissatisfied
6	No reply
7	Other
	Specify ____________________
8	Not Applicable
9	Not Known

V119. If you are at all dissatisfied, could you tell me why? ☐

0	Definite quote
1	Possible quote
2	No quote
6	No reply
7	Other
	Specify ____________________
8	Not Applicable
9	Not Known

V120. During the past week how often have you seen a relative? ☐

0	Living with relatives
1	Every day (not living with)
2	4 - 6 times
3	2 - 3 times
4	Once
5	Not seen relative
6	No reply
7	Other
	Specify ____________________
8	Not Applicable
9	Not Known

V121. During the past week how often have you had contact with relatives by letter or telephone? ☐

0	Every day
1	4 - 6 times
2	2 - 3 times
3	Once
4	No contact
6	No reply
7	Other
	Specify ____________
8	Not Applicable
9	Not Known

V122. Do you feel satisfied with the contact you have with your relatives? ☐

0	Very satisfied
1	Satisfied
2	O.K.
3	Dissatisfied
4	Very dissatisfied
6	No reply
7	Other
	Specify ____________
8	Not Applicable
9	Not Known

V123. If you are at all dissatisfied, could you tell me why? ☐

0	Definite quote
1	Possible quote
2	No quote
6	No reply
7	Other
	Specify ____________
8	Not Applicable
9	Not Known

V124. Could you tell me what relatives, if any, you turn to if you need help or advice? ☐

0	Spouse
1	Parent(s)
2	Sibling
3	Other relative
4	Could approach 2 - 3 relatives
5	Could approach 4 or more relatives
6	Could approach NO relatives
7	Other Specify ____________
8	Not Applicable
9	Not Known

V125. Is there anyone else you would turn to if you needed help or advice? ☐☐

0	Friend(s)
1	Neighbour(s)
2	Vicar or priest
3	General Practitioner
4	Psychiatrist or hospital doctor
5	Community Psychiatric Nurse
10	Hospital nurse
11	Landlady
12	Social worker (in hospital)
13	Social worker (not hospital-based)
14	Health visitor
15	Nobody to turn to (other than V124.)
16	Combination of above Specify ____________
6	No reply
7	Other Specify ____________
8	Not Applicable
9	Not Known

V126. Who do you feel is closest to you? ☐☐

0	Spouse
1	Parent(s)
2	Vicar or priest
3	General Practitioner
4	Psychiatrist or hospital doctor
5	Community Psychiatric Nurse
10	Hospital Nurse
11	Landlady
12	Social worker (in hospital)
13	Social worker (not hospital-based)
14	Health visitor
15	Other relative (not parent or spouse)
16	More than one relative
17	Combination of above Specify ____________
18	Close to no-one
6	No reply
7	Other Specify ____________
8	Not Applicable
9	Not Known

V127. Do you feel there is anything missing from your personal relationships and, if so, can you tell me what you think it is? ☐

0	Yes. Definite quote
1	Yes. Possible quote
2	Yes. No quote
3	No. Nothing missing from relationships
6	No reply
7	Other
	Specify ____________________
8	Not Applicable
9	Not Known

PSYCHIATRIC HISTORY

V128. How long ago were you first in contact with the psychiatric services? ☐

0	Less than a year ago
1	1 - 2 years ago
2	Longer than 2 years, less than 5 years ago
3	5 - 10 years ago
4	Longer than 10 years, less than 15 years ago
5	15 years ago or more
6	No reply
7	Other
	Specify ____________________
8	Not Applicable
9	Not Known

V129. How many times have you been admitted to hospital? ☐

0	Never admitted
1	Once
2	Twice
3	3 - 5 times
4	6 - 10 times
5	More than 10 times
6	No reply
7	Other
	Specify ____________________
8	Not Applicable
9	Not Known

V130. How many times have you been admitted to hospital within the past two years? ☐

