Italian Mental Health Care in the 1978 Post Reform Era: The Impact on Relatives

Thesis submitted to the University of Kent at Canterbury
In the subject of Social Policy and Administration
For the degree of Doctor of Philosophy

Chiara Samele
October 1993

In memory of Anna

Table of Contents

List of Tables

Acknowledgements

I would first like to thank my closest friends for their unveering support and listening to all the moans and groans during my long journey towards getting a PhD. I owe a lot to Dee and Jude, the two die-hards who have been with me since the beginning, and to Jeevi and Hal with their super-human patience. My thanks also go to Helen and the others for all their encouragement. A special thank you to Diogo for giving me the burning incentive to finish. Thanks too to my Father, simply for being a great dad who has always helped when I needed it most. Thank you to all the people who have taken an interest in what I have done and to all those who have asked that irritating question, 'when do you think you'll finish?'

I also owe a great deal to the relatives and patients, without them none of this would have been possible. I am also indebted to Prof. Michele Tansella for being so generous in allowing me to work in his research department during my stay in South Verona. Many thanks to the people there whose assistance was invaluable: Ermanno Arreghini (for translating the interview schedule), Guiliano, Maristella, Maria-Teresa, Stefano, Renato and Matteo. My thanks to Mirca and Graziella for their priceless secretarial support.

I would like to acknowledge Granine Fadden for providing me with a copy of the interview schedule used in the study. I am very grateful to Ian Stolerman for his interest and support during my time at the Institute of Psychiatry. I wish to thank the people at the Institute's Biometrics department for letting me use their facilities and to Graham Dunn for his statistical advice.

Many thanks to the University of Kent for the bursary awarded to me. Last but not least, a big thank you to my supervisor, Nick Manning, for all his efforts in guiding me through the PhD. Hurray, it's finished!

Abstract

A radical movement in psychiatry effectively changed the face of Italian mental health care when in 1978 law 180 was passed. For the first time this introduced systematic deinstitutionalisation of the mentally ill on a scale that generated international interest. Italy however, was ill prepared to receive the mentally ill into the community at the rapidity with which mental hospital numbers were being reduced. Little thought had been given to what this might imply. Some feared the repercussions would be devastating, others were encouraged by the successes of previous community care initiatives and the impetus to spread them nationally. Families of the mentally ill were to form one of the major cornerstones for the new reform to function. The reliance on relatives to provide care was not foreseen by policy makers. The recognition of informal carers in Britain by feminist academics pointed to the heavy burden placed by community care policies on women. Understanding the extent of impact on relatives caring for someone diagnosed mentally ill was a parallel theme for academics in clinical psychology and psychiatry. The present study sought to address some of these issues: community mental health care after the 1978 reform, the impact of care on relatives and what this signified for women. South Verona was the location chosen for the study. The success there in implementing community mental health services was well in tune with what the originators of the reform sought to achieve. Amongst the relatives interviewed remarkably little material or objective impact was found. Favourable economic and cultural factors accounted for the comparatively minimal impact materially. There was however, a notable degree of psychological or subjective impact on relatives. Most relatives were satisfied with community psychiatric services received by patients, but some were unhappy with the way staff perceived them. Some policy implications and service recommendations are considered in the final sections.

Chapter One

From Institutionalisation to Deinstitutionalisation in Italy: The 1978 Mental Health Reform and its Implementation

In 1978 Italy passed a mental health reform seen to be both revolutionary and controversial. The country embarked on a radical program of mental hospital closures. This led to a drastic reduction of hospital beds as patients were moved into the community. The trend towards 'community care' both in the rest of Europe and the US had already been underway for some years. The 'Italian experience', as it came to be known, differed from other countries in terms of the speed with which this policy sought to close mental hospitals. Compulsory admissions to these asylums became illegal.

This chapter seeks to describe the background to the 1978 Italian mental health reform and the pivotal work Franco Basaglia and his colleagues undertook prior to the reform's enactment. The political and social context in Italy prior to 1978 was instrumental in bringing to the forefront issues concerning mental health and enabling the passage of the reform itself. The subsequent implementation of this mental health policy continues to provoke debate, both in Italy and abroad. Some of the dilemmas emerging from these debates are discussed. Before doing so however, it is worth putting into context Italy's mental health care system by describing, briefly, the development of psychiatry and mental institutions in Italy.

1.1 The History of Asylums and the Development of Psychiatry in Italy

During the unification of Italy, beginning around 1860, a variety of cultural, political and scientific traditions existed, together with differing types of institutional care for the insane. The new unified state thus had to amalgamate the different laws determining a variety of approaches used throughout the country. Anna Tagliavini (1985) documented the transformation of 'Italian psychiatry' and the development of the asylum. She explained that before the political and administrative unification of Italy it was difficult to determine 'Italian psychiatry' as a national enterprise, in terms of a unique body of knowledge or a definite and homogenous profession. There appeared to be two fundamental moments of transformation. The first, in the latter part of the 18th century in which care for the insane, previously isolated as an autonomous problem, came within the realms of state control. The second, at the start of the 19th century, paralleled the spread of Pinel's reform[1] from France to Italy. By this time several state lunatic asylums had been founded. Psychiatry in Italy thus came to be regarded as a theoretical-practical paradigm and so a more modern form of social control compared to the previous form of segregating the marginalised. A model institution was provided by the lunatic asylum in Aversa (opened in 1813) which became widely accepted. It combined care with segregation or a hospital/prison type function. The blue print of psychiatric institutions was effectively drawn up and implemented by the mid 19th century.

It was not until the latter half of the century with the formation of the new Italian state that a national consciousness of psychiatry, distinct from general medicine, emerged. As the network of asylums expanded, so too did the demand for a national professional organisation of psychiatrists. With the launch in 1852 of the first specialist psychiatry - the Appendice psichiatrica (Psychiatric Appendix) - the campaign for a new psychiatry at a national level and a general reformation of the asylum began.

---

[1] Pinel's psychiatric reform was characterised by the medicalisation of madness itself, state regulation of the mad and a general humanisation of the asylum's conditions and the life lunatics led.

The new profession was to include physicians committed to the positivist experimental method in physiological and anatomical research. Thus the concept of mental illness was an organic one. Institutional issues were nevertheless, a central theme. The last 30 years of the 19th century saw the fiercest debates concerning the asylum. The use of moral treatment methods were evident following Pinel's therapeutic tradition. But a split, or contradiction, existed between medical diagnosis and moral therapy.

In sum, 19th century Italian psychiatry was generally concerned with solving practical problems rather than discussing issues of institutions and psychiatry at a theoretical level. The organisation of the asylum did not underestimate psychiatry's emergence as a science. Psychiatry's 'faith in organic accounts of mental illness, a faith which was undaunted even while seeking more sociological explanations ...' (Tagliavini, 1985, p.190).

The period between 1874-1913 signified the age of 'the great confinement' in Italy. One estimate showed an increase in the asylum population from 12,000 in 1874, to a peak of about 40,000 in 1907 (Fornasari di Verce, 1907, cited in Tagliavini). In many respects this reflected the perception psychiatrists at the time had of the asylum: on the one hand to cure those who had been incarcerated, and on the other to protect society from deviants (Tagliavini, 1985). Psychiatrists were aware that they were simply locking up their patients in an effort to defend society from 'pathogenic germs' and the danger madness itself presented. This era of confinement occurred for a number of social and economic reasons (Tagliavini, 1985). Those suffering from alcoholism and 'pellagra' (a type of madness resulting from an inadequate diet consisting mainly of polenta or maize) were commonly found in asylums (Figurelli, 1978; Finzi, 1978, cited in Tagliavini). The use of 'open door' or 'no restraint' therapeutic methods received little following in Italy as they were seen as expensive and considered of no real value (Tagliavini, 1985).

The first formal legislation on both public and private asylums came with the introduction of the 1904 law (n.36). This law was regarded as 'the single most important factor in shaping the development of public psychiatry in Italy' (Donnelly, 1992, p.35). The 1904 law established two seemingly contradictory purposes. The first, a custodial aim to regulate, with a set of public safety rules, the commitment of the mentally deranged whose behaviour disturbed the peace or who were a danger to themselves or others. The second, a humanitarian objective to somehow amend and prevent the abuse of patients in asylums and create a more suitable environment for recovery. This latter objective was made more explicit in the 1909 regulations introduced as an adjunct to the 1904 law. These regulations sought to limit the excessive number of patients admitted to institutions in order to promote a more sanitary environment and also to abolish (or use in exceptional cases) mechanical restraints. In practice however, many of the 1909 regulations were disregarded. Emergency admissions to hospital on police authority became frequent. The use of mechanical restraints as punishment, and misuse of admission procedures continued under these regulations. Subsequently, this led to an excess in the number of patients mental hospitals were able to accommodate. Psychiatrists too were blamed for failing to discharge patients following a specified observation period, and who no longer needed further hospitalisation (Durante Mangoni and Ferrari, 1983).

The need for change in Italy's mental health law began to surface and meetings in 1946 and 1948 by the Italian Psychiatric Association considered several issues for reform. The first highlighted the need for a law with a more medical emphasis, to move away from the more judiciary aspects that the 1904 Law (n.36) presented. The second that mental hospitals be brought to the same level as general hospitals in terms of the structure and organisation of the health service. The third that patient admission be authorised strictly by medical certificate (Maj, 1985).

From 1951 onwards with the presentation of several bills to Parliament and pressure by the Association of Italian Psychiatric Hospital Doctors, Italy's second mental health legislation was enacted in 1968. This introduced for the first time the concept of voluntary admissions for the purposes of diagnosis and treatment. Provisions in the 1968 Act enabled patients to change their admission status from a compulsory to a voluntary basis, although this later proved difficult to implement. Other provisions of the 1968 law included changes to the structure of the mental hospital to make them more like those of the general hospitals. Mental hospitals thus were encouraged to contain a maximum of five wards with 125 beds in each. Staff restructuring, included in this law stated that each mental hospital should consist of a director, a hygienist doctor, a psychologist, and each ward was to have a head physician, one assistant head and one other assistant. Also, a ratio of one nurse per three beds and one social worker per one hundred beds.

The significance of the 1968 Mental Health Reform became evident more at a theoretical level rather than from the practical results it yielded. The attempt to accommodate the idea of voluntary admission into a mental hospital, intended largely for custodial purposes, failed obliquely and is shown in the low numbers of voluntary admissions in subsequent years (Maj, 1985). The 1968 Law represented important changes to the history of state psychiatric care in Italy, compulsory commitments under the 1904 law and the 1909 regulations however remained unaltered. Some years prior to the 1968 reform, experiments in alternatives to mental hospitals had already been taking place and it was this work which was to revolutionise the Italian mental health system.

1.2 The Move Away from the Mental Hospital

The focus on moving away from the mental hospital had begun in the early 1960's with the work of Franco Basaglia and colleagues. Having initiated a series of experimental closures of psychiatric hospitals, Basaglia sought to eliminate the way people with mental illness were marginalised from the rest of society and kept in institutions. He was keen to set up alternative structures for psychiatric care located outside the confines of the mental hospital to promote community integration. Basaglia's work in Gorizia, Parma and Trieste included the closure of a mental hospital in Gorizia, the establishment of new alternatives in the community (Parma), and the combining of both (Trieste). Each stage of Basaglia's work: closure of the asylum, preparing care in the community, and later combining both features are described below.

1.2.1 Gorizia: Closure of a Mental Hospital

Basaglia's work began in 1961 in the small Northern town of Gorizia. The asylum contained 800 patients, part of the 100,000 patients in Italy at that time. Many of Basaglia's writings during that period emphasised the 'manicomio' or asylum as an:

> ... enormous shell filled with bodies that cannot experience themselves and who sit there, waiting for someone to seize them and make them live as they see fit, that is as schizophrenics, manic-depressives, hysterics, finally transformed into things, (cited in Scheper-Hughes and Lovell 1986, p.163).

Basaglia's initial aims sought simply to release patients from the more violent institutional regime of physical restraints, seclusion and shock treatments. As an intermediate measure he continued the use of chemotherapy. In itself this presented Basaglia with the first amongst many contradictory situations. He recognised that the use of psychopharmacy induced anxiety both in the doctor administering this treatment and the patient. At the same time, however, the doctor would be less anxious about their inability to relate to the patient as a human being. For the patient psychotropic drugs heightened their awareness of their situation acting to convince them that their case was hopeless. In seeking to resolve this issue Basaglia argued that medication could be applied usefully in order to establish with the patient some form of relationship, rather than simply suppressing their symptoms. In calming the patient, for example, the doctor would be able to talk to them.

Basaglia at this point was presented with yet another dilemma, "how to 'talk' with a patient who has lost all her subjectivity, whose only body is the body of the institution?" (Scheper-Hughes and Lovell, 1986, p.164). Basaglia had previously undergone phenomenological training and still influenced by this, challenged the clinician to seek meanings in the silences and stillness of the patient. Thus as time progressed the patient could regain his/her ego, subjectivity, sense of self, and the ability to be with another person, and maybe then speech would come more freely.

Then came the task of tackling the asylum. The contradiction Basaglia recognised was how the hospital could be transformed into a more beautiful and more humane environment, yet still remain a type of 'gilded cage'. Basic physical needs within the asylum could be met - food, safety and shelter - but at the same time human needs like autonomy, liberty and love would continue to be suppressed, Basaglia argued. In employing techniques used by other European countries, such as the 'open door policy' and models of therapeutic communities, Basaglia became aware of certain shortcomings they had. These techniques, for Basaglia, failed to facilitate the gap between inside and outside the mental hospital.

The 'open door' procedure merely re-emphasised the extent to which patients were institutionalised. Their reactions were passive as they had internalised the image of the asylums as their own sense of self. Furthermore, these inmates were simply reminded of their exclusion and rejection from the society outside. Consequently, few tried to escape and, moreover, patients remained humble to the benevolent doctor/father. Basaglia wrote:

> They sit quietly by and wait for someone to tell them what to do next, to decide for them, because they no longer know how to appeal to their own efforts, their own responsibility, their own freedom. As long as they accept liberty as a gift from the doctor they remained submissively dominated, (Basaglia, 1965, cited in Scheper-Hughes and Lovell, 1986, p.164).

In response to this situation Basaglia encouraged in patients a 'relationship of reciprocal tension, and aggressivity to challenge their mortified existence' (Schepher-Hughes and Lovell, 1986). This was expressed by physically dismantling/destroying the hospital's barriers, such as the doors, bars and window gratings. Later, in a collective expression, a wall was brought down. In another incident, with the assistance of the nurses, old and backward furniture and equipment was broken up. For Basaglia these acts became an expression of what he termed 'institutional rage'.

The process of confronting the 'internalised' institution or its 'negative logic' was more gradual, taking place at two stages. Basaglia aimed firstly to set up a system of opening up the wards and by creating paid work for patients. In Gorizia this meant in the kitchen, maintenance of the surrounding grounds, caning chairs or farming. A reason thus developed which enabled the patients to leave the wards. Here Basaglia encountered the shortcomings of previous work therapies in which unpaid labour exploited inmates of the asylum. Wages steadily replaced the system of tokens, usually given for good behaviour. Moreover, this system allowed patients to feel they had more in common with the outside world in the field of paid work. Problems about pay in a period of budget constraints were dealt with in lively discussions among patients and staff, and led to the development of work cooperatives as a non-exploitative alternative.

The second stage of change saw the creation of 'assembleas' or meetings that took place on a daily basis. The assembleas were spontaneous in structure and formal arrangements between doctors, nurses and patients were dropped. Patients were free to choose whether to attend or not. Discussions focused on the patients individual or collective needs. It is important to recognise that the assembleas were not a model of therapeutic communities. The difference lies in the 'unsafe' conditions that often stirred within them. The meetings were chaotic and anything but a controlled 'space' to express intra-psychic or interpersonal problems. The assembleas often revealed much hostility, bitterness, anger, outrage and on some occasions resulted in verbal and physical attacks. As the assembleas evolved a collective responsibility emerged for the consequences of behaviour amongst patients, whether progressive or detrimental. Participants would interpret individual problems in 'institutional' rather than psycho-analytic terms. In other words, explanations would be sought in relation to the effects of confinement in an asylum. In this way the perverse logic of the asylum became uncovered as patients used the assembleas as an outlet for suppressed anger.

As patients experienced their new freedom from the hospital wards the potential for crises or disasters inevitably increased. One incident was telling about the mutual responsibility that had developed. A patient upon his release into the community had murdered his wife and Basaglia was subsequently arrested for manslaughter. The law maintained that as Director of the asylum Basaglia would be held responsible for the action of his patients. Attempts were made by the authorities to close down the hospital and have patients transfered to another until a new Director was appointed. Students and other community activists joined in an effort to keep the hospital open and to show their support for Basaglia.

At the time decisions about the procedure for deinstitutionalisation were made not by a panel of psychiatric experts but within the assembleas. Commonsense and lay opinions set the criteria for the appropriate times of discharge for each patient. Any errors of judgement about a particular discharge became a shared responsibility in the advent of a crisis. The incident above was no exception. In essence, it provided a breakthrough in the struggle against the institution and also sparked real efforts to reach even the most regressed patients.

The assembleas provided one mode of several collective movements that were to fit in with anti-institutional practices around the country. Much of this involved consciousness raising in the community outside the hospital, spontaneous meetings with visiting family members, townspeople and discussions within formal political arenas.

Understanding how Democratic Psychiatry came about is crucial to understanding its practices. Basaglia's thinking drew from Gramsci's political thoughts, as well as from theorists of the Frankfurt School. In confronting the negative logic of the asylum Basaglia sought to spear the false-consciousness of psychiatric and institutional ideologies. He did this by disintegrating the power-relations in the hierarchy of doctors and nurses. The sharing of power between doctors, nurses and patients was symbolically affirmed by giving up their traditional uniforms, so too the roles and identities that went with them. Basaglia and his co-workers were constantly aware of the fact that their revolutionary practices were still conducted within the four walls of the asylum, which defeated many of the main objectives. Within the institution there remained a certain vulnerability in reverting back to previous exercises of maintaining control over patients by both doctors and nurses. The aim thus was to move further afield into the community. As a preparatory measure once the asylum doors were opened Basaglia created new services on the hospital grounds - a community mental health centre for ex-patients, a day hospital and a school.

In sum, the experiments at Gorizia far out stretched the boundaries of alternatives developed in models of 'therapeutic communities' at that time. Basaglia and his co-workers questioned the nature of power-relations existing within asylum practices, drawing attention to the authority, power and status between the staff and patients at Gorizia. The contradictions of the institution were broadened to larger social ones. Priority was given to analysing problems in psychiatry using a political-economy approach, rather than interpretations of intra-psychic and interpersonal phenomena at an individual or group level.

The new values created at Gorizia echoed throughout other parts of Italy. The more difficult task of social reintegration into the community was yet to be achieved. Parma provided the setting for community ideas and the problems that lay ahead.

1.2.2 Parma: Developing Community Alternatives

The Provincial Administration of Parma had long been aware of the scandalous conditions of institutions in and around the province. By 1970, following an invitation to Parma, Basaglia and the provincial director of health, Mario Tommasini, began the first initiatives in community preparations for the reintegration of discharged mental patients. Basaglia and his followers were aware that patients should not simply be released back into the same hostile families and communities that had rejected them.

It was recognised that other provisions had to be arranged and organised. Provisions such as alternative medical and social services, appropriate and adequate housing, and employment that was neither exploitative nor highly demanding. The difficulty of opening up the community had long been acknowledged. The aim was to make the community more receptive and responsive than just passively willing or indifferent towards the return of individuals troubled or disturbed psychologically. This aim proved no easy task, but nevertheless had its rewards. Basaglia was under no illusions about the readiness of Italian communities to accept those previously committed to mental hospitals. Italy was no different from other Western countries with regards to the stigma and stereo-types commonly attached to mental illness. In view of Italian communities Basaglia realised the political and cultural battle that lay ahead.

Two main areas of the community were approached. The first involved broader structural changes and the aim of working alongside other organisations, such as those related to the labour market. Negotiations with unions, factory owners and managers of small firms were arranged to convince them of employing a new class of social marginal, someone who had neither experience in working or had simply lost their skills as a result of long-term institutionalisation.

The second involved families of ex-patients. The stigma attached to mental illness was also tied to the patients' family members. Apart from the standard misconceptions mental illness was also seen as hereditary. Stigmatisation in this sense not only affected family members but disrupted their social relations in the community, especially in a society still largely defined in terms of family ties. The crisis provoked revealed that many families were ill-prepared or reluctant to receive back relatives who had been troublesome in the past. The needs of these families were understandably great, and complex. It was in this area that Basaglia failed to develop any real practical alternatives with reference to these families' special needs, despite being aware of their importance. Future developments by Basaglia's co-workers produced new types of family therapies and community support (in Rome, for example).

The central element of Basaglia's community alternative was a new form of mental health worker. Basaglia had envisaged a more active and political role for this worker, not simply to act as a go-between in the relationships between ex-patient and the mental hospital. Their role was to be without any element of psychiatric control. These workers would not be based at community mental health centres nor at day hospitals. The rationale underlying this would limit the potential barriers to participating fully in the community, or worse, create a micro-mental hospital in the community. The new worker would be situated in the hub of the ex-patient's life - both public and private. Private conflicts and troubles under whatever circumstances in the community would become public issues. Problems would be understood in political and economic terms together with the psychological factors. The traditional idea of the psychiatrist's 'neutrality', 'impartiality' and 'objectivity' would be withdrawn to allow the community mental health worker to take the side of ex-patients and their families. The subsequent focus for Basaglia and his colleagues was now to combine work conducted in terms of closing the mental hospital and preparing community alternatives for ex-patients.

1.2.3 Trieste: A Total Amalgamation

Basaglia became Director of the Trieste psychiatric hospital in 1971. It was here he was able to bring together the lessons learnt from the Gorizia and Parma experiments in closing the mental hospital and subsequently developing the community in preparation for the influx of ex-patients. The province's administrator, Michele Zanetti, was willing to accept a radical transformation of the asylum. The number of asylum patients involved amounted to 1,200.

The events at Trieste symbolised Basaglia's innovations, experiments and actions. The slogan 'Freedom is Therapeutic' captured much of the excitement aroused. Non-professionals worked as volunteers or on student fellowships and the procedures used to implement Basaglia's ideas followed much the same pattern of awareness in Gorizia and Parma. Initially the mental hospital was tackled and later the community. This enabled ex-patients to develop a new sense of personal and social identity, to re-establish links with the community, and to do battle with popular stereo-types about the representation of the manicomio and the misconceptions about mental illness.

In previous experiments there existed a minority of patients who proved difficult to relocate in the community. These patients were either too frail or elderly, senile, infirmed or bedridden, chronically mentally ill or were extremely adamant about not leaving hospital. At Trieste the solution lay in a new legal status of patient, that of 'ospite' or guest and making the asylum more available to the community. With this title the remaining patients would have their civil liberties restored and be free to come and go as they wished. There was no compulsory medication nor psychotherapy given to the 'ospite'. The wards in the asylum were converted into autonomous housing or apartments to accommodate those remaining and Basaglia and his followers were keen to encourage the community to come and visit the manicomio. Film festivals, shows, plays by local and travelling theatre companies, performances by musicians, actors and artists took place at the asylum. Some of the artists involved in these activities were invited to take part in the anti-institutional movement, and a few even moved into the vacant wards. As a consequence of these efforts the Trieste community became more aware of the distress and suffering that went on in the asylum, feeling sympathy for Basaglia's cause.

With the help of the Provincial Administrator, various political parties and the labour unions in Trieste, Basaglia and his co-workers were able to open six community mental health centres. Support from these agencies was not as reliable as Basaglia and his co-workers would have liked. On occasion alliances with these political organisations shifted or support lessened, and this often included financial backing. It was during these times that the Trieste workers pleaded with the townspeople and collaborated with other institutions, like the prison and general hospital to promote their work and gain support from other agencies.

Each event, problem or crisis Basaglia and his co-workers confronted during the mid 1970's was within a context of chronic unemployment and housing shortages in Trieste, not to mention the lack of financial resources for ex-patients. Basaglia and his staff, persisted in their cause, fighting for higher entitlements and attempted to widen possibilities and choices in the community for ex-inmates. Indeed, one of the greatest changes in any additional costs in mental health services, as a result of moving patients into the community, concerned the amount of social benefits paid to them, rather than, for example, increased staff levels or higher costs of medication, which instead had decreased (Donnelly, 1992).

By 1980 Basaglia left Trieste to work in Rome's psychiatric services. During his time in Trieste, Basaglia had successfully reconverted the asylum and integrated patients into the community. The asylum building now provides dormitories for students, a day care centre for children, a beauty shop and a pirate radio station. In effect, what had been achieved was a total elimination of the distinction between inside and outside the asylum in Trieste, together with the destruction of the idea of segregative control, discipline and punishment. In its place the asylum, or rather its shell was transformed into a positive social space. Basaglia and his fellow workers had been successful in challenging the expertise of medicine and psychiatry, as well as the archaic principles of managing the mad (Scheper-Hughes and Lovell, 1986).

Once completed the Trieste experience attracted notable attention. The issue taking precedence at that time was how to replicate the positive benefits of the experience in other parts of the country, indeed even nationally. Basaglia's ideology on institutionalisation and deinstitutionalisation became more politically formalised in the founding of Psichiatria Democratica or Democratic Psychiatry. An organisation that was to change the face of mental health care in Italy.

1.3 Psichiatria Democratica; Political Pressure and Law 180

In 1973 Psichiatria Democratica or Democratic Psychiatry was founded by Basaglia and his wife, Franca Ongaro-Basaglia. Ideologically, it opposed the traditional 'conservative' Societá Italiana di Psichiatria (Society of Italian Psychiatry). The formation of this formal organisation, together with Basaglia's original co-workers in Gorizia, aimed to bring forth many of the models and achievements in the previous experiments of deinstitutionalisation. The Movement's original pledges contained the following:

> (1) to continue the fight against exclusion by exclaiming both its structural aspects in relations of production, and its ideological aspects in cultural norms and values; (2) to struggle against the asylum as the most obvious and violent paradigm of exclusion; (3) to avoid reproducing institutional mechanisms for exclusion in the community; and (4) to make a clear link between health and mental health care, especially through the reform of the Italian health care system, (Scheper-Hughes and Lovell, 1986,

p.167).

Many of Psichiatria Democratica's objectives were detailed in a book Basaglia wrote in 1967 entitled, L'Instituzione Negata (The Institution Denied). The Group's first meeting took place a few months after they were formed and discussed 'The Practice of Madness'. The organisation soon became a reference point for political parties, trade unions and those active in public health and law administration.

By 1976 Psichiatria Democratica held its first formal, national convention. A diversity of views emerged about how best to lead the battle against the institution. Some argued that Psichiatria Democratica should retain its own political autonomy, whereby others felt it should align with institutions and parties of the Left (Crepet and De Plato, 1983). The spread of democratic psychiatry in other parts of the country had by this time reached Naples, Genoa, Rome and Turin. Arezzo, Ferrara, and Parma were other localities, like Trieste, in which a strong network of alternative practices had been established[2]. One of the shortcomings of Psichiatria Democratica's original strategy was that it appeared to operate well in small to medium sized towns/cities. In the larger cities, such as Rome and Turin (with the partial exception of Naples), and regions of the South the failure to initiate Basaglia's alternatives was indeed striking. In many of these cases Psichiatria Democratica's initiatives were resisted by certain administrators, bureaucrats, conservatives, and large, private, profit-making institutions dominated in the South.

The need to widen anti-institutional practices throughout the country, meant that changes in legislation were thought necessary by proponents of Psichiatria Democratica, and it was through political means that this was achieved. An understanding of the political context during this period not only accounts for the way

---

[2] See Appendix for a map of major cities and regions of Italy.

the passage of Law 180 occurred, but also showed how Basaglia himself became politically very influential. The leaders of Psichiatria Democratica sought to forged alliances with parties of the left, the Communist Party (PCI) in particular, and trade union groups, which at local level had proved successful in furthering their objectives.

The period of relevance starts in 1968 with the student uprisings and workers' revolts, ending in 1980 with a Centre-Left coalition government. A steady movement of reform grew during that time as the pressure for change became evident for a variety of social issues. Many of these issues for change touched many sections of the Italian population - women, workers, neighbours, youth, parents, school children and so forth, elements all playing a part in the transformation. A common theme ran through their demands and projects - subjectivity, autonomy, personal needs and diversity. The Women's Movement, for example, insisted on control over their reproductive capacity, in which to demedicalise pregnancy, birth and the female life-cycle in general. The Labour movement stressed the right to occupational safety, also demanding control over health services in which to reduce their dependency on factory and company doctors. The issue of health care came to the forefront of each of these Movements' attention.

In a much publicised conference in 1969 on Psychology, Psychiatry and Power Relationships an audience of health professionals, progressive intellectuals and union representatives discussed concrete proposals for psychiatric reform. The first joint-psychiatric care platform was presented by the PCI, who by 1971 became one of the main national supporters of mental health reform. Psichiatria Democratica, now a solid political base despite its differing viewpoints and even clashes in its alliances with the PCI, came together in acknowledging the need for a mental health reform.

At this time too, Italy was experiencing a great Cultural Revolution (Clark, 1984). The Catholic Church declined in its appeal. Religious practice no longer existed as a social habit, instead it became a minority sub-culture, or simply a matter of private belief. This secularization had its biggest impact on women, who previously had been the main church attenders. Women's views in Italy were changing and by 1972 their main priorities were education, a job away from the house, freedom to think and act as they liked, and prosperity (Clark, 1984). Views which differed substantially from priorities held by women some two or three decades before - a husband, children, a well equipped home and someone to protect them. Before 1970 divorce was rare in Italy. Marriages could be annulled or declared invalid on certain grounds. Alternatively, the State could grant a legal separation. The increases in emigration and urbanisation provoked marriage break-ups. It became evident that the issue could no longer be ignored given the large numbers of people affected. In December 1970 Italy's first divorce law was enacted in which the campaign for its introduction was assisted by the Radical Party, dormant since 1940, had suddenly revived in an era of sweeping social change. The Radical Party later become instrumental in other reforms, widened its scope to include issues concerning abortion, prisons, conscientious objection and admission procedures to mental hospitals. The Party's main device was the use of the referendum which could be held on any existing law if 500,000 signatures of registered voters could be amassed in petitions. Growing support from a variety of political groups and those keen on social reform, emerging scandals on asylum practices, and the accumulating criticism of traditional psychiatry in Italy meant that the demise of the asylum was well underway, by the mid 1970's (Donnelly, 1992). The media too also played a role in markedly shifting public opinion making the focus of psychiatric reform largely an issue of civil rights. As Pirella (1987) pointed out psychiatric reform was not discussed from the viewpoint of the specialist but that people have the right to care without compulsory admission to hospital.

Between 1973 and 1977 the Italian Parliament had seen much debating of mental health reform, although little was actually done in terms of legislation until 1977. The debates in parliament on reforming mental health care came out of discussions on proposals to organise a national health service. The idea was to integrate psychiatry into general health care to eliminate discrimination and seclusion of people with mental illness. During that time most of the political parties had drafted and introduced parliamentary proposals for a national health service. Parties of the Left in parliament put forward legislation on psychiatric reform. This legislation included many of the reforms sought by the anti-institutional movement including: closures of mental hospitals and other total institutions (like orphanages, special schools, etc); to replace the 1904 Law; establish community mental health as the primary provision for psychiatric care and psychiatric units in general hospitals for acute purposes; and a total uprooting of compulsory admissions and the guaranteed maximisation of patients' rights.

The Radical Party, at the beginning of 1977, started its campaign of calling for a petition to abolish the compulsory admission procedures set by the 1904 law. This event broke the rather slow pace at which psychiatric reform was proceeding through Parliament. The Radical Party had begun gathering signatures on behalf of a popular referendum in an attempt to invalidate the existing mental health legislation. The Party had succeeded in collecting over 700,000 signatures, which exceeded that required for a national referendum. In an effort to prevent a legal vacuum, leaving the country without a policy on mental health, Parliament began drafting a new mental health act appointing a sponsor from each Party of the coalition government. Basaglia was consulted regularly throughout the passage of Law 180, even though he did not write it. Law 180 was finally passed in May 1978, much of it a compromised solution (Mosher, 1982). The principal features of law 180 include the following:

1. - A gradual phasing out of public mental hospitals by prohibiting any further admissions to them. A deadline set for Dec 1980 (Dec 31, 1981 in some areas) continued to allow ex-mental hospital patients to be readmitted on a voluntary basis, after which admission became unlawful.
   - The construction of mental hospitals was outlawed whereby the use of existing psychiatric hospitals were to be used to facilitate the discharge of patients.
   - Staffing of new services were to be drawn from personnel of mental hospitals thus acting as a redeployment of staff.
   - The status of inpatients was to be reassessed to determine whether continued commitment was deemed necessary and to specify the probable duration of treatment.
2. - In general terms, treatment was to ordinarily take place outside the hospital in community-based facilities responsible for a predefined geographical area. These facilities were to be organised to safeguard collaboration between general and mental hospitals in order to provide both preventive and rehabilitative psychiatric interventions.
3. - The use of hospitalisation, whether on a voluntary or compulsory basis was to be treated as a last resort. General hospital psychiatric wards (Servizi Psichiatrici di Diagnosi e Cura, SPDC) were to be set up for all inpatient treatment of this kind. The number of beds available in each unit/ward was to be limited to 15 per 200,000 population and based either in community mental health centres (Centro di Salute Mentale, CSM) and/or the SPDC.
4. - Compulsory admission to private hospitals was to be discontinued. Compulsory commitment to SPDCs for evaluation and treatment can occur if i) urgent intervention was essential, ii) if treatment was refused, and iii) if treatment in the community was not feasible. Two doctors certificates were required (one of whom must provide an independent evaluation) and formally check in terms of procedures by the Mayor or his/her designate responsible for the local health district.
   - The length of compulsory hospitalisation was limited to seven days and subject to review at the second and seventh day. Applications for an extension had to be made by an independent judicial review. Appeals to court could be made by patients or relatives. The constitutional rights of involuntary patients were to be upheld.

Law 180 did not apply to Italy's six forensic psychiatric hospitals, private hospitals, residential homes or nursing homes and services primarily for substance abusers. The restructuring of mental health services aimed largely to desegregate people with mental illness, mental and physical disabilities. The purpose of closing mental hospitals was to ensure that the patient's life style could be similar to that of ordinary people. There were also attempts to shift away from the hegemony of medically-trained staff to equally distribute power and responsibility amongst all professionals involved. Law 180 promoted the integration of psychiatry into the rest of medicine. The State and local authorities became bound into developing alternative structures to the mental hospital. The short conversion period from the enactment of Law 180 to the prohibition deadline of compulsory admissions to mental hospitals was purposely designed to prevent prolonged implementation. For Donnelly, 'the most striking feature of the law is that it expressly excludes any reference to 'dangerousness', which had been the central criterion of the 1904 law', and '... abolishes what had been the major distinguishing characteristic of the mental patient' (Donnelly, 1992, p.73).

In sum, factors allowing for the passage of law 180 in the political climate of the 1970s can be located in two main parts. The first can be traced to the Parliamentary system itself. As Clark (1984) explains 'the system gave real influence to minority groups outside parliament', in this case Psichiatria Democratica (via the PCI), and to 'factions and 'opposition parties' within' (p.334). This explains the substantial 'swing' impact of the Radical Party on the coalition government. The strength also of the PCI almost forced the DC into complying with these welfare reforms even when it meant undermining their own legislative interests (Ramon, 1984), although some observers disputed the significance of PCI's role (Mosher, 1982). They argued that the PCI's main task was only to keep psychiatric reform on the national agenda (Donnelly, 1992).

The second climate of change lay in the more general socio-context of Italy during that period. A large component of the Italian population wanted drastic changes in most spheres of life, away from the facist regime that had taken place some decades before (Ramon, 1984). The radical mental health reforms and its supporting movements had coincided with a widespread social-reform orientation (Mosher, 1982). These elements enabled the passage of a revolutionary mental health reform. They were extremely unique, not only in Italy itself but also within the wider experiences of the rest of Europe and the USA.

Law 180 was quickly assimilated into the newly formed National Health Service (law 833). In administrative terms the law led to the formation of Local Health Units (Unitá Sanitaria Locale, USL) to organise health services. These units would be responsible for the functioning of socio-health services and liaise with associated welfare services within the confines of local government communes. Each USL covered a population between 50,000-200,000 people and divided into districts containing a population of around 10,000, providing basic health services, including primary care, family advice centres, pharmacies and some domiciliary services. Departments for mental health would be responsible for existing mental hospitals, and alternative facilities based in the community.

Regional administrators were given a free hand in the exact timing and modality of implementing law 180. The law itself however was simply a guideline rather than a definite prescription. The spirit of the reform categorically stated the abandoning of the asylum in favour of community alternatives for care, and promoted this principle so vigorously legislators omitted to consider, in any detail, the state of mental health services or what the implications were for transforming them (Donnelly, 1992). Subsequently, law 180 made no provision for the transition of services from the asylum to the community. As Donnelly explained, perhaps the biggest hindrance in implementing law 180 lay in its very conception, its avid supporters felt the law would enable a continuation and extension of the movement's objectives. He heightened, 'what law 180 really represents is in fact a victory of principle: it abolishes the *manicomio*' (asylum) (Donnelly, 1992, p. 79). Donnelly's evaluation of the reform, apart from dealing more specifically at a political level the process leading up to law 180, takes a more sober view of events. The literature on the evaluation of the reform's outcome has become locked in a debate of extremes. Commentators, practitioners and researchers in favour of the reform have dealt mostly with the positive outcomes without acknowledging some of the negative effects. Similarly, critics have appeared intent on reporting the bad effects of the reform and have failed to see the positive side of community mental health. Commentary on the implementation of law 180 was no exception to this polemic, and subsequently reflected in a new succession of struggles and conflicts of what was taking place at grass roots level.

1.4 Implementing Law n.180

The onset of law 180 was characterised by a sharp conflict on the practical implications of the reform and also two opposing philosophies of care (Donnelly, 1992). Those who perceived mental health in a political way continued to favour law 180. For them demarginalising the mentally ill and reintegrating them into the community had a higher priority than medical care. Opponents of the law, however, predicted a shortfall in care, which they argued was a direct consequence of the reform. These opponents were concerned with several issues: namely, that hospital care would be suspended and alternative services would be slow or patchy in developing; that there was no certainty about the quality of care alternative services would provide; and most importantly, the fate of long-stay and chronic patients would appear to worsen under the new reform. Advocates of the reform would retort to these criticisms by arguing that it was precisely because of the opponents' failure to implement alternatives that there was indeed a lack of them. Supporters of the reform felt that former long-stay patients were a legacy of the past.

Attempts to evaluate the outcome of the reform and what should be regarded as successful implementation of its objectives has again been plagued by opposing viewpoints. Indeed, much of the research literature and other observations assessing the reform's outcome have reflected this, sometimes fierce conflict of ideas about the ends and means of mental health care. But what both sides agreed upon was that there still remained much to be desired where mental health services in Italy were concerned. This ideological debate was exacerbated even further by the shortage or complete absence of comprehensive information on what was actually being carried out and what was not, subsequent to the reform. Following-up deinstitutionalised patients, unless they remain in contact with services, is difficult at the best of times but in Italy the difficulty is heightened by gaps in information. This coupled with the Government's failure to monitor or consistently collect data on the reform's progress, has led to an even greater difficulty in forming any conclusions about the outcome of the law nationally. However, some Government data are available in which various assessments and evaluations have been made. The following details the pattern of decline in both patients numbers and beds in mental hospitals, the type of services available across the country, the development of community alternatives, and the difficulties encountered in implementing the reform.

1.4.1 Compulsory Admission Rates to Mental Hospitals Following Law 180

The most notable trend after law 180's enactment was the steep fall in compulsory admissions to mental hospitals and the number of beds available. Table 1.1 below charts the decrease in the number of beds and patient figures from public mental hospitals and private psychiatric institutions between 1967-1984. Prior to the reform, the rate of decline in bed numbers was fairly consistent between 1963-68, at about 1,390 beds per year. In the period between 1973-78 immediately prior to the reform the rate was 3,305. The post reform years between 1979-83 saw a 4,140 per year reduction in beds. Length of stay, in state mental hospitals, however, showed an increase from 142 days to 236 days during 1977-84. It is argued that patients who were suitable for discharge had left hospital before 1978, whereby the more severe cases or those who would not have benefited from discharge remained in hospital (Tansella and Williams, 1987). The number of patients in private institutions peaked in 1972 reaching a total of 22,042. Again this figure declined in subsequent years to 15,025 in 1984. Length of stay in private mental hospitals was about 127 days in 1972 and decreased to about 87 days in 1984.

Table 1.1
Discharges from Public Mental Hospitals and Private Psychiatric Institutions

	Public Mental Hospitals		Private Psychiatric Institutions	
Year	No. of Beds	No. of Patients*	No. of Beds	No.of Patients*
1967	91,594	86,063	23,037	20,116
1972	85,000	77,987	26,278	22,042
1977	70,070	58,445	24,177	19,663
1981	47,871	38,358	21,905	16,872
1984	38,928	30,672	18,345	15,025

(Source: ISTAT 1964-86 *Patients on census day 31st Dec of previous year)

In general terms these figures appear consistent with what the reformers set out to achieve and the drop in compulsory admissions was seen as a positive step towards change (Pirella, 1987), and attributed directly to law 180. However, the lowest compulsory admission rates were to be found in areas that had developed alternative approaches before the reform. There were significant increases in other areas where only inpatient facilities were available. There was still doubt about whether patients sought and received the care they needed. Hence what sorts of services were available after 1978?

1.4.2 Types and Distribution of Psychiatric Services in Italy

Three models of Italian psychiatric care have been described by several authors (McCarthy, 1985; LABOS, 1987; Pirella, 1987). These models have also been considered stages of implementation. The first is typified by the persistence of mental hospitals or manicomios[3], reliance on SPDCs (general hospital psychiatric wards), (which alone are not sufficient to meet the population's needs), and the predominance of private psychiatric facilities. Community services are few or non-existent. Such services are found mainly in the South where service delivery is poor and inadequately developed. The second model is based on outpatient services with a small number of private facilities. Non-hospital residential and rehabilitation facilities are either underdeveloped or absent, with a continued reliance on hospital-oriented psychiatric care. This model can be recognised in northern and central regions and form a major part of psychiatric care in Italy. The actual block in admissions to manicomios applies, but patients admitted before the reform are still accommodated within them. The third model represents community-based services with hardly any use of the mental hospital, which is virtually empty or closed completely, and have a limited use of SPDCs. The focal point of this model of care highlighted services such as Community Mental Health Centres (CSMs), sheltered apartments, therapeutic communities, hostels, day centres, sheltered workshops and domiciliary visits implemented in areas such as Trieste, South Verona, Perugia, Venice, Turin, Genoa and Portoguaro (Gallio and Giannichedda, 1982; Martini et al., 1985).

In examining the distribution of mental health services around the country the most marked finding is the acute lack of alternatives to hospital care. There also exists a shortfall in the number of SPDCs, the only service requirment specified in law 180.

Community mental health centres are seen as the cornerstone of psychiatric services in Italy according to law 180's ideals. As of Dec 1984, 674 community psychiatric services functioned in Italy with a total number of 360,000 users in the

---

[3] These existing large mental hospitals can be used for voluntary admissions. In some cases this can become long term which is an abuse of law 180. Manicomios are referred to as 'converted' hospitals.

same year, 33% of whom were first contacts. The unequal distribution of community services can be seen when considering the ratio of services by population. In the North the ratio is 1 service per 70,000 population. In central regions one finds 1 service per 80,000 population. In the South there is 1 service per 100,000 per population and in Sicily 1 per 149,000 population. Drastic discrepancies were found in Friuili Venezia Giulia (northeast) with 1 service per 47,000 population and Molise (south) 1 service per 333,000 population (CENSIS 1985, cited in Mosher and Burti, 1989).

Thirty-seven percent of existing community services were created prior to the 1978 reform and once law 180 was introduced the trend increased until 1980 and has subsequently slowed down. Some 132 community services are still lacking where approximately one-third of the population live in USLs without psychiatric services in the community (Mosher and Burti, 1989). In terms of staffing levels only one-third of community services in Italy have all professionals present (i.e. psychiatrists, nurses, psychologists, social workers, etc). Fifty percent of community services have not provided any formal training for staff despite 43.4% of personnel having been transferred from public mental hospitals.

In identifying how patients fair, where comprehensive community psychiatric services exist, a number of studies using data from Psychiatric Case Registers in the catchment areas of Portogruaro, Lomest and South Verona reveal three main findings. The first, verified that community services have been put into practice. In 1984 Portogruaro treated 85% of its users in the community (Tansella and De Salvia, 1987). Using the same data one finds that while admission rates to SPDCs have remained low and relatively constant, out-patient and day-patient contact and domiciliary visits have shown a considerable increase in current years. The second, that these northern catchment areas have found little indication to suggest that 'new long-stay' in-patients are accumulating. A notable decrease in the number of in-patients has taken place where many of these patients have now moved to long-term community psychiatric care following the reform (Balestrieri et al, 1987). In South Verona long-term users' clinical and social characteristics have been found to be similar to those of the 'old long-stay' patients in mental hospitals (Mignolli et al, 1984). The third finding showed a substantial decrease in the number of compulsory admissions to SPDCs since 1978. The rate for South Verona in 1984 was 4.8 per 100,000. In Portoguaro during the same year no involuntary admissions to SPDCs took place (Tansella and De Salvia, 1987). Case register data of these good practice areas suggest that implementation of the reform, in its full spirit can be a success without the need to rely on mental hospitals, but also emphasises the absolute necessity for a comprehensive community psychiatric service.

In terms of implementation of SPDCs, Mosher and Burti (1989) calculated that on average each psychiatric service (a total of 95) has 13 beds, two lower than the estimated figure of 15 specified in law 180. They pointed out that in accordance with the generally accepted ratio of 1 bed per 1,000 population some 173 new units would have to be developed and contain approximately 2,595 new beds to comply with the reform. An estimate of 78,000 admissions take place per year in SPDCs. One fifth of these admissions are compulsory. The average length of stay in SPDCs is approximately 12 days with little difference in voluntary and compulsory admissions. Readmissions amount to one-third (34.1%) of the total admissions figure (Mosher and Burti, 1989, CENSIS, 1985 data).

Staffing make-up and the distribution of personnel in SPDCs again reflects an uneven spread across the country. There is a high proportion of medically oriented facilities and a general lack of formal training for staff in new services, with only one third having offered courses. Professionals who were transferred from mental hospitals to new services constitute 58.6% of all mental health professionals. Those employed after the reform make up 23% of the total number of mental health professionals. The remaining 15% come from other services. Staffing composition in SPDCs consists of 69.7% of psychiatric nurses; 21.7% of physicians; 3.8% of social workers; .4% of psychologists; and .4% other.

There are overwhelming discrepancies to be found in the distribution of community services around the country, even when accounting for the lack of reliable information on the reform's outcome. Problems relating to the reform's implementation can be identified within a wider context pointing to Italy's economic situation, its administrative structure, and not withstanding the implications for ex-hospital patients and families of the mentally ill.

1.4.3 Difficulties of Implementation and Subsequent Considerations

When trying to clarify where the difficulties of implementation of law 180 lie, one becomes immersed within a debate fundamental to how the reform is seen to function. From a macro economic viewpoint the problem in the application of law 180 is confounded by the way the budget for mental health care has been allocated. It has been estimated that 80% of the expenditure given for mental health services in Italy goes towards maintaining the old mental hospitals. The remaining 20% thus needs to cover both the development of alternative services and their operation. In calculating the overall budget allocated to psychiatric care one finds 8% of the total expenditure of the Italian National Health Service (Servizio Sanitario Nazionale, SSN) goes towards this. The mean percentage in Europe is 15% (Ongaro-Basaglia, 1987, cited in Mosher and Burti, 1989).

Mangen (1989) viewed the problems of implementation in terms of the structure of the Italian welfare state and the emergence of a fiscal crisis. He argued that many welfare policies including mental health, 'contain ambivalent and, indeed, conflicting goals so that varying interpretations of the task of implementation and the measurement of its success are inevitable' (Mangen, 1989, p.7). Regional autonomy in the organisation of health and welfare services rather than improve efficiency in formulating policies exacerbate the problems of implementation. The differing political orientations of each region also serve to influence administrative procedures in the implementation of the reform. The fiscal crisis of the welfare state in Italy and the current status of the economy and political instability - high unemployment reaching 12.6% in 1987, increasing inflation at 15% during the economic recession in the late 1970's and 1980's, and the submerged economy - have conjoined to heighten the difficulties even further (Mangen, 1989). More recent accounts of the reform's implementation and the expansion of alternatives services have reiterated the problems of uncoordinated planning of mental health services, exacerbated by the severe imbalance in the distribution of resources (De Salvia and Barbato, 1993).

At the micro level a series of problems emerge in the way a service attempts to develop according to law 180's intentions, where the hospital is still the central element in psychiatric services. One example, indicative of the majority of psychiatric services in Italy, is the mental health service in Trentino (northeast) based on intermediate structures. The difficulties were apparent at various levels where there was a decline in the care delivered and a growing tension in the team's 'therapeutic atmosphere'. This situation was exacerbated by the lack of formal training for psychiatric staff, which has either been delayed or introduced tentatively. Additonal problems included ward overcrowding, inadequate interventions and a lowering of morale from patients and families about the reform's ideals (Samele and Bologna, 1991). Developing new psychiatric services dramatically depends upon the competence and style of work by consultant heads and individual local administrators. Factors such as these contribute to decrepancies not only within a service, like Trentino's, but also within the same city.

Still at the micro level concerns by critics of the reform follow much the same lines as those who argued the negative effects of the present trend in deinstitutionalisation policies. Ardent critics of law 180 have expressed their fears of the risk of increased suicide rates, the possibility of 'wild dumping' and the abandonment of patients being discharged from mental hospitals (Crepet and Pirella, 1985; Jones and Poletti, 1985; Crepet, 1988). Contrary to these expectations the number of suicides has not shown a measurable increase since 1978 (Tansella et al., 1987). Likewise, the number of people becoming homeless has not increased in the post reform decade (Bollini et al., 1988).

A further concern often restated refers to those patients in need of long-term care and whether facilities to meet their demands have been developed. It has been argued that the inadequacy in the formation and development of alternative services to the mental hospital has resulted in an extensive use of old people's homes and similar institutions (Crepet, 1988). The inability of district services to meet the need for long-term care has led to a moderate increase in the use of criminal psychiatric hospitals (Calvaruso et al., 1982; De Salvia, 1984). Others, such as Lesage and Tansella (1993), argue that it is possible to maintain patients who require long-term care in the community without resorting to long-stay beds in hospitals. With the reduction in long-stay patients in mental hospitals, the figure for 'new long-stay' patients has remained near zero (De Salvia and Barbato, 1993). It is easy to conclude from these comments that 'new long-stay' patients have simply been redefined or recategorised. Many studies outlined here present purely statistical evidence on the post reform era and do not show what actually happens to people discharged from hospital, although some regional studies have attempted to document the fate of released patients (Centenaro et al, 1981; Casi et al, 1984; Becker, 1985).

In sum, the difficulties of implementing law 180 since its inception have been formidable. At economic and administrative levels substantial problems exist because of the limited resources allocated for mental health care. This has left little scope for developing alternatives in parts of the country that have failed to implement the reform. These fiscal and administrative restrictions have been compounded by the vast discretion with which administrators have when implementing, or not implementing, the reform's ideals. At the practical level reports and evaluations have been mixed. It is argued that where successfully implemented the reform can work effectively without the need to resort to the mental hospital.

1.5 Overall Summary

Historically, the development of psychiatry in Italy followed much the same pattern to that of the rest of Europe, in the way asylums were developed in order to provide custodial care of the insane. The subsequent 1904 Law, its 1909 regulations, and the 1968 Mental Health Act on the dangerousness of patients and subsequent rationale of custodial care. Basaglia, in his experiments in alternative forms of care, uprooted existing notions surrounding the need for the asylum. His work abandoned the mental hospital and pressed for patients to be liberated, both mentally and physically. Basaglia's ensuing political involvement led to the dissemination of his ideas and practices at a national level, and later to influence a change in the law.

The implementation of law 180 proved difficult at virtually all levels economically, administratively, and in practical terms. There was a gross neglect, during the entire reform process, to consider the full implications of the reform's impact on existing mental health services in Italy at that time. This, in part, was a consequence of law 180's speedy enactment, but it meant that regional administrators were ill prepared to implement the reform, given the lack of guidelines or regulations in the services to be developed. Perhaps one of the biggest shortcomings of the reform was its failure to consider the implications of community mental health care on families of the mentally ill.

Community mental health care has a distinct reliance on the informal sector to provide care for the mentally ill. The issue of informal care has been widely debated in Britain, not least by British Feminists. In Italy no study has attempted to assess the reform's impact on the family, where comparatively little attention has been paid to the issue. The next chapter explores the way in which community care policies affect the families of the mentally ill in the British context, drawing on Feminist theories of familial ideology and informal care and how women shoulder much of the caring responsibilities. These themes are then paralleled with the Italian context in an attempt to chart the similarities and contrasts according to cultural and familial expectations.