0 No admission
1 Once
2 2 - 3 times
3 4 - 6 times
4 7 - 10 times
5 More than 10 times
6 No reply
7 Other
Specify ____________________
8 Not applicable
9 Not Known

V131. What is the longest period of time you have spent in hospital at any one time? ☐

0 Less than a week
1 1 - 2 weeks
2 Longer than 2 weeks, less than a month
3 1 - 3 months
4 Longer than 3 months, less than 6 months
5 6 months - 1 year
6 Longer than a year
7 Other
Specify ____________________
8 Not applicable
9 Not Known

V132. How long have you been receiving injections? ☐

0 Less than 6 months
1 6 months - 1 year
2 Longer than 1 year, less than 2 years
3 2 - 5 years
4 Longer than 5 years, less than 10 years
5 Longer than 10 years
6 No reply
7 Other
Specify ____________________
8 Not applicable
9 Not known

V133. How often do you have your injections? ☐

0 Weekly
1 2 weekly
2 3 weekly
3 4 weekly
4 5 weekly
5 6 weekly
6 Not regularly
Specify ____________________
7 Other
Specify ____________________
8 Not applicable
9 Not known

V134. Where do you go for your injections? ☐

0 Clinic
1 Community Psychiatric Nurse (CPN) gives at home
2 Clinic and CPN at home
3 Contact Club
4 Contact Club and CPN at home
5 Clinic and Contact Club
6 No reply
7 Other
Specify ____________________
8 Not applicable
9 Not known

V135. What do you have injections for? ☐

Pt's description ________________________________
____
____
____

0 "Bad nerves" or similar
1 "To stay well" or similar
2 "To stop the voices" or similar
3 "To calm me down", "make me sleepy" or similar
4 "Because the doctor says so" or similar
5 "Schizophrenia"
6 "Would be alright without them" or similar
7 Other
Specify ____________________
8 Not applicable
9 Not known

V136. From description above:

0 Definite quote
1 Possible quote
2 No quote
6 No reply
7 Other
Specify ____________________
8 Not applicable
9 Not known

V137. Do your injections have any unpleasant effects? ☐

0 Shaky, trembling
1 Muscular rigidity
2 Unable to stand still
3 Unable to keep legs still
4 Heaviness, discomfort in limbs
5 Tiredness
6 No bad effects
7 Other
Specify ____________________
8 Not applicable
9 Not known

V138. Who is your Consultant Psychiatrist at the present time? ☐

0	Dr. Bale
1	Dr. Brunning
2	Dr. Fleming
3	Dr. Renton
4	Dr. Abramczuc
6	No reply
7	Other Specify ____________
8	Not applicable
9	Not known

When did you last have a consultation with the following people?

V139. General Practitioner ☐

V140. Psychiatrist or hospital doctor ☐

V141. Community Psychiatric Nurse ☐

V142. Social Worker or Naval Welfare Officer ☐

Coding as follows:
N.B. If never referred or seen by one of above, code 8 (Not applicable)

0	Less than a week ago
1	1 - 2 weeks ago
2	More than 2 weeks, less than 6 weeks ago
3	6 - 12 weeks ago
4	Over 12 weeks, less than 6 months ago
5	6 months - 1 year ago
6	More than a year ago
7	Other Specify ____________
8	Not applicable
9	Not known

V143. Thank you very much for your time and help. Is there anything you would like to mention that you feel is important and that we have not talked about? ☐

0	Definite quote
1	Possible quote
2	No quote
3	No, nothing to add
6	No reply
7	Other Specify ____________
8	Not Applicable
9	Not known

Interviewer to complete the following:-

V144. ☐

1. Interview - Completed
2. Interview - Completed in part only
3. Interview not completed
7. Other
   Specify ____________________
8 Not Applicable
9 Not Known

V145. If not completed or completed in part only, specify why:- ☐

1. Refusal by patient
2. Refusal by relative/landlady
3. Termination of interview by interviewer
   Specify (e.g. patient's mental state)
   ____
7 Other
  Specify ____________________
8 Not applicable
9 Not known

V146. Time taken for interview (in minutes) ☐☐☐

V147. Assessment of Interview ☐

1. Excellent rapport; high degree of cooperation by patient
2. Good rapport; patient cooperated well
3. Adequate rapport; cooperation O.K.
4. Rapport difficult at times; patient did not cooperate fully
5 Very poor rapport; patient was uncooperative

Appendix 4

The Method Used for the Assessment of the Diets

Twenty-four hour dietary recalls are not the most accurate form of nutritional assessment. However, they do provide an indication to the general picture of regular dietary intake in the subjects.

To assess the dietary recalls obtained in this study, each individual's intake was assessed against the five major food groups, i.e. bread and cereals, meat and alternatives, dairy products, fats and oils and fruit and vegetables.

If all the food groups were present in one day the subject received a good score. If one group was absent, the subject was given an intermediate score and if two or more groups were absent the diet was judged to be poor.

Appendix 5

HAMPSHIRE COUNTY COUNCIL

YOUTH AND COMMUNITY CENTRES

Paulsgrove Youth & Community Centre,
Marsden Road, Paulsgrove, Portsmouth PO6 4JB

Telephone: 370643

Southsea Community Centre,
King Street, Southsea, Portsmouth PO5 4EE

Telephone: 823895

Portsmouth Community Centre,
Gladstone Place, Buckland, Portsmouth PO2 7BL

Telephone: 692914

The Brook Club,
Sackville Street, Southsea PO5 4BU

Telephone: 824618

The Moat Club,
Salisbury Road, Cosham PO6 2PN

Telephone: 378181

Hilsea Club,
City of Portsmouth Boys' School, London Road, Hilsea PO2 9RJ

Telephone: 693521 (day) 693525 (evening)

Manor Court Youth Club
Springfield School, Central Road, Drayton. PO6 1QY

Telephone: 376592

Baffins Youth & Community Centre,
Westover First School, Westover Road, PO3 6NS

Telephone: 666924

Meon Road Community Centre,
Shelford Road, Milton PO4 8NW

Telephone: 825127

Portsea Youth & Community Centre,
Lion Terrace, Portsea PO1 3AB

Telephone: 827074

Hillside Youth & Community Centre,
Cheltenham Road, Paulsgrove, Portsmouth PO6 3PY

Telephone: 379738

St. Saviour's Youth and Community Centre,
Strode Road, Stamshaw, PO2 8PY

Telephone: 695215

Stacey Centre (Milton & Copner Community Association)
Walsall Road, Copnor, Portsmouth PO3 6DN

Telephone: 820830

Y.M.C.A.
Penny Street, Old Portsmouth, Portsmouth PO1 2NN

Telephone: 864341/831454

PORTSMOUTH CITY COUNCIL

COMMUNITY ASSOCIATIONS AND COMMUNITY CENTRES

Stamshaw and Tipner Leisure Centre Association,
Stamshaw and Tipner Leisure Centre, Wilson Road, Stamshaw.

Telephone: 693221

Portsea Community Association,
John Pounds Centre, St. James Street, Portsea.

Telephone: 754287

Milton and Copnor Community Association,
Stacey Centre, Walsall Road, Copnor.

Telephone: 820830

Fratton Community Association,
Trafalgar Place Community Centre, Trafalgar Place, Fratton.

Telephone: 751441

Cosham Community Association,
Cosham Community Centre, Wootton Street, Cosham.

Telephone: 384712

Anchorage Park Community Centre,
Sywell Crescent, Anchorage Park.

Telephone: 672731

Watersedge Park Community Association,
Watersedge Park Community Centre, Southampton Road, Watersedge Park.

Telephone: 387039

Wymering Community Association,
Wymering Community Centre, Sevenoaks Road, Wymering.

Telephone: 375361

Northern Parade Community Association,
Northern Parade Community Centre, Northern Parade, Hilsea.

Telephone: 693835

Somers Town Community Association,
Somers Town Community Centre, Rivers Street, Somers Town.