Chapter Two

Informal Care: The Family, Women and Caring

> '... kinship remains the strongest basis of attachment and the most reliable basis of care that we have' (Abrams, 1977, p.133)

This seemingly simple statement raises a plethora of issues and assumptions about the family and what it is expected to do. As the movement towards community care grew in Britain, particularly over the past decade, it has become increasingly clear how these policies rely heavily on informal support to provide care for dependant relatives. Feminists initially developed a critique of the family in the 1970's and 1980's, to identify women's position in the family, arguing that the family represented a major site, if not the source of women's oppression. Issues such as gender inequality and the possibility of equality with men in the family were explored by feminists interested in 'familial ideology' (Barratt and McIntosh, 1982; Beechey, 1985; Harris, 1985), and the welfare state (Wilson, 1977). With the advent of community care a second strand of feminist thought emerged dealing specifically with the issue of informal care and the way in which women in the family do much of the caring for dependant relatives. This chapter aims to outline the feminist debate concerning informal care and the 'built-in' suppositions underlying community care policies in Britain in which women become the primary carers. The second part describes the family in Italy, the changing position of women and the development of social policies over the last decade which highlight the focus of Italian feminists. With the introduction of law 180 there has been a similar reliance on the family to provide care, although the Italian literature on this has been relatively scant. The responses and issues raised by family associations however, have virtually paralleled the debate on informal care in the British context. Before moving onto the specific subject of informal care it is appropriate to provide some account of the feminist theory on the family and the welfare state.

2.1 Feminism and the Family

Feminists academics, during the 1970's and 1980's, were keen to examine the relationship between the family and the welfare state. This later became exemplified in the sudden growth of research and theoretical literature on carers. One of the main concerns for feminists was that of assessing social policies, and more specifically research and analysis examing whether care in the community could be supported and how alternative policies could further the interests of women. McIntosh's (1979) work, which provided the setting for the theoretical debate to emerge, looked at the welfare state and the needs of the dependant's family. For McIntosh, capitalism is dependant upon a system of family households. Within this system a number of family members are dependant on the earnings of a few adult members. In other words, some family members are dependent primarily on the husband/father's income, classified as the main 'breadwinner', who in turn are all dependent upon someone to clean, cook and so forth. The latter which are usually unpaid and chiefly done by the wife and mother.

The major focus of feminists was the economic dependence of women on men perpetuated by the family household system. McIntosh (1979) and Wilson (1977) showed that the State played an important role in maintaining this system and women's dependency within it. Following this recognition of the state's role feminists began to campaign, not just for equal pay and equal employment opportunities in order to promote women's economic independence, but also not to withstand state policies which exploited women's unpaid labour in the home. In controlling these aspects of women's lives, Wilson argues, the 'ideology of welfarism' also obscures the fact that women are used as a cheap and docile reserve army of labour. There are however weaknesses in the links Wilson makes, for example, the relationship between the family, the welfare state and the 'needs' of the capitalist economy. In being inherently functionalist it makes no allowance for any contradictions between these institutions. Wilson's separation of 'ideological' and 'economic' factors is far too rigid a distinction, and her analysis of the family and its subsequent ideology is monolithic and historically out of context (Beechey, 1985). In a similar vein Harris (1985) in her article, 'Households as natural units', attempted to clarify some of the misconceptions held of the relationships between household forms and ideological assumptions about 'the domestic'. This she does in extensive detail, drawing on a broad spectrum of historical and cross-cultural evidence. Harris shows how 'the domestic' entails various types of assumptions regarding the natural status of activities and relationships occurring within it. The strength and persistence of these assumptions leading to a continuation of talk about 'the family and 'the household' as universal institutions without any historical basis. Indeed, the feminist debate on the family sometimes appeared unfounded according to the above criticisms.

One of the primary focuses for feminists in the late 1960's and early 1970's was on child care, again within the context of unpaid work women do in the home. This focus later shifted away from the care of children to the care of disabled or elderly family members. In part this was due to the British government's eagerness to discuss the issue of community care, beginning in the early 1980's, and partly because of the ongoing quest of feminists to radically restructure the relationship between the state, the individual and the family (Morris, 1991/1992). The topic of informal care for the feminists subsequently became the main focus of debate.

2.2 Informal Care and the Feminists

A second strand of feminist thinking emerged to look specifically at the implications of informal care on women. Feminists considered the desirability of community care policies and went on to propose alternatives that would involve non-sexist forms of care. Before discussing these issues however it is useful to define terms and set the context. Hence initially, informal care and what it actually entails is first described, followed by a review of the evidence on who exactly informal carers are and how they come to care.

2.2.1 How Informal Care is Defined

Informal or 'personal' care, as described by Finch (1989), refers to the care given to someone who is unable to look after themself or perform domestic tasks. Parker (1981) clarifies caring as a task-oriented concept by distinguishing between 'caring about' someone (which can be expressed by donating charity, lobbying, feelings of anxiety, sadness or pleasure about what happens to others), and 'caring for' someone (which may include feeding, washing, lifting, cleaning up for the incontinent, protecting and comforting). Parker also adopts the term 'tending' to describe the second set of activities. On a broader level 'informal welfare' has been described as 'help designed to maintain or increase the physical, material or psychological welfare of the recipient, help which is not given for material reward or through the medium of a formal organisation (St Leger and Gillespie, 1991). Each of these definitions include overall what informal care constitutes, although they are not always performed by people living in the same household as the person receiving support, they could be friends or neighbours. Those who do, however, care for a dependant adult living in the same household experience the greatest burden of care (Green, 1988).

The primary source of practical care for people in need, particularly if the help is arduous, time-consuming and intimate, is almost invariably conducted by kin (St Leger, 1992), and who are vitally important in the delivery of informal welfare (Finch, 1989). In a 1991 study on informal welfare, St Leger and Gillespie, found that of 52 main carers all except one were relatives of dependants. Furthermore, the bulk of the caring responsibility is likely to fall on one person and not shared amongst other family members to any great degree (Walker and Qureshi, 1989). Walker and Qureshi (1989) characterised the existence of a perceived hierarchy of preferred carers depending on the availability of family members. According to this hierarchy, if a spouse is absent daughters come a close second, followed by daughter-in-laws, sons, other relatives, and lastly non-relatives.

2.2.2 Assuming the Caring Responsibility and the Decision to Care

There exists overwhelming evidence to conclude that females largely predominate as carers in Britain. In recent work by Parker (1990) there was evidence not only of a predominance of female carers but also how caring for a disabled dependant, living in the same household, carries a heavy physical, psychological and economical burden which falls disproportionately on these carers. Even as women have increasingly gained access to the public sphere a more equal distribution of domestic responsibilities and the care of family members has not taken place. Women continue to assume these domestic and caring activities (Lewis and Meredith, 1988). This point highlights how the responsibility for caring tends to gravitate towards women and the way in which it is ultimately decided.

In the decision to care it is important to understand that women's relationship to caring cannot be interpreted solely in terms of a series of choices, but also in terms of a complex interplay of roles and norms within the family. Familial interdependency networks are complex and power relations occur both between the generations and at the gender level. The decision to care is primarily made within a context of widely held assumptions about caring being women's work and this should ultimately take precedence over other work. Feminist academics have been productive in identifying many of the factors determining the way in which women adopt the role of carer.

In seeking to explain the 'gender-bias' in caring feminists have used theories concerning the patterns of socialisation and structural constraints, and the way women have internalised the injunction to care. One suggestion has been that the caring role, in part, provides women with a feminine identity (Graham, 1983), and fills a sense of purpose in giving support to someone who needs it.

One of the chief feminist explanations in the willingness to care is viewed in terms of obligation or a sense of duty and attachment through affection (see Finch and Groves, 1983). Or, as Gillian (1982) pointed out, women may judge themselves according to their capacity to care and if, for whatever reason, they are unable to do so feelings of guilt can often be aroused. Each of these explanations provide insight into some of the powerful influences that determine why women care. To a large degree a greater understanding of why carers are primarily women has been achieved, yet it is difficult to decide which reason(s) holds the more weight. For example, it cannot be assumed entirely that duty and obligation form the foundation of why people care (Finch, 1989). For some feminist authors (Gillian, 1982; Graham, 1983) the idea that caring provides part of the feminine identity, together with a close, usually kin, relationship is probably one of the more deeply rooted deciding factors. However, why women care can vary considerably among individual carers, and be expressed in many different ways, depending on their circumstances.

For some women caring may be a positive experience perhaps in the sense of fulfilling a duty or obligation, the affection or love felt or a combination of the two. Little research has been conducted to identify the positive aspects of the caring role, although it is gaining more attention. Much of the research available in this area has preoccupied itself with many of the negative features caring potentially entails. Clearly, not all women perceive caring as positive. Conflicting demands on women's capacity to care can come from other members of the family (i.e. from husbands as well as the dependant's other relatives). Tensions due to the demands of others and the desire for self-fulfilment might be rife. Indeed, the caring role could become a juggling act between these conflicts and tensions. Invariably they can lead the carer to experience guilt and unhappiness. Land and Rose (1985), and Ungerson (1985) in fact suggested that it is difficult to recognise where love ends and the guilt or compulsory altruism starts. These issues can contribute to the 'cost' of caring, as well as the material losses that carers may forego, which in turn add to the strain of caring. On the other hand, many carers may be glad they care, or that they are able to reach a satisfactory balance between their own wants and the demands of others.

There is an additional factor in which some feminists associate caring to motherhood, which provides perhaps another reason why women become carers. For Ungerson (1983) and Graham, (1979[1]) caring tasks are themselves imbued with sex-role stereotyping, and that many of the tasks of tending are remarkably similar to those of parenting, which is then regarded as motherhood. The convenience of this

---

[1] Cited in Ungerson (1983).

may act paradoxically to exclude men from caring tasks and opens up the issue of gender differences in both caring responsibilities and experiences. This type of exclusion is evident in a study by Wilkin (1979) who found mothers caring for a child with a mental or physical handicap least wanted help with housework and the physical care of children compared to a greater demand for help with child-minding.

The origins of a sexual division of labour in tasks are not altogether clear. For Graham (1983) the difficulty lays in not being able to separate the labour of tending from feelings of love and the ties of obligation inherent in the way women approach caring. Caring for and caring about someone are inextricably connected, at least where women carers are concerned. Incest taboos provide another possible explanation in the gender imbalance of caring and the intimacy of caring for someone of the opposite sex which includes washing, dressing and toileting (Ungerson, 1987). These highly physical caring tasks are not always relevant when caring for someone with mental illness.

There is however, a further need to understand what the caring task involves in relation to looking after a dependant relative. Indeed, there is a difference in the problems encountered when caring for those with a physical disability to those with a mental illness. More importantly, there is a difference in the way carers' perceive and experience the various problems of personal care (Lewis and Meredith, 1988). Each caring process has its own sequence and its own biography. Tasks change over time, usually in response to particular events, social (i.e. the loss of an elderly person's spouse), or physical (i.e. becoming ill and subsequently disabled). These factors, in part, explain the complexity of what caring entails. Undoubtedly, the issue of who assumes the caring responsibility and why this generally falls on the shoulders of women is a complex one, involving not only a series of choices for the individuals concerned, but also made within a context of predetermined gender stereo-types, how women perceive their own identity and role, and the intricate nature of kinship ties and familial obligations. Perhaps the most striking feature in the entire debate is the gender difference in assuming the responsibility to care. By comparison, relatively little has emerged from the caring literature on men as carers, largely because it is now well established that women form the bulk of carers. In many ways this emphasis on female carers has had the undesirable effect of neglecting male carers, and the support they contribute.

2.2.3 Gender Differences in Caring

In an article appropriately titled, 'Men: The Forgotten Carers', Arber and Gilbert (1989) argued how men make a significant contribution to caring, much more so than is thought. In a nationally representative sample of elderly people living at home they found over a third of co-resident carers to be men. They asked, 'Why, then, is there an overwhelming impression that carers are female and silence about the contribution of male carers?' (Arber and Gilbert, 1989, p.113). In their explanation of this they examine the life histories in the relationship between the carer and the person being cared for. The majority of male carers in Arber and Gilbert's study cared for spouse relatives and many of the other male carers, having never left home, looked after an elderly parent. In either situation a strong attachment existed between the carer and the cared for. A similar picture emerges for unmarried daughters who 'fall into' caring for mothers, which is often perceived as a 'natural' stage in their lives (Lewis and Meredith, 1988). The motivation to care according to gender does bear a difference. For women there are several factors associated with why they care, (discussed in section 2.2.2), which are to do with, as some feminists maintain, duty and obligation, and the 'feminine identity'. For men, on the other hand, the primary motivation to care, it is argued, is based on love. Ungerson (1987) in a study of nineteen carers of elderly relatives discussed sex differences in caring, and suggested that the men talked mainly in terms of the 'language of marriage', (i.e. love), as their primary reason for caring. Women, on the other hand, used a 'language of duty'. She then assessed the capacity to care between the sexes and stated:

> Men would be unlikely to care for someone whom they could not legitimately claim to love on an intimate basis, while women would only be unlikely to care for someone who they felt could not make legitimate claims on their time based on kinship (Ungerson, 1987, p.99)

The implication here is that men's capacity to care is limited to those who they love intimately, whereas women's capacity to care is far greater when encompassing kinship relations in their scope for caring. Levin et al (1983) however, in an earlier study, found that carers of either sex having lived with an elderly person for a long period of time were more likely to put love as their foremost reason for caring. The issue of gender differences in caring again throws up an abundance of unanswered questions, and what little research exists on male carers heightens the lack of understanding in recognising the contribution they make to caring. Yet, this does not have to undermine the fact that women play a primary role in caring for dependants.

Until now much of the feminist research in this area has concentrated on carers looking after an elderly dependant or a child with special needs. An article by Scheyett (1990) forcefully explained why women who care for relatives with mental illness are oppressed by this, and echoed many of the points made above. In her review of this literature a variety of parallels can be drawn, notably that carers of relatives with mental illness are primarily women, and often in this situation the burden of caring for a family member with mental illness is not shared equally. In a similar manner women - mothers, sisters and daughters - often manage those with mental illness at home and argued to be 'a natural extension of their culturally appointed nurturing role' (Thurer, 1983, p.1162).[2]

Gender issues in informal care are very important. It is clear that women are far more likely to assume the caring responsibility than men which has much to do with the persistence of traditional gender role stereo-types. As Baines et al (1991) argued, 'while some men take responsibility for caring, their identities and their opportunities are not structured and shaped by the same behavioural norms regarding caring' (p.23). Women thus predominate as carers in various family settings, i.e. as mothers, wives, sisters and daughters. Men, on the other hand, are more commonly carers of spouses, yet the contribution by male carers continues to be relatively underexplored. Little also exists in determining the differences in care according to familial situations, i.e. the care a parent gives to a dependant child, and how this might differ from the support given to a spouse, or even the care children provide for parents or siblings. There remains however, the broader issue of how reasonable is it for social policies to rely on the informal sector to provide care for dependant relatives.

2.2.4 Informal Care and Community Care Policy

Feminist academics have not only been vigorous in explaining why women are likely to adopt the responsibility of caring but also to identify the assumptions underlying community care policies and the reliance on informal care. This particular area tends to focus on the ideologies and rhetoric of community care. It looks too at the desirability of community care and the alternatives they suggest in developing

---

[2] Details of specific caring tasks and the impact mental illness has on carers are reviewed in Chapter 3, section 3.1.

non-sexist forms of care.

Finch and Groves (1980) in their article examined the reality of community care where there is minimal statutory resources, in view of public expenditure cuts and the search for cheaper alternatives to formal services, primary care falls not on the community as a whole but on identifiable groups and individuals and in ways that are not entirely equitable. Here, they introduced a double equation, namely, in practical terms community care equals care by the family which consequently equals care by women. With evidence of the provision of care they demonstrated and examined the utilisation of the key concepts of 'community' and the 'family'. These concepts, and the assumptions underlying them, lead Finch and Groves to form the basis of their argument, that the cultural definition of women as carers persists and will continue to do so. This is an element clearly evident at the service level, as Land (1978) showed. She went on to state, '... men are not expected to look after themselves, as much as women, and they are accordingly given more help from publicly provided support services' (p.277).

For Finch and Groves (1980) the expansion of community care as a policy has failed to distinguish between categories of family and kin, and between different types of family composition. There is a tendency, it is argued, to equate the family with household, assuming that a marriage relationship is the central feature of every family. The issues which are then obscured, in which people count as 'family' are the kinds of obligations attached to certain relationships, how they are endorsed, reinforced and whether they are based on a legal relationship (i.e. marriage). Having identified these issues feminists have subsequently endeavoured to deal with the important issue of whether women will continue to accept their cultural designation as carers or choose to explicitly reject it in ideology and practice. How then can these assumptions inherent in community care policies be dealt with in practice?

Dalley (1983) argued that while it is valid to expose the damage and stigma attached to the worst forms of institutional or residential care, in work like Goffman (1961) and Townsend (1962), 'it is not necessarily valid to counterpoise institutional forms of care with models of community care - not least because they are forms based essentially on the family model of care' (p.76). Finch (1984) rejected categorically community care policies and doubted whether non-sexist forms of care can be developed within the current context, and in essence support the return of residential care. Dalley (1988) favoured new forms of residential 'collective' care, and argued that community care counters the interests of women and the people it is supposed to benefit.

More recent concerns about British community care policies highlighted by feminists pointed to a 'crisis' in informal welfare and how this sector's capacity to care is limited (Graham, 1991). Graham explained how policy has recognised the limited capacity of informal care which may be approaching crisis level, yet Government reports continue to encourage a mixed economy of welfare and have argued for greater pluralism in the provision of care and support. These have now become engendered in legislative form in the NHS and Community Care Act passed in 1990 (see White Paper on 'Caring for People', 1989). With this in mind, Graham then stressed another fundamental problem with these policies. She found that there are a number of groups vulnerable to poverty, such as ethnic minorities and the lower classes, who are likely to find great financial difficulties in caring for adult dependants, and community care policies will act to intensify these problems.

Bridges and Lynam (1993) applied a Marxist analysis of social, political, and economic forces in determining the role of informal carers. Their focus was concerned mainly with the underlying assumptions in nursing practice on carers of the elderly. In their debate of the issues on informal carers and community care policies they raised an important point concerning the restricted choices available to carers by formal services. They argued that:

> ... administrative agencies hold the power to define what choices are available to the elderly disabled and their families, and when definitions place an emphasis on the responsibility of the family, particularly women within the family, to provide care, choices become limited (Bridges and Lynam, 1993, p.42).

Within this context formal services continue to perceive their role in terms of a 'safety net' for carers rather than share the caring responsibility. Invariably, women suffer many of the effects of community care policies, given their likelihood of assuming the responsibility for caring, and their unequal position in the labour market. One solution proposed by feminist writers is that carers be paid a wage, yet even this is observed to be exploitative of women and serves to perpetuate their general subordination (Ungerson, 1990).

It is worth at this stage citing Wenger (1985) who views community care issues from a different perspective. In her work she attempts to move away from the idea that:

> ... women are expected to do the caring because caring is unpaid, unrewarding work and women are available. I suspect it is under-valued because it is done by women rather than the other way round'(Wenger, 1985, p.28).

Putting the feminist position into context is important given there are other issues in the community care debate to be addressed. The approach adopted by many feminist academics can sometimes fall into the trap of combining the worst forms of sexism when they emphasise the burdens of caring and the subsequent exploitation of women. Feminists can also fall prey to devaluing the caring role for those carers who do not find it unrewarding (Wenger, 1985). The solutions suggested by feminists leave virtually no scope for improving the plight of informal carers within the context of community care. This has provoked criticism from those who receive care.

Jenny Morris (1991/1992) challenged the stance feminists have adopted towards community care policies. As a disabled feminist herself, arguing from a user's perspective, she stated firmly:

> Disabled people experience such research [conducted by feminists] as oppressive and alienating. Research which incorporated the subjective reality of disabled people would ask different questions ... (Morris, 1991/1992, p.22).

Morris is aware of the hard work characterising the caring role, the poverty and sometimes isolation caring often entails, but reminded feminists, such as Finch and Dalley, that people with disabilities and the elderly through their own organisational efforts have sought a better quality of life within the community (which does not include residential care), and therefore support, albeit critically, community care policies. It is on this basis that Morris found the feminist solution of residential care disturbing. Morris, furthermore, criticised Ungerson's (1987) work on carers of the elderly for not identifying the interests and experiences of the people being cared for, and points out that while most carers are women so too are the people receiving care, which Ungerson has also failed to incorporate into her analysis.

In sum, feminist theory has been fruitful in identifying women's position in the family to later focus this on community care policy and its reliance on informal care to provide support for dependant adults. Feminists have gone to great lengths in showing precisely the reasons why most carers are women and how they come to assume this responsibility. The persistent focus on 'women centred' issues in community care has at times been overstated. As a consequence this has lead to an almost negligent attitude by feminists towards other important factors, such as: the contribution male carers make; the benefit derived from caring by the carers themselves (the reciprocal relationship); and, the subjective experience of the dependant adults who may not wish to be cared for in a residential setting and be able to exercise their right to live in the community, in their own homes.

In Italy, the response to the 1978 Mental Health Reform (Law 180), in advocating the closure of mental hospitals, broadly fits some of the responses in Britain, yet the debate on the Reform and the implications for the family has been qualitatively different. For example, there has not been an outcry by feminists in Italy on the issue of community care following the reform. Instead, a number of family organisations have emerged to voice their concerns in assuming the caring responsibility for a member with mental illness. Recognising the contribution made by families in the care of the mentally ill in Italy has taken some time to be acknowledged. This is evident not only in the sparse research literature concerning this particular issue, but also at the service level. Before embarking on the response of families to the 1978 reform however, it is necessary to put into context the family in Italy and the development of social policies after the second world war. In doing this one can trace the changing structure of the family and the position of women within it, which also includes the way in which the State and the Church perceive both, and the sorts of issues Italian feminists have campaigned for. As will be shown these developments in Italy followed much the same pattern as the British context except in terms of the timing of certain social policies.

2.3 The Family, Women and Social Policy in Italy

In providing a model of Italian family life and the power it holds Barzini (1964) flagrantly depicted the importance or centrality of women in the family. By doing so Barzini confirmed, quite inaccurately, many of the notorious stereo-typical images about the Italian family. The concept of the matriarch, for example, particularly in the Southern in Italian families, has been reinforced by ethnographers of the South by perceiving the woman's role as essentially indistinguishable from that of the family's well being (Cornelisen, 1976). A concept that has been dismissed as superficial given that any power women had in the family, until recently, stemed from masculine authority (Berkowitz, 1984). The idea too that many Italian families are predominantly extended, (consisting of three generations: grandparents, parents and children) has also become a thing of the past. In demographic terms, as Golini (1988) showed, the Italian family has undergone a series of evolutionary developments since the second world war, resulting in a sharp decline in extended families. In 1951, one in every four families was of this type. Thirty years later in 1981, only one in nine families was extended. The central family system has largely been based on the nuclear family structure, (families consisting of parents and children), and made up 53% of the total number of families in Italy in 1981. Even this family structure is now declining with the advent of a vast reduction in the number of marriages taking place and the number of people living alone (Gollini, 1988).

The Catholic Church's perception of the family and the role of women after the second world war again stressed commonplace stereotypes and the differences between the sexes. The Church emphasised issues relating to motherhood and essential family functions, relations between the sexes and the idea of the body, the role of marriage and virginity, and the repression of sexual desire. Discussion of these matters, particularly on the family and the role of women, formed part of the Church's overall political orientation. The influence of the Church over issues such as these had begun to decline. In the late 1960's and early 1970's Italy experienced a great Cultural Revolution affecting nearly all sectors of Italian society. Just over a third of the Italian population went to mass on a weekly basis and just over half declared their indifference to religion (Wertman, 1982, cited in Clark, 1984). Religious practice was no longer a 'social habit'. Instead, it became a minority sub-culture and a matter of private belief. Given many church goers were women the process of 'secularisation' had its biggest impact on them. Women's views during this period were changing. The growing political and ideological awareness triggered a number of important changes[3]. This growing awareness led to the creation of a myriad of interest groups and various collectives beginning around the late 1960's, and one of the leading campaigners for change included the women's movement. The movement's association with the Italian Communist Party, despite some conflicts, enabled women's demands to gain attention at a political level, much like Psichiatria Democratica in promoting their activities for the mentally ill. The 1970's proved fertile in producing a set of social and legal reforms relevant to gender relationships and conditions, uprooting many of the existing laws formed during the fascist period.

In December 1970 Italy had its first Divorce Law. An event that horrifyed many Catholics and despite an attempt to repeal the divorce law, in a Catholic-sponsored referendum in 1972, it survived intact. In 1975 a new family law was passed which gave equal rights to husband and wives and changed the rights of children and duties of parents. Four years prior to this a law was passed improving and extending to all mothers paid maternity leave. There was also the setting up of free public family planning clinics and in 1977 a law approved sexual equality in the work place. Each legal reform concerning divorce and family law and the movement towards these had

---

[3] Including mental health reform, see Chapter 1.

their origins in politics which sought, not only to lessen formal discrimination against women but was also concerned with the implications they had for a modern society still operating with outdated provisions (Caldwell, 1991). Changes in family law and the introduction of divorce highlighted the extensive debates concerning the family and its centrality, both inside and outside parliament. The focal point in the Italian debates concerned the split between the type of existing families and what had been legally prescribed for them. The laws relating to the family and gender issues were partly an attempt to minimise this divergence and bring up to date State provisions for the relevant groups. Abortion on demand however, represented the remaining major issue for Italian feminists. The campaign for abortion, fertility control and reproductive freedom provoked much anger and indignation and centred on a woman's right to control her own body. Moves towards legislating abortion stirred a great deal of controversy for Catholic fundamentalists, much more than that prompted by the divorce law. The abortion law (no. 194) was finally passed in 1978 and allowed free abortion up to a ninety day period within State facilities for women over the age of eighteen.

Family laws, the attempt to formalise the equality between men and women in the work place, and the introduction of the divorce and abortion laws came at a time when Italy was undergoing fundamental changes. But some feminists, like Saraceno (1984) for example, doubted how many of these reforms could alter the ingrained nature of the sex/gender system. She argued that many of them are imbued with ambiguities and serious shortcomings simply because no single law can even pretend to be able to do this, particularly when they themselves are not always gender-neutral. In her article Saraceno also indicated, when discussing the emergence of some reforms during the 1970's, that the movements behind them actually relied on the gender division of labour, and the campaign to instigate law 180 represented a prime example of this. She stated that:

> the antipsychiatric movement and the reform to which it contributed gave back to the family (that is, to women) the responsibility for the mentally ill: the "humanization" of hospital care permitted and demanded that the family (again women) assist their relatives ... (Saraceno, 1984, p.10).

2.3.1 Law 180 and the Family

At nearly every stage of Italy's 1978 reform little consideration had been given to the fact that families of relatives with mental illness would probably conduct most of the caring and this has continued even up until the present time. In the available literature no study has endeavoured to examine the impact on the family caring for a relative with mental illness following the 1978 reform, and neither have Italian feminists pursued these issues and their implications for women in quite the same way as their British counterparts. Families of the mentally ill thus have been considerably overlooked in the mass of outcome studies and descriptions detailing the post reform era outlined in Chapter 1. This is surprising when, for example, one considers an area with an extensive community psychiatric service such as South Verona, some 83% of users are estimated to be living with families (Mosher and Burti, 1989). The reliance on families to provide much of the care and support is therefore considerable.

In evaluative studies of regional areas considered to have successfully applied the reform little, if any, mention is made of families. In one of a number of special journal issues assessing the reform's outcome (International Journal of Mental Health, Vol 14, 1985), Soccorsi writes about the impact of Law 180 on the family in terms of their therapeutic potential. Family therapy is widely used in the treatment of psychosis in Italy and the family of the mentally ill thus have been investigated mainly from an aetiological perspective or within a particular treatment model (Giannichedda, 1989). It is partly for this reason that the family has received so little attention in terms of the care they provide for the mentally ill.

At the one end of the scale, there are only anecdotal estimates about the increase of family stress with the closure of mental hospitals (see Jones, 1988, p.62). For the most part, little too is known about how families are supported by formal community psychiatric services in which only fleeting references are made concerning this issue (see Zimmerman-Tansella et al, 1985, p.85). More recently, however, Mezzina et al (1992) described the group work conducted with heavily-burdened families in Trieste. Here families are seen as the interlocutors of the service as well as a therapeutic resource. The service has formed a group with these families to relay information on adequate coping strategies including psychoeducation and mutual support. Hence, the community service at Trieste provides families with a forum in which they can vent the problems or difficulties they face in caring for a mentally ill relative, and a means of learning to cope more effectively. These type of family groups are still uncommon in community psychiatric services in Italy.

A more detailed discussion of families and relatives with mental illness in Italy is provided in Giannichedda's (1989) paper which addressed the close association between institutional transformation in mental health within the family's own structural changes and the care of dependants. She described the emergence of family associations following the 1978 reform and how each requests a number of changes to existing mental health services. In doing so, Giannichedda listed the main themes each family organisation requests which highlighted not only the problems families face but questioned the responsibility of care handed to them by the State. Other countries with similar policies of deinstitutionalisation have also witnessed an emergence of family organisations, such as the in the US (Bernheim, 1987), in Britain (the National Schizophrenia Fellowship), and in Spain (the Ferderación estal de asociaciones de familiares de enfermos psiquicos, FEAFES).

Many of the organisations in Italy, created in the early 1980's, originated from central and northern regions, which unlike the South have much less institutional based care. Their plight therefore is levelled at the extent of services which have been reformed or in the process of being so, and express both their own needs and the needs of their mentally ill relatives. Many of the members are women, either mothers or sisters of the mentally ill, who are largely employed outside the home. The Associations themselves fall under two main national networks: the Coordinamento Nazionale Salute Mentale - Associazioni di Familari, Utenti e Cittadini (Coordinating Committee for Mental Health - Associations of Families, Users and Citizens); and the Difesa Ammalati Psichici Gravi, DIAPSIGRA (Defence Committee for Patients with Severe Mental Disorders). An additional third group, smaller than the associations listed above, is the Association for the Reform of Psychiatric Care (Associazione per la riforma dell'assistenza psichiatrica, ARAP). The groups differ in their objectives. The Coordinamento condemn the lack of implementation seeking to create network alliances to oversee that the services are established according to law 180. DIAPSIGRA's activities are aimed at local and regional levels to denounce individual cases of abandonments, criticise regional policies, demand new services and so forth. Their current priority is not concerned with the revision of law 180, but the implementation of local treatment services and facilities for long-term care. ARAP, on the other hand, is committed to changing the existing legislation by seeking its consensus from political and media arenas.

Giannichedda (1989) outlined three aspects of what the family organisations propose. The first involves the critical issue of the 'impact of care'[4]. Families of these organisations ask for the relief of some burden where in some areas existing out-patient clinics offering psychotherapeutic and pharmacological inventions are not enough to provide support for them. Cutbacks in crisis intervention services have also presented a shortfall in meeting the needs of both patients and their families, which subsequently exacerbates the caring impact. The most common request therefore, is a community service open 24 hours a day to provide support and assistance for the mentally ill. The two family networks differ in their demands where inpatient facilities are concerned. The Coordinamento seeks that beds be made available in CSMs and residential homes. The DIAPSIGRA however, suggested small or medium-sized wards to be made available for severe and long-term care as a means of guaranteeing a more consistent provision of care.

The second theme family associations contend is the detrimental attitude mental health professionals have towards families in which they are viewed as being 'sick' or at fault in some way for the patient's mental illness. The effects of such an attitude mean that families are often dealt with in a rejective manner or that staff fail to realise the disruption mental illness has on the daily routine of families' lives and the distress it causes. ARAP, for example, have gone so far to exert that only a decisive acknowledgement of the biological bases of schizophrenia can withdraw the 'blaming' stance professionals have towards families and the resulting guilt families experience.

The third theme demands that services take on the responsibility for the mentally ill or share care with the family. Families have rejected too the passive role of caring for mentally ill members. It is not simply that families demand more

---

[4] This is reviewed in greater detail in Chapter 3.

information, rather they wish to play a more active role in the decisions professionals make.[5] The suggestion of family committees overseeing the work carried out by mental health services has been forwarded. In the initial years following the reform family associations drew into debate the conflict of where the rights of patients not to be confined clashed with rights of families to then have to assume the responsibility for their care. Rossetti (1987), in a chapter on the family before and after law 180, highlighted the divergent positions held by family associations in view of this conflict exemplified in the quote 'normality for us without confinement for them' by the Coordinamento (cited in Giannichedda, 1989, p.65). In other words, families belonging to these associations have recognised the legitimacy of their own rights and the rights of others, rejecting the responsibility impinged upon them, and have identified their needs and demand for empowerment.

The 'provision of care' by the family in the post reform era and the issues subsequently voiced by family associations reveal a number of similarities with the British context and the literature on informal care. The most obvious is that families have become the major providers of care following the 1978 reform. Judging also from the members of the Italian family associations it seems safe to assume that many carers of relatives with mental illness are likely to be women. The feminist literature in Britain covering informal care and the implications for women can be incorporated in an almost identical way, although there is virtually no analysis of informal carers of the mentally ill by Italian feminists. The difficulty in attempting such an exercise overlooks the probable cultural differences in caring between the two countries. One therefore needs to be wary of equating directly the experiences of community mental health care in each country. In broad terms both countries have recognised the burden

---

[5] Chapter 3 also reviews this issue.

of care on members, the frugal support for families by formal services, the absence or minimal provision of community services, and so forth. In qualitative terms there may well be differences. The 'ideological stronghold' underpinning the reform, for example, differs from the rhetoric of community care policies in Britain which some have argued has more to do with savings in public expenditure on services and harnessing the hidden resources of informal care (see Finch and Groves in section 2.2.4). The solutions called for to the problems encountered with community mental health care in Italy appear to differ in each context. The two main family associations have not called for a return of institutional care or a repeal of law 180. These demands are limited to a minority of families. The majority of families request more services in the community.

One approach within the reform movement, in an area with well developed community services like Trieste, has sought to overcome the reliance on families to provide the bulk of care by instituting a particular model of community care. The service designates itself the main 'care-giver' by offering both full-time, day and night care facilities, and out-patient visits. It relies however, on a network of agencies, both public and private to act as the 'middle ground' between the service and society. There is also a reliance on voluntary support to provide some care, and this, of course, raises yet another set of problems as to whether the State will eventually absolve itself of its responsibilities (Ascoli, 1987). This system too however, would still require families to provide a certain level of support, but this time the caring responsibility is shared amongst various agencies. In Italy and Britain, the choice between community care and the reintroduction of residential care - argued by feminists as necessary in order to move away from the reliance and 'exploitation' of informal carers, essentially women - is a difficult one to make. Returning to institutional care however, is unlikely to occur for any of a number of reasons, whether economic, political and social. For those suffering mental illness who prefer to be in the community, and for the relatives who wish the same, the solutions suggested by feminists represent a step backwards. It may well be thus more useful to develop community services so that families (and women) are not simply burdened with the care of their mentally ill relatives, and instead share the responsibility.

2.4 Overall Summary

British feminists have made a significant contribution in identifying the degree to which families, primarily women, have been affected by community care policies. Much of the feminist theories developed on the issue of informal care are also relevant to Italy's experience of community mental health care. Italian feminists in their analyses of the development of social policies and the implications for women however, have only hinted at the reform's impact on women providing care. Research studies or other analyses of the impact of the Italian 1978 reform on the family are scarce. This is surprising given the magnitude of its importance. Family associations in Italy appear to have instead done much of the work to illustrate the plight of families. One of the themes family organisations in many countries implementing deinstitutionalisation policies focus on is the 'burden of care' itself. In Britain again an abundance of research literature can be found which shows the type of impact on relatives caring for someone with mental illness. The following chapter reviews the impact literature, much of it more technical rather than theoretical, and overlaps into the domains of clinical psychology and psychiatry.

Chapter Three

The Impact of Care: Relatives Caring for Someone Diagnosed with Mental Illness

Caring for someone diagnosed with mental illness is rarely found in the informal care literature reviewed in Chapter 2. The 'impact of care' literature - more commonly known as the 'burden of care' or 'family burden' - originates mostly from psychological or psychiatric sources. The literature on caring for a relative with mental illness developed separately from the research on informal care of the elderly or people with physical or mental handicap. By comparison, the work on 'impact' has tended to minimise the plight of carers to concentrate on the patient's well-being. There is thus a need to identify not only the position of carers, but to also understand what the caring process actually entails for the carer looking after someone with mental illness. As a preliminary introduction, there are at least three ways in which caring for a person with mental illness differs from physically demanding tending. Firstly, compared with carers looking after dependants with more physically restricting disabilities (the elderly, etc), caring for a person with mental illness tends to involve more responsibility rather than providing personal care. Secondly, with mental illness the degree of practical help and the assumption of responsibility fluctuates with the course of the illness. There may be periods where family life can be resumed normally and disturbances may only occur during episodes of illness or during a crisis. Thirdly, due to the onset of mental illness, typically occurring during adolescence or adulthood, the relationship between the dependant and the carer is different in nature from those caring for dependants who may have had their disabilities since birth.

The concept of 'family burden' or use of the term 'burden' to describe what caring for a relative with mental illness involves, has been criticised for both its negative and restrictive implications (Creer, Sturt and Wykes, 1982; Perring et al, 1990). These authors suggested more neutral terms such as 'support' or 'impact' to widen the scope of relatives' experience, to focus less on the negative aspects of caring, to include the positive features of the relative/patient relationship. It is for this reason the present study adopted the term 'impact' to describe the effects of caring for a relative diagnosed with mental illness.

This chapter reviews the research on what caring for a person with mental illness involves, including the tasks of caring and the areas of the carer's life which are affected. Differences in the 'impact of care' among various groups, in terms of kinship, gender, age of carer, and the patient's psychiatric diagnosis/status are then explored. There are several factors that can alleviate some of the more tense aspects of caring for patient's relatives, which are also considered. The limitations of burden studies are described, followed by the potentially harmful premises underlying theories of family therapy and 'expressed emotion' in terms of the practical implications of relatives caring for patient members. The relationship between carers and formal services is often fraught with difficulties and most times relatives' own needs tend to be overlooked in client-centred services. Carers needs therefore, are examined with reference to the current 'impact' literature.

3.1. Caring Tasks, Coping with Behaviour, and Adopting New Responsibilities

The literature in this area, in identifying what sorts of caring tasks are involved in looking after someone with mental illness, is relatively sparse. Perring et al (1990), in a review re-examining the impact of care literature, grouped caring tasks into three main categories: practical tasks, coping with difficult behaviour and new responsibilities. Help with practical tasks, such as washing and dressing for example, is not always a primary feature in caring for someone with mental illness. Help was needed in areas concerning household chores and financial affairs, assistance with medication, and 'caring attention' with socially difficult aspects relating to the patient's behaviour (Creer et al, 1982).

In most cases coping with difficult behaviours present the bulk of problems for carers. Most studies have tended not to describe what some patient behaviours mean to carers, but instead have identified groups of behaviour, classified in terms of 'withdrawal' or 'florid symptoms' (Perring et al, 1990). Social withdrawal, for example, can severely constrain the carer's own life, where the patient no longer feels confident enough to pursue a social life outside the home and the carer is unable to leave his or her relative alone, which then leads to a decrease in communication. Other types of behaviour include neglect of appearance and lack of basic hygiene; uncontrollable restlessness or excessive activity which can cause tension with both the family and neighbours; the patient may have strong beliefs or certain strange ideas that can also create difficulties (i.e. where the patient may believe he or she is slowly being poisoned). Relatives have found negative symptoms such as 'quiet misery' and social withdrawal more difficult to deal with than symptoms of a more florid nature as with schizophrenia (Creer and Wing, 1974).

Relatives sometimes have difficulty in distinguishing between what behaviour is attributable to the dependant relative's character or is a part of the mental illness (Fadden et al, 1987a). Occasionally relatives have interpreted social withdrawal and 'quiet misery' as the patient being selfish or lazy (Vaughn, 1977). This has often left carers uncertain about how they should react to these behaviours, whether to encourage relatives to socialise or allow them to remain withdrawn. Relatives too, have felt frustrated and baffled by bizarre behaviour in which they have tried to be sympathetic but would find such behaviours embarrassing in public.

When symptoms are present, dependant relatives are sometimes unable to maintain their own personal care, financial and household responsibilities and personal relationships. Carers, often a spouse, may find themselves having to adopt a new role, perhaps having to make decisions about finances or even becoming the main breadwinner. A carer of an adult child, diagnosed mentally ill, will confront a different situation whereby the adult child may revert to the sort of dependency of when she/he was a child. How carers experience these changes can differ according to their kinship, gender and age.[1]

The adoption of new responsibilities in the family largely concerns carers of spouses. Fadden et al (1987b) in a study of 24 carers of depressed spouses examined these sorts of changes in familial responsibility. They found that spouse carers not only had to take on more of the household responsibilities but also had to deal with the loss of a confiding relationship. This feeling has been associated with a sense of loss or bereavement carers experience when the change in a family member's behaviour is so marked it gave relatives the impression they were living with someone else (Creer, 1975). A shift in responsibility (often without warning), a change in the family role (sometimes long-term or permanent), and the sense of loss in the person the carer once knew are factors that fall upon one person, usually a spouse carer.

The type of tasks carers of relatives with mental illness perform are thus much less physically demanding. Instead, carers may find themselves having to cope with challenging, sometimes distressing behaviour. If carers are spouses they may well

---

[1] See section 3.3 below.

have to adopt new domestic and familial responsibilities and assume a different role in the family. These three points of impact distinguish between the care given to someone with mental illness and that given to an elderly dependant or a child with special needs. What then have researchers identified as impact on relatives caring for someone with mental illness?

3.2 Impact on Family Life

Early assessments of impact (burden) estimated the effect the patient had on family life in terms of work, leisure, income, health of the children and on family relations with neighbours. The type of care provided and the ability of the family to provide care for the patient was also examined in these early studies. Other data gathered recorded abnormalities of behaviour that proved troublesome to families (Grad and Sainsbury, 1963; 1968).

In the late 1960's studies by Hoenig and Hamilton made a major advance in the definition of burden by distinguishing between objective and subjective factors. 'Objective burden' was the concrete factors seen to disrupt family life as a result of the patient's condition (Hoenig, 1968). These were further subdivided according to the specific effects on the family household and the health of other family members including children, and on the family routine; and, the occurrence of abnormal behaviour in the patient which was likely to cause distress. 'Subjective burden' referred to the subjective experience or psychological/emotional impact, (i.e. feeling worried or strained) when caring for someone with mental illness (Hoenig and Hamilton, 1967).

The research on impact has subsequently focused on areas such as employment activities, financial circumstances, social and leisure activities, household routine, personal relationships, emotional impact (or subjective burden), and physical and psychological health of the carer. These, in turn will be reviewed briefly according to some of the findings highlighting the specific effects or changes carers encounter when they begin looking after someone with mental illness.

3.2.1 Financial and Employment Difficulties

Financial hardship for carers can be a formidable problem as a number of studies have found (Thompson and Doll, 1982; Gibbons et al, 1984; Fadden et al, 1987b). Determining patterns of financial consequences can be complex and vary with household composition (Glendinning, 1989). Difficulties relating to financial and employment circumstances are more likely to occur if the patient is married, the main breadwinner and unable to continue in paid employment (Fadden et al, 1987b). MacCarthy (1988) also pointed out how the time of onset of illness also plays a part in the impact made in these areas when she said:

> early onset might be expected to cause more economic burden because the illness has greater power to interfere with long-term earning power, in practice, higher levels of pre-morbid functioning seem to be associated with greater burden (MacCarthy, 1988, p.217).

Parents, on the other hand, who have continuously supported their child find the impact of the child's mental illness relatively easier to adapt to materially. However, onset of illness in later life can create economic problems where there may debts to settle or possessions to deal with which often create conflict and distress for carers of older patient relatives (MacCarthy, 1988).

Impact on carers' employment in some studies appeared less evident. In others, this impact appeared more notable. Fadden et al (1987b), for example, found few carers making changes to their work routine, although half of those relatives interviewed reported work to be a strain. Only two women in the sample of 24 spouse carers had assumed full-time work for reasons of finance. Johnstone et al (1984), however, found that almost half of the relatives in their study had to either give up work or take time off to care for the patient member. Relatives who care on a long-term basis and continued to hold down jobs could often negotiate flexible arrangements with employers, to the extent that taking time-off did not necessarily lead to a loss of income, although it limited their chances for promotion or the opportunity to gain more interesting work (MacCarthy, 1988). Drawing any firm conclusions about the impact on carers' financial and employment activities can be difficult but it does seem that spouse carers are more likely to be affected.

3.2.2 Social Activities and Interpersonal Life

A more consistent finding in the impact literature is the restriction and/or disruption of the carers social life. Of the few studies in this area using a control group, McCreadie et al (1987), found a marked difference in social and leisure activities between relatives with a patient member and the community sample. Fadden et al (1987b) found that the relatives in her study suffered considerably in terms of a reduction in social activities. Social isolation is another a prominent feature for carers of relatives with long-term psychological distress and very often leads to limited social contacts (Anderson et al, 1986). In some cases social isolation might help relatives maintain their supportive role and may not be stressful. In other cases the restriction on social activities, and any subsequent social isolation, can be particulary stressful for carers. This type of isolation often, as MacCarthy (1988) described, 'impairs the relationship between patient and supporter, and reduces coping resources more fundamentally than material hardship' (p.217).

3.2.3 Emotional Impact or Subjective Burden

Investigators in this area have attempted to examine relatives' emotional responses to the various aspects of their situation. This is generally known as 'subjective burden'. Studies have mostly sought to recognise the more negative parts of relatives' situation and how they respond emotionally. Amongst the negative emotional responses by carers are feelings of marginalisation, fear of the patient, resentment, anger and shame have been found (Kreisman and Joy, 1974). The sense of being overloaded (i.e. a noticeable emotional drain or interference to the family) and of being trapped has also been identified (Thompson and Doll, 1982). Some of the more positive emotional responses relate to the warmth and love towards the dependant relative (Namyslowska, 1986).

Studies have used measures of satisfaction, resignation and dissatisfaction to assess subjective impact on carers. Resignation appears to be a more common response by carers which acts to alleviate subjective distress, and it suggested that carers may learn to deal with their situation by being resigned (Gibbons et al, 1984). Other sorts of distressing emotions include fears for the future, a current situation that was unlikely to change and prove frustrating, the loss of the schizophrenic relative's 'former self' and the feeling of having failed as a parent (Creer, 1975). Carers' subjective responses are thus an important determinant of how they deal with their situation and how it might affect their physical and psychological well-being.

3.2.4 Physical and Psychological Health

Determining the effects of caring on a supporter's physical health is difficult to ascertain given there are many other variables likely to affect health. As Parker (1990) pointed out physical health problems increase primarily because of age. Parents thus caring for mentally ill relatives are likely to be of an age where they may be susceptible to health problems. Other factors affecting health include class, race and gender, although this has not been examined in this particular literature in any great detail (Perring et al, 1990).

The effects on psychological or psychiatric health, on the other hand, have been easier to associate with the carer's situation, and certainly a more consistent finding in the literature. Noh and Turner (1987) looked at the relationship between objective and subjective burden and the psychological distress of carers of relatives with schizophrenia. They found that carers unable to 'master' their situation well experienced chronic strain, or family burden, which in turn was linked to their distress. They also found a relationship between the carer's distress and the length of time the patient lived at home since their discharge from hospital. The longer the carer lived with the schizophrenic relative the greater the risk of increasing distress levels among them. Gibbons et al's (1984) drew similar conclusions when they found that where relatives who had been living with a patient for less than a year were likely to show higher levels of emotional distress. In some cases the impact on relatives psychological health can be serious enough to warrant clinical attention (Creer et al, 1982; Fadden et al, 1987a).

The initial stages of caring for a relative with mental illness or carers with a shorter caring history also show significant levels of distress (Gilhooly, 1984) and could be related to the fact that they had relatively little time to adjust to their situation. Most studies in this area have samples of families who, to whatever extent, cope with their circumstances, whereas families who do not survive break up. Little thus is known about carers who are unable to deal with their situation and subsequently put an end to their caring role (MacCarthy, 1988). In pursuing this theme, Parker (1990), highlighted a potential pitfall. He maintained that once relatives adapt to their caring role it is not then considered particularly stressful for them. Subsequent deterioration in their health due to caring over a long period may be then overlooked. Parker added that families who cope with their situation and remain intact do so precisely because they become accustomed to such distressing circumstances, but at the expense of the carer experiencing above average levels of psychological distress.

Summary

Assessments of both objective and subjective impact on carers play significant parts in identifying some of the effects encountered. How the impact of care takes shape for carers, or who might experience more difficulties, can vary depending on certain socio-demographic factors, which are explored in the following section.

3.3 Differences in the Impact of Care

Socio-demographic characteristics such as kin relationship, gender and age of the carer represent the sorts of factors that determine some of the differences in the impact of care. Different patient diagnoses or differences in the patient's psychiatric status can also create varying degrees of caring impact. Each of these factors are examined in the following section.

3.3.1 Kinship Relations

The effect of kinship has not been fully explored in the carer literature. Parker (1989) did however acknowledge some of the differences in impact between spouse and parent carers. In the main however, studies that have looked at the association between kinship and level of strain for the carer have not found any association between the two (Thompson and Doll, 1982; Gibbons et al, 1984; McCreadie et al, 1987). These studies have however, reported a variation in the concern shown according to the type of kin relationship. As expected, parents tended to express their concern in terms of their children's future care, and spouses expressed their distress in terms of their changing marital role. There is therefore, little in the literature that explores, in any detailed way, differential impact of care where kinship is concerned. Perring et al (1990) attributed this to the insensitivity of the measures used to identify strains according to kinship, and it is still difficult to ascertain whether spouses are more affected by their caring roles than parents of patients.

3.3.2 Gender Differences

Few studies in the literature have looked specifically at differences in impact according to the carer's gender, and this is important given women are more likely to experience greater impact. Work focusing on this issue has not revealed any consistent findings. Barusch et al (1989), in a study of 131 older spouse caregivers, found that women experienced greater subjective burden than did men. Conversely, Gilhooly (1984) examined gender differences and the level of morale associated with caring for relatives with dementia. She reported males as having far more morale compared to women in the sample. Gilhooly provided three possible explanations for this. Firstly, that men in the sample appeared less emotionally involved with their dependants. Secondly, that males had less qualms about leaving the house and the dependant unattended and were subsequently less socially isolated. Finally, she suggested that males who are generally satisfied with life are less likely to admit distress.

In terms of the more objective features of caring impact, other studies have assessed the extent of disruption in the family according to the caregivers gender. In spouse relationships, where wives were the carers there appeared to be higher levels of family disruption (Mandlebrote and Folkard, 1961; Fadden et al, 1987b). Rogler and Hollingshead (1965) showed the reverse: where they found greater disruption of family organisation when the husband was caring for his wife. Adoption of a new role in the family by spouse carer, where a wife may take on responsibility as the main breadwinner, represents one potential difficulty as gender roles are exchanged.

Variation in impact according to the carer's sex is a relatively under explored theme in the literature compared to the informal care literature reviewed in Chapter 2. The few studies that have looked at this issue point to female carers of someone with mental illness enduring more hardship, but again knowledge about male carers in this area is sparse.

3.3.3. Age Differences and Caring

How the impact of care varies according to the carergiver's age has become a matter of concern in the literature where single adult patients are dependent upon ageing parents. Again, the findings are contradictory. Some studies have identified some of the difficulties ageing carers in particular encounter. Lefley (1987), for example, illustrated the substantial distress elderly carers felt when thinking about who will care for their child when they are gone. There are studies maintaining that the continual strain of caring for a person with mental illness is cumulative over time (Kreisman and Joy, 1974; Goldman, 1982; Gubman and Tessler, 1987). This suggests that elderly carers might well be more distressed than their younger counterparts. Another difficulty for ageing parents in this situation, as Greenley (1979) noted, concerned the time spent outside the home working or otherwise, guards against the anxiety patient behaviour may induce in relatives. Ageing parents however, have no career activities that can act as a buffer in moderating the stress reaction to difficult behaviour.

In contrast to this, other studies such as those by Thompson and Doll (1982) and Gibbons et al (1984) found no association between ageing and the impact of care. This contradicts what might be safely assumed that caring for a relative diagnosed with mental illness can become difficult with age when certain limitations begin to set in. Age specific investigations in this area probably highlight the limitations. Perring et al (1990) explain this succinctly when they state:

> The findings on age may more usefully contribute towards an understanding of those aspects of the caring situation that are most salient at a particular stage of family history, rather than demonstrating that the role of caring is more stressful for older than for younger carers. It is clear that the diverse situations of carers present diverse difficulties (Perring et al, 1990, p.25).

Again, there is little that can be decisively concluded from this literature on aged caregivers and impact. More decisive evidence to show differences in impact is related to the patient's psychiatric status.

3.3.4 Patient Psychiatric Status and Differential Impact of Care

Findings on the clinical status of the dependant and its relationship to the carer situation perhaps provides the strongest evidence so far on the causes of family distress. Gibbons et al (1984) found that relatives were notably distressed in the presence of disturbed behaviour if the onset of illness was quite recent. Disturbed behaviour in dependant relatives, according to Platt and Hirsch (1981), caused more distress to the family than disruption to household affairs or the patient's social performance. When patients exhibited clinical symptoms Thompson and Doll (1982) found carers to be significantly and consistently upset, and even where patients did not display clinical symptoms carers continued to be distressed by their situation.