Telephone: 752294

Highbury Area Community Association,
Highbury Community Centre, Hawthorn Crescent, Highbury.

Telephone: 325274

Eastney Community Association,
Eastney Community Centre, Bransbury Park, Eastney.

Crookhorn Community Association,
Crookhorn Community Centre, Crookhorn Lane, Crookhorn.

Central Southsea Community Association
c/o Mr. S. Bonner, 42 Chetwynd Road, Southsea.

Telephone: 816895

Appendix 6

A Mother's Story

'It is now seven years since my son , ---- was first taken ill with mental problems. You are no doubt well aware of the events leading up to this breakdown and also have his medical history. I am not going to belabour this aspect of his troubles, rather I intend to place before you some of the stresses and emotional effects his illness has had on myself, his mother, and the rest of my family.

To begin with, I really was hopeful that, with medical help and treatment, he would recover and then lead a normal life, even if it would be somewhat restricted. I should think that during the past seven years, every emotion has been my misfortune to experience, even a form of boredom, which is now prevailing.

At first, after a spell in St. James' he appeared sufficiently well enough to hold down an office position at Marconi. Even during the nine months he was there I was still uneasy. Eventually, he gave in his notice and seemed physically exhausted. Initially, I was filled with pity for his plight, then, after a while, I became very resentful that we, as a family, had this enormous problem thrust upon us.

I really did make a lot of effort to talk with him - trying to get him to be more positive - in this I did have one friend who helped me. At this time my daughter would not visit the house because she was, I think, very frightened at ------'s apparant loss of control over his mind. She simply could not handle the situation. For a period of about eighteen months to two years I became very introverted myself - not going out, or having friends to visit - because of ------'s unpredictable behaviour.

Then I began to pull myself together and tried to really understand his problem. I am sorry to say that I did not get much help from St. James', even though I was always given an appointment with his doctors, not much information was imparted to me.

I found being with ------ was very depressing. In fact, at one point I, too, became very negative in my own life, coupled with frustration and resentment. I came to the conclusion that no treatment, apart from masking the symptoms with drugs, was possible and that I must actually change my attitude. I have learnt not to argue with ------: my anger spilled outwards to him which now, on reflection, seemed to be very bad for him. One problem seemed to be to get him to accept regular injections - this has now been overcome.

At one stage I was told, in no uncertain terms, to "get out of ------'s life and let him grow up." At that time he was living in his flat which I managed to get vacant after ten months, in order to let him have it. Incidentally, it cost me £400 in solicitors' fees to do this.

From the beginning he never made much effort to fend for himself. Personally, I had a great deal of sympathy over this as even to ask a fit and well person to live on (at that time) £29 a week seems to me to be asking a lot. But for a sick person it is virtually impossible. It meant, in effect, that I was, and still am keeping him in practical ways - by doing his washing, giving him at least one hot meal every day, helping him to pay his bills and buying his clothes etc.

Fortunately, I'm no longer so resentful over the whole situation. I realise, in part, that the medical profession are acting under restrictions - my anger is now directed towards our unfeeling government. I feel if caring relatives and hospital staff unite to demand a larger slice of the national cake, then we may get somewhere.

Underlying all the surface emotional stress, I always feel a lot of pain for my son. I marvel his loss of an ordinary life; I deplore the loss of his expression of his abilities; I am sad for him that he spends his life in this limbo. I also, although perhaps I shouldn't, feel the loss of my right to see his children, my grandchildren.

In conclusion, I have decided to be as kind as I am able because it seems he gets a raw deal from society. Although there are times when I feel like washing my hands of the whole sad business I know I never could. I also feel that if, at the outset, I had been even partially treated with more openness by medical staff, a lot of unnecessary suffering may have been avoided.......I would like to suggest that a great more liaison between hospital staff and caring relatives could be accomplished if we were given more information and suggestions from both sides on practical matters and also on the psychological level.'

A Mother.

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