In Fadden et al's (1987b) study relatives found negative symptoms such as worrying, irritability and nagging, apathy and withdrawal the most troubling. This the authors explained was due to relatives not perceiving these behaviours as part of the patient's depressive illness. Florid behaviour such as strange ideas, hallucinations and overactivity were relatively easier for relatives to deal with emotionally. Yet, the authors note, at the time of interview these carers were not confronting florid symptoms, although relatives undoubtedly found them upsetting when they did occur.

Summary

Differences in impact of care described so far can be determined by factors such as the carer's kinship, gender, age, as well as the patient's psychiatric status and display of symptoms. Much of the literature covering these issues tends to be lacking and there is still a need for more clarity concerning how impact varies depending on certain characteristics of both the carer and the person being cared for. Much of the focus of existing impact studies has tended to be towards the more negative features of caring for someone with mental illness. There are however, some factors that buffer or relieve carers from some of the negative effects of caring and in many ways contribute to some of the positive aspects.

3.4 Factors Alleviating Burden

Negative aspects of the impact of care can, to some extent, be alleviated or moderated by certain factors. The way in which a carer copes with their situation is one example. Another is the carer's social support network whilst providing care. Each is important, together with the characteristics mentioned above, in assessing how impact on a carer ultimately takes shape. Coping responses are particularly important and could be a key factor in whether a carer is able to continue supporting a dependant relative.

3.4.1 Coping Responses

Much has been written on what coping entails. One definition by Pearlin and Schooler (1978) described coping as:

> behaviour that protects people from being psychologically harmed by problematic social experience, a behaviour that importantly mediates the impact that societies have on their members (Pearlin and Schooler, 1978, p.2).

And, Titterton (1989) in his outline of coping stated:

> All coping behaviour can be considered as involving efforts to a) change and alleviate a difficult situation; b) alter and reduce the perceived threats of the situation; or c) manage the symptoms of stress arising out of the situation (Titterton, 1989, p.17).

Some authors distinguish between 'problem-focused' and 'emotion-focused' coping. The first type included coping that tries to change or eliminate the cause of stress through one's own efforts. The second type included behavioural or cognitive approaches in dealing with the emotional consequences that stress (or a stressful situation) provokes (Pearlin and Schooler, 1978; Folkman and Lazarus, 1980). Other authors have distinguished between 'coping resources' and 'coping styles'.

The difficulty in searching for an all encompassing, satisfactory definition of coping is difficult to achieve. Many coping studies have used normal populations in their analyses and therefore provide relatively non-specific details about coping with a relative diagnosed mentally ill (Perring et al, 1990). Resignation, noted earlier, is a common way of alleviating distress identified in the caring literature. Gibbons et al

(1984) suggested that 'supporters may become progressively more resigned or detached as they learn their roles by trial and error and become more skilled' (p.77). Inevitably, relatives who find they cannot adopt a resigned attitude or find alternative ways of decreasing their distress as a consequence of behaviour problems or continuous and increasing adversity eventually come to separate from their dependant (Gilleard, 1987). Relatives also use other strategies to cope with their situation and some are unable to. Fadden et al (1987b) found spouse carers using mostly cognitive coping strategies. For instance, 92% of their sample of 24 relative 'wished the situation would go away' or 'looked for the silver lining' in 58% of cases. Forty-five percent of these supporters reported they had no practical way of dealing with the patient's mood disturbance and the resulting effects it had on their lives. Half of this sample were spurred on by the thought that the patient would be 'cured' at some point, with 29% feeling this would be any day now. A third of the sample felt they could not cope and needed to find a way out.

What remains unclear however, is how some carers manage to cope with their circumstances and some find it comparatively more difficult. Several factors could well be involved such as age, sex and socio-economic status/class, as Titterton (1989) suggests. One method of coping with the stress of caring concerns carers' social support networks.

3.4.2 Social Support Networks

The assumption in early studies claimed that adequate levels of social support could help prevent ill health as a consequence of stress. This became known as the 'buffer theory' where social support acts as a shield between stress and possible illness (Alloway and Bebbington, 1987). The subsequent association between social support and psychological health was a taken for granted idea in the literature (Paynes and Jones, 1987). It does however bear relevance to the impact of care, both for carers and patients. As reviewed earlier[2], a mentally ill relative may socially isolate families from the rest of the community (Creer and Wing, 1974; Sommer and Osmond, 1984). This form of isolation for some carers is often an unpleasant experience, and Crotty and Kulys (1986) showed that better levels of social support also changed the degree of burden families carry. Their study also found that a carer having a confiding relationship with the person diagnosed with schizophrenia proved equally alleviating. Social support thus appears to be an important factor in relieving some of the more burdensome aspects of caring for someone with mental illness.

Summary

Carers' coping responses and the degree of social support they receive are significant in determining how well carers are able to deal with their situation and the degree of stress they may experience. These factors may well be more important determinants of the level of impact than characteristics such as carers' kinship, gender and age. The patient's psychiatric status however, as far as the evidence suggests, perhaps has the biggest impact on the carer. Much of the evidence in the impact literature however, is either contradictory or mixed in its conclusions. Inevitably, the research in this area suffers weaknesses that hamper a better understanding of what the impact of care actually means for carers, although work on impact and the mentally ill appears to have slowed down in more recent years.

3.5 Limitations of Burden Studies

---

[2] See section 3.2.2.

The limitations of this literature largely stem from definitional/theoretical problems with the concept of burden and the methodological difficulties many of the studies suffer. Primarily six such shortcomings have been recognised in various critiques of burden studies, each of which will be considered in present section.

The lack of a theoretical framework upon which to analyse the impact on the family and the individual carer constitutes the first major weakness. As Maurin and Boyd (1990) argued:

> On the whole, while most researchers have differentiated between objective and subjective burden, the operational definitions have not been consistent; this only serves to obscure the conceptual basis of burden (Maurin and Boyd, 1990, p.103).

Despite attempts to differentiate between objective and subjective burden Hoenig and Hamilton run into difficulty with this distinction and subsequently their research on four counts, Platt (1985) pointed out. The first relates to the crude summary scales they use to assess objective burden. The second is their unsatisfactory measure of subjective burden using a single global scale providing no examples of differing levels of this aspect. The third leaves doubt about the validity in their distinction between objective and subjective burden. And lastly, psychometric aspects such as validity, reliability and sensitivity are not known. Pai and Kapur (1981) in their search for a standardised method of assessing burden run into similar difficulties in measuring the distinction between objective and subjective burden. Even though to some extent the theoretical distinction between the two types of burden has been established the measurement of subjective responses may be ambiguous (Noh and Avison, 1988). In response to some of the definitional problems Nolan et al (1990) attempted to reconceptualise the measurement of carer burden. Following their analysis they contended that a better understanding of carer impact might be best achieved using a transactional model of stress. They argued:

> carer malaise is also more likely when there is a lack of family support and adverse financial burdens imposed by caring *and* when the carer perceives these as stressful (Nolan et al, 1990, p.552).

The second main shortcoming is that much of the work conducted on impact has selected only one member of the family for interview. In the parental family setting this is usually the mother of the client member, or in a conjugal setting the client's spouse. The data drawn from these interviews are then referred to as 'family burden', which is misleading given each family member is likely to have a different experience of impact (Maurin and Boyd, 1990).

The third difficulty is the failure recognised, in many of the studies cited above, the volatile nature of the patient's illness which only require intense care when symptoms are present. There may thus be periods lasting months or years where the patient is well and able to resume normal activities (Perring et al, 1990). Burden studies not recognising this have usually only taken a cross-sectional look at families situations at one point in time (Maurin and Boyd, 1990). In so doing these studies neglect to document, in any meaningful way, what the carers life actually consists of, highlighting the fourth difficulty of previous work on impact. Much of the time the precise impact on the primary carer could well be overlooked (Perring et al, 1990).

The fifth difficulty is the lack of comparison or control groups used in impact studies to identify what factors are specific to families with a relative diagnosed mentally ill. Namyslowska (1986) who used a control group found that families in the research group spent more of their leisure time at home which was attributed to the client member's condition. Further differences included children not participating as much in extra school activities. There were however, no significant differences between groups in terms of financial and educational activities. Perring et al (1990), however, argued that the 1,832 families used in this study to determine 'normal' levels of functioning did not allow for possible psychiatric disturbance within them, and the lack of differentiation between the two groups could be a result of that. The shortfall in comparative work in this area is also relevant at an international level which leads onto the sixth limitation. One of the main advantages for conducting comparative research at this level enables a distinction between the general and the specific (Higgins, 1981). In other words, there may be general factors relevant for all countries and some that are specific to each.

Giel et al (1983) attempted a comparison of the impact on families from four developing countries. In a WHO Collaborative study, Giel et al (1983) assessed 259 families in Colombia, India, Sudan and the Philippines to determine the extent of social burden using criteria such as levels of subsistence, previous illness, financial burden, personal relations, social acceptance and family life cycle. The authors found that in all four locations studied financial reserves were suggested to be minimal for most families. Housing too was often not large enough to cater for a severely disturbed person without affecting other family members. One study area showing a higher disturbance of personal relationships was viewed as a consequence of a greater population density, which perhaps accounted for their finding of an increased social burden in urban areas. Family life cycle also affected socio-economic activities and was dependent upon who was able to take over if the person who had become ill was the head of the household (i.e. whether the eldest son was able to take on his father's commitments easily or not). Outcome of illness was also viewed as an important determinant of how a family managed, and the extent to which the illness was debilitating, whether it was self-limiting, chronic, if the person lost all touch with reality or no longer had insight. The authors then discussed the relevance of culture and how it:

> ... determines the concepts of disease, which in all four study areas with regard to mental illness still contained a strong supernatural element with little expectation regarding the effects of modern health care (Giel et al, 1983, p.199).

They continued by adding:

> culture is to some extent synonymous with religion which also influences attitudes towards the insane ... The political system is also a part of culture, and it is to a large extent responsible for the type and availability of the health care system (Giel et al, 1983, p.199).

This point of focus on impact is beneficial in the way it broadens the debate into a much wider context to include cultural differences and political/economic factors.

In assessing what direction future research in this area should go, Maurin and Boyd (1990) outlined three broad items that need to be taken into consideration: the differentiation of objective and subjective burden and distress; a more sound theoretical basis from which to base this research; and, be methodologically more reliable and valid using more standardized questionnaires and care with sampling. Discussing impact within the wider political and economic context might well highlight other factors that contribute to the level of distress caring can entail. A remaining issue not often discussed in this literature concerns the validity of relying on family care. From a psychological or psychiatric perspective then, should the family be the main carers of relatives with mental illness? At least two theories in psychology are relevant to this issue. One includes family therapy, the other the concept of 'expressed emotion'. Both consider the client's well-being within the family setting and are reviewed in the following section.

3.6 Suitability of Family Care: Theories of Family Therapy and Expressed Emotion

Evaluating the benefits of living with relatives from the patient's point of view has hardly been dealt with by the research on impact. Theories of family therapy and the concept of 'expressed emotion' have pointed to some of the disadvantages the family environment might pose for the patient member. In many ways this focus on the patient's well being within a family environment often has negative implications for the family, in particular the carers.

3.6.1 Theories of Family Therapy

Family therapy starts with the basic premise that the fault of mental illness lay not with the individual but rather the logic of interactions within the family network. Bateson and Ruesch (1951) argued, for example, that schizophrenia was a consequence of distorted communication in the family. Bateson (1972), in a later book, postulated that when such breaches of communication occur, most notably between mother and child, we must expect pathological responses. These breaches are what Bateson called 'double bind', a message where the receiver has trouble identifying the logical type or order of the message. Bateson runs through a list of traits in the double-bind situation, giving examples of how it works and some common characteristics of a schizophrenic family system. Adding to this list, Bateson adopted the idea of family homeostasis, in which families have a tendency to develop patterns of interaction that become stable and secured. Any disruptions to the family system are met with resistance by its members, and indicative of pathological families. Accordingly thus, a schizophrenic who show signs of improvement during a period of hospitalisation is likely to cause a crisis family system upon his/her return. The patient will either resume the schizophrenic condition or another member of the family will become ill. This situation, as far as Bateson is concerned, highlighted at least two problems in returning a patient suffering a mental illness to his/her family. The first, involved the family itself, the idea of disrupting the family system; and secondly, to the patient who perhaps resumed their condition.

In analysing some of the relationships between family members in relation to mental illness, Wynne et al's (1968) theory has also been influential within family therapy. Wynne and colleagues started by defining three family types on the basis of three forms of relatedness: mutuality, non-mutuality and pseudo-mutuality. Each type constituted a different combination of two universal needs - personal identity and relationships with others. Families described as pseudo-mutuality are those with a tendency to develop a schizophrenic member. The procedure by which they are defined as such is through a pattern of emotional investment that fails to accurately take account of the changing needs and expectations of family members. The emphasis instead lays upon the maintenance of a sense of reciprocal stability which induces a rigid structure of relationships or a fixed family role structure without considering the changes family members undergo. What emerged from Wynne's et al's theory of family therapy is how it set up an ideal of family functioning. Following this, the theory then attempts to divide 'sick' families from the 'healthy' ones as a means of distinguishing the group mechanisms evoking the illness. In this sense the structure of 'normal' families is never called into question.

The assumption thus seeks to preserve the general structure of the nuclear family, as Poster (1978) argued. Any deviations from that are viewed as entirely within the family and need to be eliminated in order to bring the family back to the norm. Wynne et al's work has also been criticised on this basis of preserving the present form of the family and other general institutions in society (ie. capitalism) (Poster, 1978).

One subtle, potentially harmful, underlying assumption running through many of these family systems theories and approaches of family therapy is displayed in the focus of mothers. The implication is that mothers control the pattern of family communication and have a unique capacity of inducing and maintaining a pattern of double-bind communication to suit their own purposes. This is quite evident in Bateson's theory. In these sorts of analyses the mother becomes the scapegoat. Bad mothering has often been linked to the development of schizophrenia. Conversely, good mothering assists in the development of meaningful and mutually gratifying relationships. Fathers have been attributed a small share of this blame. Spiegel (1982), as one example, demonstrated how the 'link between mothering, fathering, and mental illness is weakest when the outcome is psychiatrically the most disastrous' (p.105). In discussing the implications of dismissing the extreme idea that mothers and fathers drive their young mad leaves one wondering how parents influence their child's development. This leads onto quite a complex area of analysis which includes the changing concepts of male and female sex roles. Much of the responsibility for child care has been disproportionately attributed to mothers. Similarly, mothers have been unduly blamed for the mental illness of their children. Spiegel, acknowledged this and asked, 'how can we avoid scapegoating parents, and especially mothers and at the same time learn from past mistakes about the best way to raise children and foster psychological growth?' (p.105-106). Spiegel's main concern is another version of the issue of 'good' and 'bad' family care and an equitable basis of child responsibility.

The most obvious implication thus of these theories of family systems described above is the inappropriateness of the family to care for relatives with mental illness.

In essence these theories hold quite derogatory views of family members in relation to the person with mental distress. This is particularly evident in the parental setting where mothers are perceived as perverting a child member's psychological well-being. These theories stand in direct contrast to the concerns of the research assessing the impact on carers. In light of these concerns, particularly as many mothers are carers of children with mental distress, perhaps family system theories need to be re-evaluated to avoid the derogatory assumptions made about the parents which underpin many of them. The theory of 'expressed emotion' has, to some extent, attempted to re-evaluate theories about family interaction and mental illness. And, for the first time introduced a package of intervention that sought to prevent relapse in patient members.

3.6.2 Expressed Emotion

The concept of expressed emotion (EE) came to replace the idea of family interaction as the cause of schizophrenia. This construct views both the attitudes and behaviour of the family as influencing either positively or negatively the course of a preexisting disorder. The idea emerged following a study conducted by Brown et al (1958) who noted that discharged patients functioned less well when living with spouses, parents and/or hostels compared to other living arrangements outside the hospital. A second study led Brown and associates (1972) to examine several factors which appeared to influence the way schizophrenic patients performed in the community. This study included a family interview evaluating the level of emotion and hostility expressed by the family members, which they discovered correlated significantly with relapse in the subsequence year. The Camberwell Family Interview was later developed in order to assess systematically a range of attitudes held by family members towards patients, including criticism, hostility, dissatisfaction, warmth, overinvolvement and positive remarks (Brown and Rutter, 1966).

The most prominent of these features, shown in subsequent studies detailed below, in predicting relapse became 'critical comments' and 'emotional overinvolvement'[3]. Hostility also became a significant variable in predicting relapse, although it is dependent upon the presence of critical comments and the number of rejecting remarks made[4] (Leff and Vaughn, 1985). Early EE studies yielded impressive results finding a significant relationship between family attitudes (and subtle/implicit behaviour) and patient relapse (Brown et al, 1972; Vaughn and Leff, 1976). These studies differentiated between families with high and low expressed emotion and examined its relation to subsequent patient relapse over a nine month period. The rates for relapse in high expressed emotion families were doubled compared to those with low EE. The Vaughn and Leff's (1976) study looked at the interaction between level of EE and patients taking neuroleptic medication. Again, low relapses were found in families with low EE whose patient members took their medication on a regular basis.

Some studies started to introduce a package of social interventions with families that aimed at reducing 'face-to-face' contact between the relative and the patient member (Leff et al, 1982; 1985). The amount of time a relative and patient spent together is another primary factor considered to elevate expressed emotion. The

---

[3] Critical comments were measured on the basis of the number of statements made about the patient that were seen to be critical and included the content and tone of the relative's voice whilst making these comments. Emotional overinvolvement is assessed on a global 6-point scale measuring the relative's own reports of their exaggerated emotional reactions, self-sacrificing and overprotective behaviour.

[4] Hostility is seen as present when the patient is attacked for 'what he or she *is* rather than for what he or she *does*' (Leff and Vaughn 1985).

package of intervention included a programme of psychoeducation. These consisted of lectures to relatives on the aetiology of the patient's condition, course and management of schizophrenia; a relatives' group bringing together high and low EE families; and, family sessions which brought the family together as a whole (Leff et al, 1982). The findings from these studies produced remarkable results. To give some idea of the outcome achieved the control group, in the Leff et al (1982) study, had a 50% relapse rate compared to 9% in the experimental family group. In 73% of experimental families no relapses were experienced. In a subsequent two-year follow-up the same experimental families demonstrated a 14% rate of relapse compared with 78% for the control maintained solely on medication (Leff et al, 1985). For Leff and colleagues these results provided causal evidence for the role of relatives' expressed emotion in schizophrenic relapse. They also emphasised the therapeutic importance of social intervention when combined with drug treatment. Disputing the efficacy of 'expressed emotion' and the social intervention package that clearly has an effect on preventing relapse in patients appears foolhardy at first. The criticisms of 'expressed emotion' however, are aimed deep within the concept itself and the appropriateness of its clinical applicability.

In a critical review of EE studies Kanter et al (1987) examined these issues when discussing the validity of this research and asked: does expressed emotion cause relapse? Does a global expressed emotion rating have clinical validity? And, what is the clinical significance of EE ratings? In the first question, Kanter et al (1987) have doubted the simple causal relationship between EE and patient relapse found in EE research. Hogarthy et al's (1986) intervention and aftercare study found that a fall in relapse rates was not always linked to a fall in high EE. It may also be, as Hogarthy et al continued, that certain families change their EE status from high to low as the patient's condition improves.

In questioning EE's clinical validity as a global rating Kanter et al stated:

> there is no evidence that expressed emotion indicates more than the presence of a critical, hostile, or overinvolved attitude on the part of family members (Kanter et al 1987, p.377).

This they support with a study by Miklowitz et al (1983, cited in Kanter et al, 1987) who argued that the association between expressed emotion and criticism and hostility, as a single global construct, is not apparent. The clinical significance of EE ratings therefore, fall into a similar trap to that of family therapy. In making a decision about the extent of 'overinvolvment' professionals can devalue the legitimacy of family loyalties (Grunebaum, 1984; Terkelsen, 1984, both cited in Kanter et al, 1987). The EE approach therefore contains elements of blame where the family, especially parents, are seen to exacerbate the patient's condition if they are too 'involved', too 'critical' and/or too 'hostile'. The use of intervention programmes such as psychoeducation, family sessions and relatives' groups are, on the other hand, useful for relatives who feel they require them. Do all families caring for someone with mental distress need these forms of intervention? McCreadie et al (1991) in a study of 63 relatives of schizophrenic patients living at home found only 17 relatives finally took part in their intervention programme. Many of the relatives who had accepted intervention had patient members who had been readmitted into hospital in the past year. This suggests that relatives might only need such intervention during periods of crisis.

A more recent study assessing expressed emotion over a five year period still found that patients in low-EE families relapsed considerably less often than those in high-EE homes (McCreadie et al, 1993). At the same time, however, this group also found that some patients living throughout the five year period in high-EE homes did not relapse at all. It remains unclear therefore whether EE can predict precisely what triggers relapse in some patients and not in others. Other more recent literature on EE and families has shown its expansion into other cultures (Marcolin, 1991; Kuipers, 1992). These papers argue that EE is not culturally specific and can be applied to different carers. It is perhaps wiser, however, to regard these comments with scepticism not simply because of the problems inherent in the concept of expressed emotion, but also because it has failed to consider cultural differences. The assumption here appears to be that expressed emotion can be applied in a way that makes it immune to other influences such as culture, language, meaning and so on.

On the whole it is difficult to say in precise terms what exactly expressed emotion measures. There is a strong possibility that it may be measuring carers' distress. Distress itself is viewed as distinct from expressed emotion by those who employ it. Some argue however, that where a patient's behaviour is distressing for relatives they may well react in ways that heightens the situation (Gibbons et al, 1984). It could thus be that responses to some EE ratings are a reflection of this distress. How can we be certain they are not an expression of emotional impact on carers? MacCarthy (1988) expands on this theme when she explains how EE levels could well be a result of a number of complex factors concerning long-term interactions between the patient's behaviour, premorbid relationships and family burden. Perhaps, as Kanter et al (1987) argued, a more plausible approach might be to focus not on lowering levels of EE to prevent relapse, but instead for professionals to 'focus their efforts on establishing a liveable home situation for all family members and facilitating the patient's survival and rehabilitation' (p.379).

Summary

Both the theories of family therapy and expressed emotion have proved beneficial in some ways for patients and family members. The theories have at least addressed the issue of the family and have made attempts to improve the situation for patients and the relatives they live with. One of the pitfalls however, is that these theories start with an 'accusatory' premise directed towards families, that they are in some way responsible for the patient's condition. Very often not only does this undermine the family's value as carers and supporters of patient members, but also overlooks the distress they may experience in the process of caring. This attitude however also extends into the approach adopted by professionals towards patients' relatives when one assesses the research on carers and the formal services.

3.7 Carers and the Formal Services

All too often families of the mentally ill are neglected by psychiatric services. Rarely are families asked by services in any systematic way what they would regard as beneficial in their role as carers. Three areas of service provision and how they relate to families and carers can be identified (Perring et al, 1990). These include the differing impact on families in the types of services provided whether community- or hospital-based; the provision of information to relatives by services about the patient's condition; and, how families perceive their experience of service provision. Each will be explored in turn.

3.7.1 The Impact of Service Provision

The research findings on the impact of service provision tend to be contradictory. On the one hand, studies show family burden to be greater where only community services are provided (Brown et al, 1966b cited in Perring et al, 1990; Grad and Sainsbury, 1968). On the other, one study demonstrated day treatment to be effective in producing low levels of distress and family burden compared to families of hospital stay patients (Washburn et al, 1976). More recently, Muijen et al (1992) in comparing the efficacy of home-based care to hospital care saw a reduced rate of admission for patients who lived at home. These authors however, say nothing about family impact, but note that home-based care offers slightly more advantages for patients and their families who prefer patients to be at home. Another study reported no major differences between families despite the alternatives and the different forms of services compared (Test and Stein, 1978). Hence, it is quite difficult to draw any firm conclusions from these findings on the impact of formal services on relatives. Many of these studies suffer various methodological differences and differing follow-up periods which account for some of the discrepancies in their findings (Perring et al, 1990).

A number of studies, however, have included intensive, community-based treatment programmes. Hoult (1984; 1986), for instance, in an Australian study introduced an interdisciplinary team available at short notice offering a daily crisis intervention on a 24 hour basis. Eighty percent of the relatives in the experimental group who received this service viewed it positively. Many reported the service to be far more helpful, both to themselves and their patient members, than the usual hospital care and aftercare. The problem with studies such as these is that they tend to provide a high level of service intervention, much more than is ordinarily available in the community (Perring et al, 1990). They have demonstrated the value such input can provide for carers and patients, but once intervention is discontinued families no longer benefit. It remains difficult thus to say if community-based care is more advantageous without first understanding the long-term effects of this form of care.

Another form of service provision and the impact on relatives concerns giving information about various aspects of the patient member's condition.

3.7.2 Families and Information about the Situation

As described above in section 3.6.2, psychoeducation is one means by which relatives gain knowledge about the patient member's condition. It is not certain whether increased knowledge leads to a subsequent improvement in the way families adapt or cope with their situation. Ferris and Marshall (1987), for example, adopted a 'non-blaming' stance towards families in a study to show the effectiveness of education on the nature and management of schizophrenia, effective communication and problem-solving. In their package they included educational workshops and seminars (attended by patients, professionals and families), sheltered employment for patients and an advocacy role to improve public facilities. It is difficult to ascertain from this study whether the increase in knowledge actually led to an improvement in the families' situation. What was certain, however, was that psychoeducation alone is not enough to enable families to deal effectively with their situation (Ferris and Marshall, 1987). It can assist families in understanding why the patient relative behaves the way he/she does, or reduce some of the anxiety, distress or despair relatives may experience when not knowing what is happening. Psychoeducation needs to be supplied as part of a package of service intervention along with a relatives' group and a crisis service to obtain optimum effectiveness.

3.7.3 Carers Satisfaction with Services and How they Perceive their Needs

Services are primarily geared towards meeting the needs of the patient and to some degree this can benefit the carer. Studies on how satisfied relatives are with services often point to the poor quality and frequency of contacts they have with services and professionals (Johnstone et al, 1984). The concerns relatives express include the turnover of professionals (Johnstone et al, 1984) which can forestall the development of a therapeutic relationship that is crucial to the well-being of both patient and carer, particularly when long-term (Thompson and Doll, 1982). Seldom have studies shown that relatives are satisfied with professional cooperation (Perring et al, 1990). Parents of patient members, for example, may be ignored until the situation reaches a crisis point and admission to hospital takes place (Creer et al, 1982). Furthermore, relatives are given little or no advice when the patient returns home (Creer, 1975).

Frequency of contact with service professionals can be poor or lacking altogether. Johnstone et al (1984) showed in a follow-up study that 77% of 66 families in the sample had no social or medical contact, and it was amongst these families that the highest levels of distress were found. The attitudes and perceptions of relatives by staff are also problematic where professionals can be unsympathetic towards the difficulties carers face (Creer, 1975). Family burden itself often goes unrecognised by professionals (Johnstone et al, 1984). This however appears to be changing, even if slowly. Hanson and Rapp (1992) in their study noted that professionals are aware of the distance between them and the families of patients. Professionals have also recognised that bridging this gap means a better understanding of families subjective experience of caring for patient members (Hanson and Rapp, 1992). In a similar vein, the role of the community psychiatric nurse in working with families and trying to address their needs has dominated much of the more recent literature (Brooker and Butterworth, 1991; Shaw and Halliday, 1992).

Carers' needs in terms of types of services cover aspects such as day and respite care and better communication with professionals. Fadden et al's (1987b) study asked carers to suggest what they felt they required from services. The majority of relatives (83%) wanted more information and consultation over treatment, advice on how to deal with patients (33%), meetings with other relatives and earlier admissions to hospitals (17%). Only two carers reported wanting a break or rest from the patient. When asked in general whether they were satisfied with services only three supporters responded positively. Fadden et al's study gives some idea of the level of dissatisfaction carers in receipt of services express. Little research exists, however, on the views of those carers who have lost contact with services and whether they did so because of their dissatisfaction. It must also be borne in mind that the changing course of illness from onset to crisis, to periods of respite reflect the changing degree of support carers need at any one time. This might thus vary from acute crisis intervention, or long-term support for patients who do not recover.

Identifying unmet needs amongst carers is also an important issue for services. Relatives may not be aware of their own individual needs or have difficulty imagining or voicing what services they would have liked (MacCarthy et al, 1989b). Some relatives might feel they have no right to approach services for help or may not be aware services exist for that purpose (Creer and Wing, 1974). MacCarthy et al (1989b) found most relatives were resigned to their situation and did not wish for any extra help, feeling it would be futile given their circumstances. Low expectations, low demands and unmet need thus cover the main reasons why carers' needs go unreported. One reason for low expectations amongst relatives is that some services respond mainly to a crisis. Little or no attention then is paid to prevention or maintenance, and inevitably carers looking after patient relatives on a long-term basis tend to be left out. Many services are 'demand-led' and avoid being intrusive assuming that if a carer requires a service they will ask for it (Perring et al, 1990). Creer and Wing (1974), however, noted that even where relatives are articulate and knowledgeable their needs still go unmet.

Some studies have attempted to detect unmet needs amongst carers in terms of services (Creer et al, 1982; MacCarthy et al, 1989b). Creer et al (1982), in their work, developed five categories of unmet need. The first, and most frequent unmet need, was the lack of practical assistance and advice (i.e. welfare rights advice, home help, meals on wheels, etc) offered to carers. The second, relatives wished to be included in plans and decisions concerning the patient's care. The third need relatives expressed was the opportunity to discuss with staff the management of difficult behaviour or have access to more information about the patient's illness. Relatives also felt they could provide relevant information to staff about the patient that could avert a potential crisis. The fourth involves the emotional support carers needed, helping carers deal with their own feelings about the patient member's behaviour and the care they provide. And lastly, the need for respite. These cover just some of the unmet needs amongst carers recognised by researchers. The concept of unmet need however, is a difficult one. Families caring for relatives with mental illness have many needs and it may be hard to present a package of services that matches all of them (Perring et al, 1990). Perring et al later add, 'it is difficult to maintain a focus on the need of relatives and carers when the needs of patients are so clearly visible' (p.44). In part, this difficulty is related to how services perceive carers. Often these perceptions are confused and contradictory, and sometimes services do not see themselves as having any obligations towards carers (Twigg, 1989).

Summary

Summary

In patient oriented services carers' needs are either secondary to those of the patient member or overlooked. Formal services need to take account of families if they are to assume much of the caring responsibility of patient members. Even if it is difficult for services to identify and meet the needs of families it is clear from the literature that basic support, advice and information about the patient's illness, and simply acknowledging the impact they may be facing can serve to benefit carers.

3.8 Overall Summary

The concept of 'impact of care' is in itself wrought with difficulties which have been heightened by the methodological inconsistencies of the research in this area. The distinction between 'objective' and 'subjective' impact is perhaps too simple a definition in attempting to uncover the experiences of carers. In many ways objective factors, such as a loss of income or having to give up one's job, can be distressing for carers. What makes caring more difficult for some than others still needs clarification but there is some indication that factors such as kinship, gender and patient's psychiatric status play some part in determining impact. The way a carer copes with their situation is also an important determinant in how impact takes shape for them. It is also clear that formal services can be far more instrumental in assisting families cope with their situation.

The present study on impact of care seeks to examine some of the issues discussed in each review chapter, within the Italian context, to gain some idea of the experience of carers after the 1978 mental health reform.

Chapter Four

Methodology

4.1 Research Questions

The impact of care literature, reviewed in Chapter 3, drew upon a number of important areas crucial to understanding some of the issues involved in caring for a relative with mental illness. The present research study attempted to establish the level of impact on relatives after the 1978 mental health reform in Italy. This is the first study to assess the impact of the 1978 reform on families of the mentally ill. The study also aimed to explore the differences in impact according to relatives' kinship and gender, and according to the patient member's diagnosis, given the need to explore in more detail the extent to which these factors differentiated the caring impact.

The current study sought to combine both the extent of impact relatives experienced within the Italian context and how this impact differed according to kinship, gender and patient diagnosis. The five points listed below indicate some of the main features of interest. These included:

1. How changes in occupational, financial, domestic and social activities differed according to family structure.
2. Whether the impact of care fell largely on female members of the family.
3. How the impact of care manifested itself during the course of the patient member's condition and what factors alleviated the impact on the carer.
4. How supporting relatives coped with the patient member's behaviour.
5. The support formal psychiatric services offered to both relatives and patient members.

The categories of relatives' kinship, gender and patient's diagnosis gave rise to a series of additional questions outlined in the following sections.

4.1.1 Kinship and the Family

Amongst the more common kinship roles carers of patients tend to be either a parent, a spouse or a child[1]. This provided a useful framework of analysis in identifying the sorts of demands placed on the patient and how they fulfil them in view of their condition. The responsibilities the carer may then have to assume is in many ways dependent upon these factors. In employment terms, to what extent did the patient's employment provide the main family income? How many patients stopped working as a result of their condition? Under what circumstances have relatives had to take on, or give up, employment due to the patient member not being able to work? Were patients able to continue working despite their condition? If so, what enabled them to do this?

Questions concerning household income were similar to those dealing with employment and the assumption of various responsibilities relatives may otherwise not have had. In view of this, how many patients provided the main family income? If then, due to the patient's condition, the carer assumed financial responsibility how is it achieved? Financial difficulties can also occur through the accumulation of debts, have these been generated?

Household activity is considered a potential area of change with the onset of illness where the carer is likely to conduct much, if not all, of the housework and other domestic activities. In this case assessing whether the patient is partly or fully responsible for these activities is crucial to determining the subsequent impact of care in this particular area. Conversely, relatives caring for patient members may have always conducted most of the domestic activities prior to the patient's onset of illness.

---

[1] Siblings who care for a brother or sister with mental distress are less common compared to these other two types of kin relationship.

Hence, patients may not be expected to perform any housework or share in the management of household affairs in general. Disruptions in household affairs often do occur, (see Chapter 3), especially during crisis situations, and are necessary to examine.

Social support networks are also important in understanding how they act to alleviate some of the negative aspects of the caring impact: for example, if relatives were able to confide in someone. A comparison of social activities among the different family structures would reveal how each type spent their free time, and the extent to which it attenuates any negative impact in each kinship group. Do relatives caring for patient members who have free time take part in social activities? If relatives' free time is limited due to the patient's condition does this result in strained relations between patients and relatives. The patient's social life is an equally significant factor in assessing impact. If patients do have a social life are relatives then able to conduct their own social activities? Were employed patients more socially active compared to those who were not? Carers' kinship status and impact are also closely linked to the carers' gender.

4.1.2 Gender Considerations

Understanding the changes due to the differential impact of care on employment between the sexes, draws further on the roles ascribed to them by the family. Establishing the number of female relatives who work and the reasons why indicate the extent to which they do so as a result of the patient's condition. The patient's employment status is one crucial determinant in the outcome of their illness. What reasons might there be for relatives not having to make changes to their employment in any way? Is this related to male and female roles in the family, i.e.

where it may not be necessary for the wife/mother of the family to work, especially where the male patient member continues working?

Similarly, how many male relatives have taken on the responsibility for household affairs when the patient becomes unwell? How many female relatives have assumed responsibility for managing the family finances, or have sought a job to maintain the family income? Were there other areas of responsibility where the relative has had to assume? Were there more female members of the family conducting the household affairs any way? How many men in the sample carried out the housework? Did female relatives compared to males differ in terms of their social activity? Were there any sex differences between relatives in social support networks and who they confided in? Did more female or male relatives report more strained interpersonal relations with the patient? Similarly, were there any sex differences in relatives' physical or psychological health? Did differences exist in the way male and female relatives reacted to the patient members' behaviour? Was there a difference in the way they coped? How did men in the sample express their concern for the patient member? What elements of this concern could be considered caring for patient members? Was it confined to what they actually did for them? Is there an overall difference in what male and female relatives actually do and the changes they make to their routines in view of the patient's condition? Areas thus where kinship and gender of relatives' are closely associated tend to be those concerning familial responsibilities such as the family members who work to provide the family income, and those who manage household activities.

4.1.3 Patient Diagnosis

Few investigations have looked directly at different patient diagnosis and how impact can vary according to this (see Chapter 3). In many ways the patient's psychiatric status and the impact relatives may experience could vary according to certain patient diagnoses. It is quite feasible that some patients diagnosed with one condition may differ in terms of symptoms compared to someone with another diagnosis. Very little is known, for example, in the differences of caring impact between someone diagnosed with schizophrenia and someone with depression. Were some types of mental distress more incapacitating than others? The patient's performance, (i.e. the degree to which they are able to pursue their employment, social activities and so forth), is thus important to examine with reference to their diagnosis. Did any of this have a direct bearing on impact?

Patient behaviour is also an important determinant of impact on relatives. Establishing the sorts of behaviour common to each of the three diagnostic categories may influence the impact relatives encounter. Further to this, how much did relatives know about the nature of the patient's condition and the patient's future prospects? Did this determine in anyway how relatives reacted to the patient's behaviour? In what ways did severity and frequency of behaviour determine how relatives reacted? How did relatives cope when a difficult situation arose at home or elsewhere? What support were relatives able to obtain from formal services during times of difficulty and was that another determinant of how impact took shape?

4.1.4 Satisfaction with Services

The assistance offered by services reveals the direction in which they orient themselves. If the focus is largely on patients how did relatives obtain support from services? Did any formal services exist for relatives? What help and support did relatives require from services, especially in the event of a crisis? Did relatives feel neglected by services? Did relatives feel that patient members lacked certain services? What proportion of relatives felt they could contact the service easily should they need to? What rehabilitative aspects of service intervention were there for both patients and relatives? Did patients who lost contact with psychiatric services still require assistance from them?

Summary

The research questions of interest revolved around the theme of impact of care and the differences impact according to kinship, gender of relatives and patient diagnostic groups to be looked at in the Italian context. The following sections describes how these issues of interest were incorporated into the study and the methods by which they were explored.

The Study

The principal aim of the study was to examine the impact on relatives living with someone diagnosed with mental illness in Italy after the 1978 reform. The study, conducted in 1988, was based in a catchment area of Italy acknowledged to have fully implemented and adhered to the reform's ideals. The South Verona catchment area was selected primarily for two reasons. The first because South Verona has been recognised to provide a fully comprehensive community-based mental health service which is in line with the 1978 reform. The second because of the Psychiatric Case Register kept in South Verona which provides information on all patients in contact with the service, both past and present.

4.2. South Verona

The provincial city of Verona has a population of around 260,000 people, a north-eastern city located between Milan and Venice in the region of Veneto[2]. Verona is, traditionally, an agricultural town but currently only 2.6% of the work force are employed in this area. The bulk of those employed, 64.5%, work in the service sector and the remaining 32.9% work in industry (Mosher and Burti, 1989). The unemployment rate stood at 6.5% (Provincial Office of Labour, Verona, cited in Mosher and Burti, 1989).

4.2.1 South Verona's Psychiatric Services, Staff and Organisation

The department of psychiatry in South Verona, created in 1970, functioned as a 36 bed ward attached to the University of Verona's general teaching hospital

---

[2] See Map of Italy in the Appendix.

(Policlinico). Patient admissions came from one of two sources, either the waiting list or the hospital's emergency department. The level of care provided in the psychiatric unit at that time was essentially limited to inpatient care. Patients considered dangerous either to themselves or others were not admitted and sent instead to the 1,000 bed mental hospital situated 10 miles from Verona.

By the end of 1977 the department and its team began its move away from inpatient care to include outpatient follow-ups. Teams made home visits to families and undertook immediate crisis intervention in order to prevent hospitalisation. The department by then had halved its number of beds to 15. Once the reform had been passed in 1978 the University psychiatric department was given the option of becoming integrated into the public domain of service provision. The department then assumed responsibility for a specifically defined geographical area and subsequently became the South Verona Community Psychiatric Service. In adopting this responsibility the team were then required to provide a range of services, including long-term care, compulsory commitments and rehabilitation. Community programmes at this stage had not been developed until a day programme was initiated and situated temporarily in the inpatient unit. In 1980 the Community Mental Health Centre opened. This became a 'walk-in' service open six days a week, twelve hours a day. The Centre provided day care for patients requiring continuing care, an emergency service, domiciliary visits and rehabilitation (Faccincani et al, 1985).

The psychiatric department in the general hospital currently consists of a psychiatric emergency room and a 15 bed inpatient unit. It also provides a liaison service with other medical and surgical departments of the hospital and an outpatient department for consultations, and individual and family therapy. Private facilities include two inpatient units with a total number of 220 beds. There are also three sheltered apartments with varying levels of supervision. South Verona community psychiatric services no longer rely on the 1,000 bed mental hospital situated outside city.

The number of permanent staff in South Verona consists of nine psychiatrists, three psychologists, three social workers and twenty-four psychiatric nurses. Staff were distributed equally into the three teams to cover the entire South Verona catchment area. Table 4.1 shows the area and staff divisions, and includes the population each team is responsible for.

Table 4.1
Areas, Staff and Population Divisions

Team A	Team B	Team C
Borgo Roma Buttapietra	Cadidavid Golosine	Santa Lucia Castel d'Azzano
28,000	18,500	28,500

There are an additional thirteen psychiatric residents in training who work unpaid for approximately two years. Up to six medical students work on rotation with the psychiatric service, usually for four months and a number of volunteers also assist. Professional staff have also assumed research and teaching responsibilities. All staff, with the exception of 10 nurses covering shifts in the hospital unit, work both in the intra- and extramural services.

Summary

The service is entirely community-based, having implemented, as far as possible, the 1978 reform. This provided an ideal setting in which to assess the impact on relatives following the reform. A further benefit included South Verona's psychiatric case register.

4.2.2 The Psychiatric Case Register

The psychiatric case register based within the service in South Verona. The case register is kept and maintained in the department of Psychological Medicine (Cattedra di Psicologia Medica). It was created in 1978 to record all contacts made to South Verona's psychiatric services. The information recorded is gathered from psychiatrists, psychologists, social workers and psychiatric nurses working in the service.

The information includes socio-demographic characteristics of the patient's first contact with services, clinical data (i.e. previous admissions to psychiatric hospitals and medical history), educational and occupational status, where the patient is resident in South Verona, and with whom they live. Patient diagnosis, also recorded, was set according to ICD-9 (World Health Organization, 1978) in 1988 and coded into eleven standardized diagnostic categories. Details of patient contact with all services, (the Community Mental Health Centre (CMHC), the day hospital, outpatient services, the state mental hospital, private psychiatric clinics and (from Jan. 1982) neurological wards in the general hospitals), are registered. Each contact made by South Verona residents to the service is recorded and updated, including domiciliary visits and any attendances to the psychiatric outpatient clinic. Psychiatric professionals in private practice, however, do not give information to the Register.

The case register thus contained ample information about patients in touch with

South Verona's public psychiatric service. It proved to be an extremely useful means by which to collect a sample of patients living with their relatives.

4.3 The Schedule

The schedule employed to interview relatives was based on that used in the Fadden et al (1987b) study of carers of spouses with depression. The schedule was a combination of schedules used in other work examining the impact of care and the mentally ill. These included the Social Behaviour Assessment Schedule (SBAS, Platt et al., 1983), the abbreviated version of the Camberwell Family Interview (Rutter and Brown, 1966; Vaughn and Leff, 1976), the Camberwell High Contact Survey, the schedule used in the Paykel et al (1982) study, and a Satisfaction of Services schedule (LeSage and Pollini, 1989).

The schedule, overall, focused mainly on objective impact on relatives, as well as assessing patients' role function and allocation, challenging behaviour, relative's knowledge of the patient member's condition and their views about the services received. The Fadden schedule of spouses was adapted for the present study and broadened to incorporate other kinship groups such as parents and children of patient members. There were two sections of the Fadden schedule that were omitted. These were, the effects on children and the impact on other family members to shorten an already lengthy schedule and to reduce the time needed to complete an interview.

Parts of the schedule allowed for ratings of subjective impact. These were included in the section on patient behaviour, asking relatives the extent of distress this might invoke for them. There was also a modest a list of 17 items dealing with how relatives coped following any specific incidents, in the areas of household activities and challenging behaviour, in the month prior to interview. The Fadden schedule used items to examine three dimensions of coping a) appraisal focused coping attempts to define the meaning of the situation, b) problem-focused coping seeks to modify the source of stress, and c) emotion-focused coping tries to manage the emotions elicited by the situation (Moos and Billings, 1982). No standardised schedule exists to explore these coping issues, hence the Fadden schedule used 14 items based on a questionnaire used by Folkman and Lazarus (1980) in their coping study, and the remaining 3 items described by Pearlin and Schooler (1978)[3].

For the most part, the schedule consisted of closed-ended questions with predetermined responses for each. A series of open questions, however, were considered important, and placed at the end of each section. A general open question at the end of the schedule was included to give relatives an opportunity to express whatever they felt was relevant for their situation that had not been mentioned previously.

Table 4.2 provides a list of the principle areas measured and the sorts of issues explored within them to determine the impact of care on relatives.

---

[3] See Chapter 3, section on Coping Responses, for a review of these coping issues.

Table 4.2
Principle Areas of Impact of Care Used in the Schedule

---

1. **Employment**
    - How relative was finding work
    - If relative had to make any adjustments to their working hours, time off, change jobs or give up work completely
    - If such changes were a consequence of patient member's condition

2. **Household Finances**
    - Changes to family income, i.e. loss of earnings
    - Difficulties with money and in making ends meet
    - Whether difficulties here were a consequence of patient member's condition

3. **Household Affairs**
    - Difficulties relating to the management of household affairs, any disruptions, etc
    - Changes in the responsibility of general management, i.e. in the housework and other household chores, like shopping, etc
    - How these changes were related to patient member's condition
    - If relative had experienced a problem regarding household over past month. Then followed by a 'coping' questionnaire

4. **Social and Leisure Activities (Relative and Patient)**
    - Amount of free time relative has and how they used it
    - Whether both relative and patient take part in any social or leisure activities and if they do any of these together
    - If the lack of either is a consequence of patient member's condition

5. **Interpersonal Relationship Between Relative and Patient**
    - How well relative and patient member were getting along
    - If this had been affected by patient's condition

6. **Effects on Relative's Physical/Psychological Health**
    - If over the past month relatives had experienced any physical or psychological problems
    - If this bore any relation to patient's condition

7. **Problems with Patient's Behaviour**
    - Whether patient member had over the past month shown any of the 30 types of behaviour listed
    - Followed by a series of 4 questions including:
        - a) how relative had reacted to behaviour
        - b) frequency of behaviour
        - c) severity as defined by the relative
        - d) the causes of behaviour according to relative, medication, condition, etc
    - 'Coping' questionnaire included here

Table 4.2 contd

8. **Satisfaction with Services (Relative and Patient)**

Relative

- Contacts with professionals and other staff
- Information about patient's diagnosis and medication
- Information about patient's future prospects and what to expect
- If there was a need for more such information
- Whether relative felt the need for some respite
- Home visits received and if there was a further need
- If relative felt they could approach services easily
- Open question regarding what relative would find of more benefit from the service

Patient

- Type of services patient member has received
- If relative felt this was adequate
- Open question concerning whether patient member could benefit by something else from services

9. **Housing Situation**
    - General questions about:
        - a) type of abode
        - b) owners of their house or rent accommodation
        - c) number of rooms
        - d) how long they have been living there
        - e) if they have made any attempt to move

10. **General Open Question**

The schedule was translated into Italian by a research psychiatrist at the Cattedra di Psicologia Medica, and double checked with other researchers proficient in English. This I piloted on two to three interviews to check for the type of responses given. Only a few minor modifications were made on some words used in the translation. In these pilot interviews I discovered that some relatives spoke in the regional dialect. I then allowed myself time to become accustom to this. The first few interviews I was able to tape. These were later checked by the same psychiatrist who translated the schedule, against the responses I noted in these interviews.

4.4 Defining the Sample

Four main sampling criteria were used to define the sample of patients. These, as mentioned earlier, were selected from the case register. Table 4.3 lists the four criteria used in the study. The case register was able to select patients according to each of these criteria. The year of last contact was checked using a separate register output.

Table 4.3
Selection Criteria for Collecting Sample

i) Patient resident with carer or significant other

ii) Patients between the ages of 18-60

iii) Patients with a diagnosis of functional psychoses either schizophrenic or affective, or depressive neurosis

iv) Patient's last contact with services in either 1986, 1987 or 1988

The original aim was to conduct 50 interviews with relatives. Three diagnostic categories were chosen, functional and affective psychosis, and depressive neurosis. This allowed for comparisons between patients' diagnostic categories. The same selection procedure employed to obtain patients from the register diagnosed with psychosis was applied to the patient group diagnosed with depressive neurosis except for two items. The 1986 last contact year for the non-psychosis group was omitted given the large numbers eligible for inclusion in the sample. The number of patients selected from the register fitting the sample criteria were 54 with a diagnosis of one of the two psychoses, and 66 from the depressive neurosis group.

4.5 Contacting Relatives via the Patient Member and the Response Received

Names and addresses of patients were also provided by the register. Initially, it was advised that contact with the patient be made through their psychiatrist. This was largely to minimise the potential rate of refusal, which may have been higher had patients been contacted directly. However, certain difficulties arose from approaching patients in this way. Staff were sometimes reluctant to contact patients for research purposes or would often delay doing so to see to more urgent priorities.

I later decided that the most effective way of contacting patients was to write to them directly. Each of the three consultant psychiatrists heading the catchment area teams were given lists of patients whose relatives were eligible for interview. Once permission was given to contact patients letters were then sent, in the first instance, to the 54 patients diagnosed with psychosis. The letter briefly outlined the research and asked if it would be possible for a relative closest to the patient member could come forward for an interview. A period of two weeks was given for either patients or their relatives to reply. If no response had been received a reminder letter was sent following the two week period. Failing this, patients were telephoned or a home visit was made in order to obtain a reply.

Twenty-one patients (39%) or their significant other in the diagnostic group of psychosis declined to be interviewed and 8 (15%) had changed address and lost contact with services. There appeared to be two main reasons for refusing an interview, either the patient or the relative simply did not want to be interviewed, or current difficulties or tension in the family did not permit the arrangement[4]. In some

---

[4] If it appeared that interview with a relative might exacerbate tension between both them and the patient member an interview was not organised.

cases the psychiatrist involved with patients whose relatives were eligible for interview advised not to do so due to certain difficulties.

The refusal rate in the depressive neurosis group was markedly higher compared to the other diagnostic category. Of the 66 patients sent letters 51 (77.3%) were not interviewed, the reasons for which are similar to those mentioned above. Nine patients could not be traced, having either lost contact with services or changed address. However, there was a larger proportion of patients/relatives refusing an interview. Some relatives questioned the relevance of an interview as their patient member was not particularly unwell at the time, or some felt no need to maintain their contact with services and declined to be interviewed. One spouse, agreeing to an interview, never turned up for the appointment. Given time constraints not all patients in the depressive neurosis group, who had been sent two letters, could be followed up in the same way as relatives in the psychoses group. This was finally counted as a refusal. The next stage was to choose the appropriate informant for interview.

4.6 Choosing the Informant

One person was selected for interview. The task was to choose a relative who could be identified as one of the following: a) the key carer, b) the person closest to the patient, or c) according to kinship. The order of preference for identifying the significant other in the conjugal home was the patient's spouse or cohabitee. In the parental home the patient's mother or father; the patient's child; or, the patient's friend. Details of who the patient lived with were not available and selecting the relative suitable for interview could only be determined once replies to letters had been received. In response to the letters sent relatives would either reply directly or if the patient responded would be asked if a close relative living in the same household could be interviewed.

4.7 The Relatives Interviewed

Interviews with relatives usually took place in the patient/relative's home. If for any reason this proved difficult the relative would come to the research unit. The patient was not present at the time of interview. Each interview was conducted by myself and lasted anywhere between 1½ to 3 hours. Twenty-five relatives (46% of the sample frame) with patient members in the psychosis diagnosis group were finally interviewed. In the depressive neurosis group 15 relatives (22%) were interviewed. A total of forty interviews were carried out. During 3 of the 40 interviews performed fathers of patient sons came forward for interview, although the mothers might have been a more appropriate informant. These particular mothers, however, were unavailable during the three to four month period in which interviews took place. Nevertheless, these fathers were able to give sufficient information regarding their own concerns and experiences with the patient member.

For the most part, patient members not were interviewed, although on some occasions patients accompanied relatives who came for an interview. Relatives, however, were always seen without the patient being present during the interview. Information concerning the patient member was, without exception, sought from relatives. If patient members happened to be present during the time of the relative's interview when finished would be asked their views on the services they have received or were in the process of receiving. This additional information supplemented the information provided by relatives. Given not all patient members were seen, their information was not applied in the same way as that of information from relatives.

4.8 A Personal Account of the Research

Gaining access to relatives for interview was occasionally met with disapproval from some of the professionals working with patients. It was felt that I might create difficulties within families when asking questions about how burdensome the patient was. Professionals were worried that this might exacerbate any existing tension between relatives and patients. These professionals often resisted the nature of the study given the orientation of South Verona's community mental health services being geared towards systemic family therapy. This sometimes acted as a hindrance in gaining access to patients and their families. I had to negotiate with, as well as reassure professionals that I would remain sensitive to any familial tensions and make every effort not to aggravate them. Once professionals had become more familiar with me and the work I was doing tensions did begin to ease, and we become much more cooperative with each other.

Collecting data from interviews was a relatively straightforward procedure. The main difficulty which did emerge, however, concerned the patients and relatives who had not responded to my request for an interview. This meant having to contact these relatives either by phone or visit them at home. When approached in this way most of these relatives made clear their refusal to be interview. Some were however, persuaded.

Organising and adjusting to my surroundings South Verona took slightly longer than I had anticipated. I spent a total of nine months conducting the fieldwork. The first six months was used to familiarise myself with the regional dialectic, accustom myself to South Verona, and set up interviews with relatives. I was fortunate to have secretarial support in arranging appointments with relatives. The last three months were used to conduct interviews, which were sometimes exhausting, but nonetheless rewarding.

4.9 Analysis of Data: Advantages and Disadvantages of the Approach Used

A quantitative approach to the study was adopted for several reasons. Previous impact-of-care research in the area of mental health has often been carried out by clinical psychologists and psychiatrists. As a consequence research on impact of care in the area of mental health has tended to be both quantitative and medical in approach. Using the standardised interview schedule developed from other impact work had greater advantages than adopting a purely qualitative and social approach to the study. These latter approaches however, were considered important and an effort was made to incorporate them into the current study. The purpose of the present study was not to create a new schedule or questionnaire to measure impact, rather to take what has already been established to assess what was happening in the Italian context. This also had the advantage of allowing direct comparisons with the British context.

The quantitative/medical approach fitted in well with the South Verona Research Unit where I was based during fieldwork. Relatives seemed to take the study more seriously given this approach. In many cases relatives did not want interviews to be tape recorded. Even writing lengthy notes often interrupted relatives' while they were talking during interviews. For these reasons it would have been impractical to attempt a purely qualitative approach to the study. It was easier, and less disruptive for relatives, if I wrote notes to open questions once the interview was over.

Some of the disadvantages in using a quantitative/medical psychiatric approach is that it can often overlook a deeper understanding of a person's experience. The essence of a person's individual and subjective experience can sometimes be missed by the quantitative/medical approach.

The data obtained from interviews were analysed using SPSS PC+ (Statistical Package for the Social Sciences), version 4.0.1. In the first results chapter (Chapter 5) descriptive statistics such as frequencies, percentages, means and cross-tabulations form the basis of an analysis of responses obtained from relatives. The second results chapter (Chapter 6) incorporates t-tests to compare groups of relatives and patients to determine how impact varied amongst them. The responses gathered from open ended questions, included in the schedule, provided information for describing families' situations at a more qualitative level.

Chapter Five

Descriptive Characteristics of South Verona Relative and Patient Samples

The following chapter offers an introduction to the results obtained on the relatives interviewed and their patient members. A more detailed analysis to determine how impact on relatives within specific groups is examined in Chapter 6. The preliminary results of this chapter outline relatives' and patients' kinship status, in the first instance. Socio-demographic factors of both sample groups are described, including sex, age, marital status, family size and residence. The patient's length of illness and clinical characteristics, again according to kinship and gender factors, provide the next theme. Relatives' knowledge on various aspects of the patient's condition follow. The type of services received by patients and the professionals both they and relatives have come into contact with is then covered.

The areas of impact encountered by relatives provide the other main focus of this chapter. These include general characteristics of relatives' employment and financial status, their recreational activities, their interpersonal relationship with the patient, and their physical and psychological health. The patient's own employment, financial, domestic and social activities. The patient's behaviour and relative's reaction to it, the frequency and severity with which it occurs, and what relatives attributed patient's behaviour to are outlined in the final section.

Characteristics of Relatives

5.1. Kinship

Three basic kinship groups were covered: spouses, parents and child relatives, shown in Table 5.1 below. Of the 40 relatives interviewed the majority were spouse relatives, who constituted half the sample (20 or 50%). These were predominantly wives of patient members (27.5% of the total sample). Parent relatives formed the next largest kinship group (15 or 37.5%), consisting mainly of mothers of patient members (25% of the total). The smallest kinship group were child relatives who represented 12.5% (5) of the total sample of relatives interviewed, mainly daughters of patient members.

Table 5.1
Relatives' Kinship Status According to Patient Diagnosis

Diagnosis **Kin**	Functional Psychosis	Affective Psychosis	Depressive Neurosis	**Total**
Parents	15(83.4%)	-	-	15 (83.4%)
Spouses	3 (16.6%)	5 (71.5%)	12 (80%)	20 (50%)
Children	-	2 (28.5%)	3 (20%)	5 (12.5%)
Total	18 (45%)	7 (17.5%)	15 (37.5%)	40 (100%)

Among the 16 (40%) male relatives 22.5% were husbands of female patient members. Fathers of patients followed and formed 12.5% of the total relative sample. Two sons of patients made up the final kinship group of child relatives.

Mothers of patients with a diagnosis of functional psychosis were the most common kinship relative, and featured exclusively in this particular diagnostic group. In the affective psychosis group relatively minor differences in terms of kin were found. Similarly, for the depressive neurosis group differences according to kin were less pronounced, although slightly more husbands emerged as the more common relative here.

Summary

Spouses were the largest group of relatives in the sample overall, whose patient members were mostly diagnosed with depressive neurosis. Parents formed the second, and the majority of patient members here had been diagnosed with functional psychosis. A small number of child relatives formed the third and final kinship group in which their patient members were either diagnosed with affective psychosis or depressive neurosis.

5.2 Socio-demographic Characteristics of Relatives

This section includes details of relatives' sex, age, marital status and family size. Table 5.2 provides a breakdown of each of these socio-demographic characteristics of relatives (excluding residence) in both numbers and percentages according to patient diagnosis.

Table 5.2
Socio-demographic Characteristics of Relatives According to Patient Diagnosis

Diagnosis	Functional Psychosis	Affective Psychosis	Depressive Neurosis	**Total**
Sex				
Male	5 (27.7%)	3 (42.8%)	8 (53.3%)	16 (40%)
Female	13 (72.2%)	4 (57%)	7 (46.6%)	24 (60%)
Total	18 (45%)	7 (17.5%)	15 (37.5%)	40 (100%)
Age (years)				
Mean	57.8	38.3	40.9	48.3
Std.dev.	10.9	12.2	11.4	14.3
Marital Status				
Single	-	2 (28.5%)	3 (20%)	5 (12.5%)
Married or cohabiting	14 (77.7%)	5 (71.4%)	12 (80%)	31 (77.5%)
Widowed	4 (22.2%)	- -	4 (10%)	
Total	18 (45%)	7 (17.5%)	15 (37.5%)	40 (100%)
Family size (no. of members)				
Mean				3.5
Std.dev.				.9

5.2.1 Sex of Relatives

The distribution of gender among each of the patient diagnoses revealed a large percentage of female relatives (72.2%) with patient members diagnosed with functional psychosis. As described above in section 5.1 on kinship characteristics, many of these particular female relatives were mothers. Within the affective psychosis diagnostic group the difference in numbers according to gender was relatively slight (see Table 5.2). In the depressive neurosis diagnostic group male relatives out number females, although the difference was marginal (see Table 5.2).

The gender distribution thus of relatives within the latter two diagnostic groups (affective psychosis and neurotic depression) was moderately even. The functional psychosis group however, revealed a hefty percentage of female relatives. There were two principal reasons for this. The first concerned the actual type of diagnosis. Schizophrenic psychoses and other functional psychoses of this kind typically affect young male adults (Iacono and Beiser, 1992). Indeed, having drawn up the patient sample from South Verona's Psychiatric Register (see Chapter 4) a high proportion of males emerged. Many were single - as the section on Patient Characteristics outlines (see below) - and living in the parental home. Within this particular family structure mothers of these male members diagnosed with functional psychosis, if present, were more likely to be the patient's significant other, which provided the second reason why female relatives were highly represented in this diagnostic group. The highest percentage of male relatives (53.3%, see Table 5.2 above), on the other hand, had patient members with depressive neurosis.

Summary

Female relatives were mostly interviewed, particularly mothers of patient members with a diagnosis of functional psychosis. Male relatives were present in each of the diagnostic categories, although more prominent where patients had a diagnosis of depressive neurosis.

5.2.2 Age of Relatives

The range of ages amongst relatives varied from the youngest at 16 years to the oldest at 77 years old. The mean age for the entire sample of relatives was 48.2 years (SD 14.23)[1]. When examined according to diagnostic groups relatives with the

---

[1] Data on age were missing in one case.

youngest mean age (M38.2, SD 12.17) were those whose patients who had received a diagnosis of affective psychosis. The oldest (M 57.8, SD 10.90) were relatives of patients with a diagnosis of functional psychosis. These latter relatives were far more likely to be parents and thus tended to be older. Indeed, there was also a very small number of elderly relatives above the age of 70.

Relatives of patients from the depressive neurosis diagnostic group had a mean age of 40.9 years (SD 11.39, 14 cases). Both this group and relatives of patients diagnosed with affective psychosis were predominantly spouses, and notably younger than parent relatives in the sample. The mean age of child relatives was 25 years (SD 7.1). The diagnoses of patient members common to these particular relatives were affective psychosis and depressive neurosis.

Summary

Parent relatives had the oldest mean age, most of whom's patient members were diagnosed with functional psychosis, and heightened differences between diagnostic and kinship groups. Spouse and child relatives in terms of their mean ages were younger, the latter group of relatives much more so but were adults.

5.2.3 Marital Status of Relatives

Of the 12.5% of relatives who were single all were children of patient members. The majority of relatives (77.5%) included in the sample were married and roughly distributed between each of the three diagnoses. Cohabiting was rare among South Verona couples. There was a small percentage (10%) of relatives who were widowed, representing most of the elderly relatives in the sample. One of the primary criteria for inclusion in the sample was that relatives and patient members lived within the same household. It was inevitable therefore that separated or divorced spouses of patients were excluded, unless they shared the same accommodation.

Summary

Given the bulk of relatives interviewed were either spouses of patient members or parents and thus married. The few relatives who were single were all child relatives of patient members. The remainder were mostly elderly widows. None of the relatives interviewed were either separated or divorced.

5.2.4 Family Size

Family size ranged between 2 to 5 members. Families containing only two members (15%) usually included just the relative and the patient member. Where the number of members exceeded two children, another adult relative such as a spouse or parent (not a child), or perhaps an extended family member, (although this occurred only once), all occupied the same household. Indeed, the majority of families had more than 2 members, whereby 67% of families consisted of 3 or 4 members. The mean family size was 3.5 (SD .9), (see Table 5.2 above).

Over 65% of families in the sample had no other adult family members other than the relative interviewed and any children. The remainder (32.5%) had one other adult member, mostly husbands of the relatives interviewed. The mean age for these particular adult members was 58.2 (SD 6.7). These additional adult members were commonly found amongst patient members diagnosed with functional psychosis.

Children, both male and female, on the other hand, were present in 65% of families. Their mean age was 18.9 (SD 6.5). Of all the children 50% were within families whose patient member had a diagnosis of depressive neurosis, and 32.3%

where the patient member had a diagnosis of functional psychosis.

Summary

The presence of other family members, both adults and children, were mainly found where patient members had either a diagnosis of depressive neurosis or functional psychosis.

5.2.5 Residence and Housing Situation

The South Verona catchment area covered 6 areas: Borgo Roma, Castel d'Azzano, Cadidavid, Buttapietra, Santa Lucia and Golosine[2]. South Verona's psychiatric services are based in Borgo Roma in which 50% of the sample were resident. Half of these patients had received a diagnosis of functional psychosis. The more peripheral localities included Castel d'Azzano, Cadidavid and Buttapietra, where between 2 and 7 percent of relatives in the sample lived.

Relatives' housing circumstances were quite mixed in terms of whether they were owner occupiers or lived in rented accommodation. Almost 80% of all the families lived in flats, apart from those who lived in the peripheral localities in which small houses were the main type of accommodation.

A greater percentage of relatives lived in owner occupied accommodation (62.5%). The remainder either rented unfurnished or furnished accommodation. The number of rooms ranged from 2 to 5, where most relatives (77.5%) and patients lived in accommodation with 3 or 4 rooms, which consisted of 2 to 3 bedrooms.

The number of members living within these households ranged from 2 to 8 (see

---

[2] See Chapter 4, section 4.2.1 for a fuller description.

section 5.2.7 above). In some cases where families were comparatively large, between 5 and 7 members (over 50% of the sample), the accommodation lacked enough space for family members. Subsequently, 32.5% of relatives described the problems they had with their housing. Indeed, for 12.5% their accommodation problems were quite serious and had considered moving.

Summary

Relatives and patients mainly resided in Borgo Roma. Many families owned their accommodation. Most were satisfied with their housing circumstances, although for some larger families their housing was sometimes restrictive in size, which subsequently presented problems.

5.2.6 Summary of Socio-demographic Characteristics of Relatives

Females, usually mothers of patient members, represented the majority of relatives interviewed. Parent relatives had a higher mean age compared to spouse relatives in the sample. Very few relatives were single, these were usually the children of patient members. There was a small number of widows. The majority of relatives were married and many of the families included a moderate number of children and/or other adult members, living mostly in Borgo Roma.

There appeared to be a clear distinction between various groups of relatives the patient member's diagnosis. Relatives of patient's diagnosed with functional psychosis were typically mothers of male patient members. Relatives of patient members diagnosed with either affective psychosis or depressive neurosis were typically wives. Husband relatives, for the most part, usually had patient member wives with a diagnosis of depressive neurosis.

Characteristics of Patients

5.3 Kinship of Patients

There was a predominance of sons (35%) in the functional psychosis group, followed by husbands (7.5%), and one mother. Those diagnosed with affective psychosis were distributed between spouse (7.5% husbands; 5% wives) and parent (5% mothers) kinship groups. With this particular psychosis patients tended to be older, and were invariably spouses. In the depressive neurosis category wives (17.5%) predominated, followed by husbands (12.5%) and then mothers (7.5%).

Summary

The predominance of sons diagnosed with functional psychosis was quite evident. Their role in the family was less likely to consist of any key responsibilities compared to spouse or parent patient members. These latter two patient kinship groups however, were more prevalent in the diagnostic groups of affective psychosis and depressive neurosis.

5.4 Socio-demographic Characteristics of Patient Members

This section covers patients' sex, age and marital status, the figures and percentages for which are listed in Table 5.3 below.

Table 5.3
Patients' Socio-demographic Characteristics (Numbers and Percentages)

Diagnosis	Functional Psychosis	Affective Psychosis	Depressive Neurosis	**Total**
Sex				
Male	17 (94.5)	3 (42.8%)	5 (33%)	25 (62.5%)
Female	1 (5.5%)	4 (57%)	10 (66%)	15 (37.5%)
Total	18 (45%)	7 (17.5%)	15 (37.5%)	40 (100%)
Age (years)				
Mean	32.2	44.2	45.9	39.4
Std.dev.	9.1	10.6	8.9	11.3
Marital Status				
Single	14 (77.7%)	-	-	14 (35%)
Married/ cohabiting	3 (16.6%)	7 (100%)	13 (86.6%)	23 (57.5%)
Separated	1 (5.5%)	-	1 (6.6%)	2 (5%)
Widowed	-	-	1 (6.6%)	1 (2.5%)
Total	18 (45%)	7 (17.5%)	15 (37.5%)	40 (100%)

5.4.1 Sex of Patients

As section 5.3 on patients' kinship status indicated, almost all patient members diagnosed with functional psychosis were males (94.5%). Only one female in the patient sample had a diagnosis of functional psychosis. Female patient members had mostly been diagnosed with depressive neurosis, and there were slightly more females diagnosed with affective psychosis.

Summary

Males were mostly present in the functional psychosis group. Female patient members were more commonly located either in the affective psychosis group, and notably more so in the depressive neurosis category.

5.4.2 Age of Patients

Patients representing the youngest mean age group (32.5 years, SD 9.1) were those diagnosed with functional psychosis. Just under half of the 18 patients with this diagnosis were in their twenties. The remainder were in their thirties.

In the affective psychosis and depressive neurosis groups patient members are somewhat older compared to the functional psychosis group. The mean ages of these patient members (in the affective psychosis and depressive neurosis groups) were very similar, 44.2 (SD 10.6) and 45.9 (SD 8.9) years respectively, (see Table 5.3 above).

Summary

Younger patient members in the sample were diagnosed with functional psychosis. In the affective psychosis or depressive neurosis group the mean ages of patient members tended to be older, differing substantially from the functional psychosis group.

5.4.3 Marital Status of Patients

A high proportion of patient members overall were married (57.5%), over half of whom had received a diagnosis of depressive neurosis. Of the married patients 17.5% were diagnosed with affective psychosis. Single patient members represented the second largest group representing 35% of the total patient sample, all of whom had a diagnosis of functional psychosis. A marginal percentage of patients were separated or widowed (7.5%).

Summary

A large majority of married patient members were mainly diagnosed with depressive neurosis, and to a lesser extent with affective psychosis. Single patient members all had a diagnosis of functional psychosis.

5.5 Patients' Length of Illness and Clinical Characteristics

This section deals with patients' first and last year of contact with services and the types of services used.

5.5.1 First Year of Contact with South Verona Services

The collection of interview data took place in 1988. Patient members' year of first contact with psychiatric services thus was either in this year or prior to it. Two patients had began their service contact in 1973, signifying the earliest first year of contact amongst the patients whose relatives were interviewed. Just over 12% of patients had contacts with services spanning over a ten year period or more, prior to 1988. These patients were spread across each of the three diagnostic categories selected and represented the patients with chronic mental illness.

There were 32.5% whose first contact with services was between 1981-1984. The bulk of these patients had received a diagnosis of functional psychosis. A great many patients in the sample (55%) had their first contact with services between 1985-1988. Just under 30% of these had been diagnosed with depressive neurosis. There were 10% of patients with the same diagnosis, whose first year of contact with South Verona's community psychiatric services was in 1988. Their contact with services thus was less than a year.

Not all patients had their onset of illness at the time when they first contacted South Verona's community psychiatric services. Some had received treatment from other psychiatric services and later came to live within South Verona's catchment area.

Precise information on some patients' onset of illness, particularly those who had been unwell for much of their lives, was not always available. However, this applied to only a small number of patients, not more than two or three. None of the patients had ever been admitted to the mental hospital located 10 miles from South Verona.

Summary

The percentage of patients in the sample was roughly divided between those with short- and long-term illnesses. Patients whose contact with services stretching over ten or more years represented the minority. A third of patients had their first contact with services between 1981 and 1984 and were mostly diagnosed with functional psychosis. The largest number of patients, however, were those whose first contact with South Verona services had been three years prior to 1988.

5.5.2 Last Year of Contact with South Verona Services

Patients' last contact with South Verona psychiatric services was recorded in October of 1988 when interviews with all forty relatives had been completed. As described in the Methodology (Chapter 4), one of the four criteria for selecting patients specified that their last year of contact with South Verona community psychiatric services be between 1985 and 1988. Sixty-five percent of patients had their last contact with services in the same year interviews with their relatives took place, 1988. A large percent of patients in the sample thus continued to be in receipt of psychiatric services when relatives were visited. Just over a quarter of patients had not been in contact with services since 1987, and two patients had not been in touch with services since 1985 and 1986.

Summary

The percentage of short- and long-term users of South Verona's community psychiatric services was roughly divided between the two, thus providing a mixture of both. In each of the three diagnostic groups there were those patients whose condition had spanned over many years and those whose mental illness had been relatively brief or short term.

5.5.3 Referral to Services

Referrals to services and subsequent appointments, once initial contact with services had been made, were in 70% of cases made by a professional. In 20% of cases patients had referred themselves to services. Only 7.5% of patients were referred to services by a relative.

5.5.4 Number of Services Used by Patients According to Diagnosis

The mean number of service contacts for the entire sample of patients was 52.5, (see Table 5.4 below). When assessed according to patient diagnosis the mean number of contacts with services was much higher for the two psychosis groups compared to patients with depressive neurosis. The former two diagnostic groups had on average 65 to 70 contacts with services, where the depressive neurosis group mean number of contacts was 24.7. Patients thus, with either one of the two psychoses had a substantial number of service contacts, much more so than patients with depressive neurosis.

The range of service contacts amongst patients was fairly wide, between 1 and 258 contacts. Only one patient (diagnosed with affective psychosis) had visited the service once. Patients with a high number of service contacts were usually those suffering long-term illnesses. There were, however, two patients whose contact with South Verona's services began in the 1970's and had made only 30 visits or less. One of these patients however, had their last recorded visit to services in 1985, the other in 1988. Apart from these extreme cases, many patients (just over half the sample) had fairly regular contact with services over a number of years. A further 40% of the patient sample had their first contact with services in the latter part of the 1980's. These patients had made no more than 15 visits to services. One exception to this included a patient whose first contact with Borgo Roma services was in 1986 whose number of contacts with these services reached 138 by 1988.

Summary

Patients who had used services quite extensively (i.e. over a hundred or more visits to services) had begun contacting South Verona services either in the 1970's or early 1980's. Many of these patients had been diagnosed with psychosis. Contacts made by short-term users appeared to have much briefer episodes of illness and subsequently less contact with services, and over a much shorter period of time compared to long-term users.

5.5.5 Patients Not in Contact with South Verona Psychiatric Services

There were a series of patients included the sample who were no longer in contact with South Verona Services. These made up 30% of the total sample. In some of these cases patients had only one acute episode of illness and received a diagnosis of functional psychosis. Many of these particular patients were well during the time relatives were being interviewed, and had suspended contact with services for that reason. There were, however, some patients here diagnosed with depressive neurosis, who after an episode or two of being unwell had recovered sufficiently to resume their normal activities, and no longer required assistance from services. All these relatives talked at length, during interviews, about events when the patient member became unwell and the disruptions subsequently occurring. Relatives described the shock of seeing the patient member behaving in a strange manner and talking in a way that was bizarre and sometimes hurtful for relatives. One father whose son had an acute episode of psychosis and unwell for about 14 months was perplexed by his son's behaviour. The patient member stayed in bed all day, having to be persuaded to eat, be accompanied to the bathroom, and be helped with getting dressed, but had since recovered fully. An additional 12.5% of patients had ceased visiting services for the time being. In one case, however, a patient decided to transfer to private psychiatric facilities, which he considered much better, and another patient had moved outside the South Verona catchment area, hence her reason for transfer to another service. There was only one relative in the sample whose husband had completely lost touch with South Verona services, but it was clear he still required care. There was no doubt about the work involved for this particular relative's role as carer. Her husband was still unwell, not just in terms of his mental health but his physical health too deteriorated. He would spend the day sleeping on the sofa until his wife returned from work. The carer's task in looking after her husband was becoming more demanding and she contemplated leaving her job to care for him on a full time basis. The relative made little complaint about her situation. It was also evident that services could still play a part in assisting the patient member and this relative, but the patient was reluctant to see a professional.

Summary

Patients who had lost contact with services completely were mostly people with acute episodes of illness who recovered fairly quickly. For some patients contact with services had ceased only for the time being. Only one relative who cared for her husband had no contact with services, yet clearly still needed them.

Table 5.4
Patient Members' Mean Number of Contacts with South Verona Psychiatric Services and Admissions to Hospital (Mean Numbers)

Diagnosis	Functional Psychosis	Affective Psychosis	Depressive Neurosis	**Total**
Mean Number of Sth Verona Contacts	70.83	65.00	24.73	52.52
Std.Dev.	79.86	80.50	37.95	69.09
Mean Number of Admissions	5.64	4.20	4.50	5.08
Std.Dev.	9.77	4.08	4.23	7.66
Longest Period of Admission (No. of Days)	20.4	18.6	27.8	21.54
Std.Dev.	13.08	12.56	18.37	13.93

5.6 Patients' Type of Contact with Services

This section describes the type of contact patients in the sample had with South Verona's community psychiatric services.

5.6.1 Admissions to Hospital

Twenty-five patients (62.5%) had been admitted to South Verona's psychiatric ward at some stage during their illness. The number of admissions varied from a minimum of 1 to a maximum of 39 admissions to the ward. Table 5.4 lists the mean number of admissions to hospital of patients with reference to their diagnosis. Patients diagnosed with functional psychosis had a higher mean number of admissions (5.64, SD 9.77) compared to the other diagnostics groups. For most patients the number of admissions to hospital did not exceed three. For some patients admission to the ward appeared to be a regular event, although this applied to a very small percentage of patients (7.5%).

The time spent in hospital during admissions varied considerably. The period of admission for patients in the sample was anywhere between 2 to 50 days. Diagnostically, patients with functional psychosis tended to have longer periods of stay when admitted to the general hospital's psychiatric ward.

Summary

Over half the patient sample had been admitted to hospital. Patients with functional psychosis had a higher rate of hospital admission compared to the other diagnostic groups, and tended to have longer periods of admission.

5.6.2 Other Types of Psychiatric Services Received by Patients and Professionals Seen

This section provides a brief overview of what services patients received and the professionals seen. A fuller account of other services received, such as home visits, respite care, and family therapy, is described in the section under Relatives and Service Provision (see section 5.10 below).

The following information was gathered from the Psychiatric Case Register. The most common form of contact for 47.5% of patients was individual consultations. This accounts for the high percentage of patients (57.5%) across all three diagnostic groups who, for the most part, had seen a psychiatrist, who was thus the most frequented professional. This was particularly so for patients diagnosed with depressive neurosis. Very few patients with this diagnosis used other forms of services such as the Day Hospital or other general services provided by the Community Mental Health Centre (CMHC).

Patients diagnosed with one of the two psychoses again had mainly individual consultations, but used the CMHC more extensively compared to patients diagnosed with depressive neurosis. Meetings at the CMHC were largely attended by patients in the sample with a diagnosis of functional psychosis. Indeed, 30% of patients had seen the catchment area team with a psychiatrist present at the Centre, rather than in the general hospital, and 5% had seen either a psychologist or a social worker.

Summary

Individual consultations with professionals represented the most common form of service contact for all patients in the sample, where the psychiatrist was the professional seen the most. This was particularly so for patients diagnosed with depressive neurosis, who tended to use this type of service almost exclusively. Patients with functional psychosis had a wider use of services by comparison, having attended the CMHC much more, and had seen professionals other than the psychiatrist.

5.6.3 Summary of Patients' Contact with South Verona Services

The patients included in the sample illustrate an amalgam of people with differing lengths of illness and in their use of South Verona services (either short- or long-term users). Around half the patients had used services extensively and over a long period of time. Individual consultations with a psychiatrist represented the most popular form of contact with services and professionals, particularly amongst patients with a diagnosis of depressive neurosis. Patients who had been diagnosed with functional psychosis had tended to use the CMHC, and in some cases on a regular basis. Patients with functional psychosis had comparatively longer periods of stay in the admissions ward compared to the other diagnostic groups. The patient sample also comprised of people who had lost touch with South Verona services, either as they recovered from an acute episode of illness or for other reasons.

The following section gives details on how much relatives knew about the patient member's condition, essentially obtained from South Verona services.

5.7 Relatives' Knowledge on Patient Diagnosis, Condition and Medication

Information about the patient member's diagnosis had been provided by professionals to a number of relatives interviewed. Over half the sample of relatives had, to some degree, knowledge about the patient's diagnosis. Understanding the nature of the patient's condition and what their future prospects might be as a consequence was discussed to a much lesser extent with relatives. The majority of relatives, some 77.5%, had not been informed on the nature of the patient's condition and what subsequently lay ahead. Only 10% of relatives felt they fully understood what the nature of the patient's condition entailed.

A high percentage of relatives, however, (45%), had received information on medication and its side effects. Information on the patient's medication and its possible side effects was comparatively scant for 40% of relatives.

Summary

For the most part, relatives had been well informed about their patient member's diagnosis and the medication used in treatment. Relatives were much less aware of the nature of the patient's condition and what its future prospects were likely to be.

5.8 Relatives' Responses and Service Provision for Patient Members

The following section deals with services received by the patient member from the relative's perspective. Relatives described the service interventions such as home visits, crisis services, respite care or alternative accommodation for the patient member, and the professionals relatives had come into contact with. The need for more services of this kind is explored in greater detail in Chapter 6.

5.8.1 Home Visits

Home visits by professionals were received on a regular basis by 22.5% of relatives. A high proportion of home visits were to patients diagnosed with one of the two psychoses, whose relatives were mostly parents.

5.8.2 Crisis Intervention

Over 80% of patients, from all three diagnostic groups, had received crisis intervention services and for most was probably the first type of contact with psychiatric services both patients and their relatives had encountered. For 55% of relatives the crisis services received had been adequate. They also had no doubt about its availability for any future crises.

Twenty-five percent of relatives however, felt that emergency services used by the patient member had not been obtained easily. A quarter of patients during an episode of illness had been taken to casualty and then referred to the psychiatric ward of Borgo Roma's general hospital. Approximately 30% of relatives following a request for crisis intervention received either no help within 24 hours or were given an appointment to see a psychiatrist at a later date. For some relatives and patients (17.5%) crisis intervention took the form of a home visit, many of whom had received a diagnosis of functional psychosis.

5.8.3 Alternative Accommodation and Respite Care

Respite care offers a break for relatives whose caring role is consistently wearing. If it then reaches a stage where the relative can no longer cope effectively with his/her caring role then alternative accommodation for the patient member may be necessary. In the sample of relatives and patients included in the study this particular service was reserved for the most extreme cases, i.e. where there was a threat that the carer would not be able to continue caring for the patient member. Alternative accommodation had been offered to one patient member whose elderly mother was finding it increasingly more difficult to care for her son.

Respite care, as a formal service, had not been offered to any relatives by South Verona services. The only time in which relatives might have a break from caring would be if the patient member was admitted to the general hospital psychiatric ward or attended the CMHC during the day.

5.8.4 Professionals Seen by Relatives

As described above the professional most frequented by patient members in the sample was the psychiatrist. This was true also for their relatives. In 80% of cases relatives, at some point during the patient's involvement with services, had come into contact mainly with the psychiatrist. Contact with other professionals, such as nurses, social workers and psychologists was minimal by comparison. Interaction with psychiatric nurses for relatives would largely take place if the patient had either been admitted to the psychiatric ward or if relatives had accompanied the patient to the CMHC and happened to see a nurse. Contact with a social worker, based primarily at the CMHC, would be to deal with quite specific issues concerning the patients social welfare. This type of intervention had been received by a small number of relatives (15%).

The psychologist's clinical role included either individual consultations with the patient member or family therapy where all members of the family were included. Consultations with the psychologist represented a forum for patients and relatives to give vent to their psychological problems. There was no formal service, however, that gave relatives an outlet of their own to address any psychological difficulties they may have encountered. Within this context 17.5% of relatives had been invited to discuss such problems with these professionals.

5.8.5 Summary of Service Provision from the Perspective of Relatives

Crisis intervention was a service the majority of relatives and patients were familiar with. Home visits were limited to just under a quarter of patients, mostly those with a diagnosis of psychosis. Respite care had not been offered to relatives, although on occasion sheltered accommodation could be provided for a patient member in need of continuing care if the relative was unable to perform this. Of the professionals seen the psychiatrist was the most popular amongst both patients and relatives in the sample. Having outlined areas concerning relatives' and patients' characteristics and the contact with South Verona's community psychiatric service the next main section provides an introductory overview of relatives' responses concerning the areas of impact.

5.9 Impact Areas and Relatives

Impact areas described in the following section covers the possible areas of burden a relative may experience when caring for a member diagnosed with mental illness. These include employment, financial, domestic, leisure and social activities, interpersonal relationship between relative and patient member and relatives' physical and psychological health. All of these areas are described with reference to relatives' kinship, gender and patient diagnosis.

5.9.1 Relatives' Occupational Status

Table 5.6 provides a list of relatives' occupational status with reference to patient diagnosis. Just under half the sample of relatives were in paid employment. Of these relatives 42.5% were employed on a full-time basis, and almost two-thirds of whom had a patient member diagnosed with depressive neurosis. The majority were spouse relatives, both wives and husbands of patient members. By contrast, only one parent relative was in full-time employment. Parents in the relative sample were either retired, mainly fathers, or homemakers and mostly mothers of patient members. Child relatives of patient members made up the other kinship group working full-time, except for one daughter in full-time education. None of the relatives was unemployed.

Table 5.6
Occupational and Professional Status of Relatives According to Patient Diagnosis (Numbers and Percentages)

Diagnosis	Functional Psychosis	Affective Psychosis	Depressive Neurosis	**Total**
Occupational status				
Employed (full-time)	2 (11%)	4 (57%)	11 (73%)	17 (42.5%)
Employed (part-time)	1 (5.5%)	1 (14%)	-	2 (5%)
Unemployed	-	-	-	-
Retired	6 (33%)	2 (28%)	2 (13%)	10 (25%)
Homemaker	9 (50%)	-	1 (6.6%)	10 (25%)
Student	-	-	1 (6.6%)	1 (2.5%)
Total	18 (45%)	7 (17.5%)	15 (37.5%)	40 (100%)

In terms of professional status, of the employed relatives 40% performed either unskilled or blue collar jobs. Twenty-percent were in clerical jobs and a small minority held semi-professional and professional positions (5%).

5.9.2 Relatives Employment Activity

This section applies to employed relatives and those who had recently given up their job to stay at home, and not to the long-term retired or homemakers. The themes covered here describe not only the changes relatives may have made to their employment routine, but whether they had experienced difficulties in maintaining their customary work standards, and if they have had to take leave or time off due to the patient member's condition.

Making actual changes to their employment due to the patients' condition affected 12.5% relatives in all and ranged across each of the diagnostic categories. These were mainly wives, and one husband, who represented the more extreme cases in the sample having given up work to care for children and the patient member. To a lesser extreme a quarter of all relatives had taken some time off when the patient member became unwell. For the majority of these 10 respondents (60%) the amount of time taken off work was relatively brief, not lasting more than a week. At least 4 (40%) of these respondents had patient members diagnosed with depressive neurosis. A small percentage of relatives (5%) had taken more than 6 weeks off work to care for patient members diagnosed with of one of the two psychoses.

Of the 19 relatives employed, 47.5% were not finding work a problem in terms of maintaining their normal standards or routine. Some (26%) did find their work stressful, although this was said not to be related to the patient member's condition. The same percentage of relatives found work tense because of difficulties relating to the patient member. For two of these relatives finding work stressful only lasted for as long as the patient member was unwell. For the remaining three relatives (15.7%) the effect of the patient member's condition on their work routine was a constant concern. The relatives experiencing difficulties with their work were all spouses, and almost exclusively wives of patient members. For two of these relatives the stress was so great, where their standards had declined so much, they feared not be able to continue working.

Summary

The sample of relatives with regards to their occupational status was roughly divided between those who were actively employed, either on a full- or part-time basis, and those who were retired or homemakers. The majority of working relatives held either unskilled or blue-collar jobs. Relatives in employment were mainly spouses whose patient members had a diagnosis of depressive neurosis. Those who were not employed, retired or homemakers, were mostly parent relatives with patient members diagnosed with functional psychosis. Spouse relatives, almost exclusively wives, were the main group to have given up work to care for the patient member.

5.9.3 Financial Activity

Thirty-two percent of respondents were the main people responsible for the family finances. In 20% of cases this responsibility lay with another family member, not including the informant nor the patient member. For some 30% of families managing the family income was shared between the relative, the patient member and other members of the family. Under circumstances where a child was the patient member this form of family responsibility was not always relevant and inevitably reflected in the number of families who did not include patient members in these activities. In only 10% of families the patient member was the sole person responsible for the family's finances, 2 were spouses 2 were parents of child respondents.

For 33 relatives (82.5%) the person in charge of the family's finances had stayed the same, despite the onset of the patient's illness. There were few incidences (10%), as a consequence of the patient member's condition, where a change in the person responsible for the family finances took place, and for half these relatives this would be a temporary measure until the patient member was well again. This small percentage of relatives also had disagreements concerning the family's financial affairs. Some worried about money quite regularly, either on a weekly or daily basis. Yet, for the majority of families problems with money were minimal. This is partly to do with the fact that none of the relatives in the sample was unemployed. Even those who were retired or homemakers were reasonably secure financially.

Financial problems for South Verona relatives were thus limited for most. Some 29 (72.5%) respondents experienced no change to their family income as a consequence of the patient member's condition. Nine relatives (22.5%) mentioned however, that a change in their family income had occurred which created some difficulties. Just under half these relatives' financial situation had become much worse since the patient member's onset of illness, and just over half experienced a drop in income of up to 50% or more. Such a steep drop in family income is usually connected to a loss in earnings of either a relative having to give up work or a patient member having to leave his/her job due to illness. Indeed, this was the case for families who had experienced this vast fall in income.

One of the consequences of difficult financial circumstances for families included having to reduce the family's spending and/or the accumulation of arrears from various domestic payments, which for some families this had continued for a year or more. Not all relatives associated their financial difficulties to the patient member's condition however. Some respondents had linked a loss in family income to other members of the family and not simply a consequence of the patient member's condition. Those, however, who experienced the highest drop in family income amounting to more than 50%, made a direct association with this decrease and the patient member's condition.

Summary

Financial circumstances, including the person responsible for finances, appeared fairly stable for most South Verona families included in the study. Disruption of the family income usually meant a substantial drop where a loss in earnings may have occurred when the patient member became unwell and for a minority of relatives this had been the case.

5.9.4 Household Activity

Impact of the patient member's condition on household or domestic activities was examined in terms of the amount of housework the relative performed, whether these responsibilities had changed and if any disruption to the domestic routine had occurred. Forty-two percent of relatives conducted most if not all the domestic chores around the house. They included parents, spouses and almost all of the five child relatives. A further 40% of respondents found that the amount of housework they performed varied according to the patient member's condition, increasing when the patient was unwell, resuming normal household activities when recovered. This was especially so for relatives with patient members diagnosed with functional psychosis. The remaining number of relatives (18%) either partly contributed to the household chores by doing some of the housework or were not responsible for these activities.

Nearly all relatives interviewed were involved in running other household affairs such as paying bills, even if this did not include performing the housework. For 11 (27.5%) relatives this would change depending on the patient member's condition. Just over 50% of relatives were not affected by an increase in managing domestic affairs. Those affected by an increase in household responsibility, a quarter of all relatives, were mainly spouses whose patient member had been diagnosed with depressive neurosis.

Disruption of household management, when the patient member became unwell, for most relatives (52.5%) did not present any major problems. As with household responsibilities a minimal number of relatives, in this instance 8 (20%), found the disturbance to household management difficult. The house would temporarily become completely disorganised, whereby certain things would be neglected, particularly the more physically demanding chores such as washing floors, making beds, and so forth. In some cases this was a constant occurrence given the chronic nature of the patient member's condition.

Summary

Not all relatives interviewed were directly involved with performing domestic chores such as the housework. Virtually all, however, had some degree of responsibility concerning the household, whether this included paying bills or contributing in some other way. Disruption of household activities was minimal and for most relatives short-lived, although around a quarter of respondents did encounter domestic problems when the patient member became unwell.

5.9.5 Leisure and Social Activities

The free time relatives could spend enjoying leisure or social pursuits appeared limited for most. Fifty-five percent of respondents either had no time to pursue these activities or could do so only on some days. Subsequently, a seemingly large proportion of relatives (47.5%) never pursued leisure or social interests, particularly those with patient members diagnosed with functional psychosis. Most of the remaining relatives who pursued social activities did so on a regular basis.

Relatives who could go out for social reasons usually did not foresee any problems in leaving the patient member alone at home. For 30% of relatives however, there was some reluctance to leave the patient member unattended, although they did so despite their apprehension. An additional 12.5% of relatives however, rarely left the patient at home unattended and for a further 5% they did so only when the patient was unwell.

Changes to relatives' social activity in terms of having reduced the number of times they went out revealed similar percentages in not being affected by the patient member's condition (around 40%) and those that were (over 50%). Of the relatives who had reduced their social activities some (32.5%) did not feel much like going out socially, either because of their concern for the patient member or difficulties connected with the patient's condition. For most, this was only an occasional feeling of not wanting to go out for the same reasons. For at least 6 (15%) relatives not feeling much like going out was present nearly all the time, and more evident in relatives with patients diagnosed with one of the psychoses.

Even if relatives did not pursue social or leisure interests nearly all, however, had some form of social contact with close friends or other relatives outside the home, which was at times affected. About 15 (37.5%) noticed a decrease in the number of people making social visits. For 6 (40%) of these relatives the drop in friends calling round was substantial and in some cases these social calls stopped entirely after the patient member became unwell, especially those diagnosed with one of the psychoses. For 11 (27.5%) relatives contact with friends before the patient became unwell was notably higher, where half these relatives were unable to afford the time to visit other people given their caring responsibilities. Yet for 8 (20%) relatives contact with friends had increased after the onset of the patient's condition.

The bulk of relatives, with the exception of a few and those who preferred not to discuss personal matters with other people, had someone they could confide in. The feeling of being socially isolated thus pointed to those who had no one they could confide in (17.5%).

Summary

The sample of relatives again seemed split into two groups where social activities were concerned. One group regularly pursued leisure interests. The other was restricted by what they could do socially as a result of the patient member's condition. Nearly all relatives had some contact with close friends or relatives outside the home, although their were some who felt isolated, having no one to confide in.

5.9.6 Interpersonal Relationship Between Relative and Patient Member

Relations between the relative and patient member were viewed within the context of the patient's condition and whether things between them were good or had become more tense as a consequence. Twenty-three relatives (57.5%) had what they considered to be a very good relationship with the patient member, despite the patient's condition. Difficulties in terms of relationship became increasingly clear for a number of relatives (42.5%) when describing the problems they had in getting along with the patient member. For some the relationship had become very tense. It was these latter set of relations that worsened once the patient member had become unwell. For these relatives the problems encountered in their relationship with the patient member included an increase in the number of disagreements/arguments occurring regularly.

The 'strain of things' took its toll even on relatives who got along well with the patient member. A number of these (22.5%), largely with patients diagnosed with depressive neurosis, expressed how things could become stressful, but somehow they could cope. There were however, relatives (30%) who found relations with the patient very difficult, and a few were uncertain about whether they could continue the relationship, given things between them were so bad.

Summary

Respondents' relationship with the patient member revealed an amalgam of those who got on well with the patient member and those with apparent difficulties following the onset of the patient's illness.

5.9.7 Physical and Psychological Health

There were a large percentage of relatives 65% (26) with what they described as significant problems with their physical health. Many of whom were parents of patient members diagnosed with functional psychosis. Twenty of these relatives had been to see their General Practioners about their physical complaints, most had been prescribed medication in which to treat them. At least a third of relatives had their physical health problems for some time, up to a year or more. When asked if their physical ill health was in some related to the patient member's condition 42.5% (17) said there was no connection between the two.

A large proportion of relatives 67.5% (27) reported psychological difficulties. Unlike those with significant physical health problems slightly fewer relatives mentioned having serious emotional problems, 30% in all. Over half the relatives with significant psychological difficulties had patient members diagnosed with functional psychosis. Relatives who did not perceive their emotional problems to be serious subsequently never sought professional help. Twenty-two percent (9) of respondents did seek treatment for their psychological problems. Of all the relatives describing some degree of psychological difficulty 35% had them for more than a year. A further 15% had always had psychological problems, suggesting that some relatives were psychological vulnerable to begin with and may not have been brought on by the patient member's condition.

Considerably more relatives, compared to relatives with physical health problems, attributed their psychological difficulties to the patient's condition. At least 30% claimed there was a definite link between their emotional difficulties and the patient member's condition. These too were mostly relatives whose patient member's had received a diagnosis of functional psychosis.

Summary

Many of the respondents had problems with their physical and/or their psychological health, and some significant enough for them to warrant professional help or treatment. Relatives with substantial health and psychological problems tended to have patients diagnosed with functional psychosis.

The following section describes some of the patient members' activities, such as their own performance in terms of working, socialising, carrying out domestic responsibilities, and the sorts of behaviour relatives had encountered.

5.10 Patient Performance

Several areas in which patients' own performance and contribution to the domestic realm were explored, including their occupational activity, their financial status and capacity to manage money, if they helped with household chores, and the extent to which they pursued recreational activities and maintained social contacts. Behaviour exhibited by patient members is also described in terms of its frequency and severity as relatives perceived them.

5.10.1 Occupational Status

A great many patient members were in full-time employment, 52.5% in all, particularly those diagnosed with functional psychosis, (see Table 5.7 below). These patients were also much younger than those from the other two diagnostic groups and thus less likely to be retired, although they would be more susceptible to becoming unemployed if their condition prevented them from working. Indeed, all the patient members classed as unemployed had been diagnosed with one of the two psychoses. Of the patients who were not employed (12.5%) 10% of their relatives viewed this as a direct consequence of the patient's condition. Even for patient members who were either retired or had never worked it was evident that this was in some way related to their condition.

In terms of patients' professional status most of the employed patient members were largely in unskilled or blue collar jobs (30%), as with relatives. A smaller percentage held clerical jobs and some worked for commercial companies as professionals or executives. Homemakers, mostly wives of respondents, made up the second largest occupational group in the patient sample.

Table 5.7
Patient's Occupational Status According to Diagnosis

Diagnosis	Functional Psychosis	Affective Psychosis	Depressive Neurosis	**Total**
Occupational Status				
Never worked	2 (11%)	-	2 (13%)	4 (10%)
Unemployed	2 (11%)	3 (42%)	-	5 (12.5%)
Employed	13 (32.5%)	2 (28.5%)	6 (40%)	21 (52.5%)
Retired	1 (5.5%)	-	1 (6%)	2 (5%)
Homemaker	-	2 (28.5%)	6 (40%)	8 (20%)
Total	18 (45%)	7 (17.5%)	15 (37.5%)	40 (100%)

Summary

The patient sample thus primarily consisted of people who were employed. Homemakers made up the second largest group in terms of occupational status, most of whom were wives of relatives. Smaller percentages of patients were out of work or retired.

5.10.2 Financial Activity

The majority of patient members (70%) were in receipt of some income, whether it included wages from a job, money for housekeeping, or a retirement or invalidity pension. Relatives were asked if patients were able to manage their money, according to their own needs, or if they were spouses, those of their family's. Many were able to budget their money each week and did so without any difficulty. Patients who could administer their money included 70% of all spouses, 46.6% of child patient members, and all five parent patient members. Fifteen percent of patients were unable to manage money and subsequently did not do so, 5% of whom were spouses and the remainder were child patient members. Relatives of patients unable to administer their money attributed this to the patient's condition.

Summary

The bulk of patient members were in receipt of some form of income. Managing money for the majority did not present many problems. Most patients were able to do this and did so regularly. Those unable to manage money, largely as a consequence of their condition, were comparatively fewer in number.

5.10.3 Domestic Activity

The contribution by patient members to domestic activities included chores like the housework, the shopping and the cooking. Whether a patient conducts these activities partly depends on their kinship position in the family. Female spouse patient members, particularly if they are mothers, were more likely to have these responsibilities than their husbands or their children, unless these tasks are shared amongst all members. Patient members who are sons were far less likely to be the main person responsible for these activities.

Of the twenty spouse patient members in the sample 50% performed the housework regularly, without any prompting. There were 12.5% of spouses who did no housework. These were mostly husbands of respondents. Similarly, of all the patients diagnosed with functional psychosis (37.5%), (predominantly male family members), only one contributed to the housework regularly. Most made the occasional effort to tidy or clean the house, and some simply never did this at all. Parent patient members, mostly mothers, point to a potential area of impact if they previously performed domestic activities. In three of the five cases the contribution to the domestic realm was, for the most part, marginal and this was undoubtedly a consequence of their condition. In these particular cases other members of the family had to assume this responsibility. There were however, two mothers of respondents who still managed to performed the housework regularly despite their condition. This was also the case for a number of the patient members who were wives of respondents. Fifty-five percent of spouse patient members overall were also involved in other household responsibilities, such as paying bills.

In terms of doing the shopping or running errands a similar picture emerges. Just under half the patient members, children of respondents, did not perform these activities, nor help with them in any way. In many of these cases relatives did not see this to be consequence of their condition. The remainder however did help with the shopping and in two cases did so regularly. For spouse patient members again half were very active in doing the shopping, and 30% were not because of their condition. All parent patient members, except one, did the family shopping regularly. Cooking, as with performing the housework and doing the shopping, represented no major difficulties for most patient members in the sample. Only one was unable to cook because of their condition.

Summary

Many of the domestic activities such as the housework, shopping, cooking and other domestic affairs were performed by most spouse patients whose responsibility it was to conduct these. A minority were unable to perform these tasks because of their condition.

5.10.4 Leisure and Social Contact

A high percentage of patient members (50%) were not socially active, neither pursuing leisure activities nor seeing friends. These were predominantly patients diagnosed with either functional psychosis or depressive neurosis. Thirty-two percent of these patients were spouses.

A few patients occasionally went out, about once a month, and 17.5% would go out 2-3 times a month. A quarter of all patients however pursued recreational activities both on a regular and frequent basis, either weekly or daily.

Summary

Patients' leisure and social activities tended to be limited, in terms of the number of those who never pursued them, when compared to other activities such as maintaining their employment, managing their finances, and conducting domestic chores. A large percentage of relatives too had quite restricted social lives and in the majority of cases could be ascribed to the patient's condition.

5.11 Patient Behaviour

Twenty-nine items of behaviour were included in the study covering social withdrawal and somatic/florid types. Table 5.8 below provides a list of these behaviours according to each diagnostic group, and the numbers/percentages of relatives reporting behaviour as present in the month prior to interview. Relatives described their reaction to the patient's behaviour, whether they felt it took place frequently, how severe they considered it when present, and what they attributed the behaviour to.

Table 5.8
Social Withdrawal and Somatic/Florid Behaviours by Patient Diagnosis

Diagnosis	Functional Psychosis	Affective Psychosis	Depressive Neurosis	Total
Social Withdrawal Behaviour				
Misery	14 (77.7%)	6 (85.7%)	9 (60%)	29 (72.5%)
Underactivity	9 (50%)	4 (57%)	5 (33%)	18 (45%)
Worrying	10 (55%)	5 (71%)	7 (46.6%)	22 (55%)
Fearful/anxiety	9 (50%)	5 (71%)	7 (46.6%)	21 (52.5%)
Irritability	12 (66.6%)	4 (57%)	10 (66.6)	26 (65%)
Withdrawal	13 (72%)	6 (85.7%)	8 (53%)	27 (67.5%)
Slowness	6 (33%)	4 (57%)	3 (20%)	13 (32.5%)
Overdependency	6 (33%)	3 (42.8%)	5 (33%)	14 (35%)
Self neglect	3 (16.6%)	3 (42.8%)	1 (6.6%)	7 (17.5%)
Indecisive	12 (66.6%)	5 (71%)	7 (46.6%)	24 (60%)
Forgetful	8 (44.%)	4 (57%)	4 (26.6%)	16 (40%)
Attention seeking	6 (33%)	2 (28%)	6 (20%)	14 (35%)
Nagging/Grumbling	11 (61%)	6 (85.7%)	8 (53%)	25 (62.5%)
Somatic/Florid Behaviour				
Sleep disturbance	8 (44.4%)	4 (57%)	3 (20%)	15 (37.5%)
Unpredictability	6 (33.3%)	1 (14%)	3 (20%)	10 (25%)
Somatic complaints	9 (50%)	5 (71%)	9 (60%)	23 (57.5%)
Odd ideas	5 (27.7%)	2 (28%)	3 (20%)	10 (25%)
Appetite	5 (27.7%)	3 (42.8%)	2 (13%)	10 (25%)
Rudeness	9 (50%)	1 (14%)	1 (6.6%)	11 (27.5%)
Offensive behaviour	4 (22%)	1 (14%)	-	5 (12.5%)
Suicide threat/ attempt	-	-	4 (26.6%)	4 (10%)
Overactivity	7 (38.8%)	1 (14%)	2 (13%)	10 (25%)
Odd behaviour	1 (5%)	-	2 (13%)	3 (7.5%)
Obsessionality	9 (50%)	4 (57%)	8 (53%)	21 (52.5%)
Elated mood	1 (5%)	2 (28%)	1 (6.6%)	4 (10%)
Destructive behaviour	2 (11%)	-	-	2 (5%)
Hallucinations	4 (22%)	-	-	4 (10%)
Violent	3 (16.6%)	1 (14%)	-	4 (10%)
Drink heavily	2 (11%)	1 (14%)	3 (20%)	6 (15%)
Total	18 (45%)	7 (17.5%)	15 (37.5%)	40 (100%)

5.11.1 Social Withdrawal Behaviour

There were a number of behaviours common to each of the three diagnostic categories included in the study. In general, social withdrawal behaviour was far more evident in the sample of patient members than somatic/florid symptoms. The latter being more commonly present during relapse. Of the social withdrawal behaviours misery, underactivity, worrying, fearful/anxious, irritability, withdrawal, indecisive and nagging/grumbling were the most common in patient members, especially those diagnosed with one of the psychoses.

In terms of how relatives reacted to the patient's behaviour, misery for example, was difficult to confront for 38% of the 29 relatives reporting this behaviour. Forty-five percent of the same number of relatives occasionally worried when the patient member became miserable, but did not find it difficult to tolerate. Very few relatives, however, accepted misery without expressing some concern. The frequency with which this behaviour occurred was at least weekly in 83% of the 29 patients, and in 31% of cases it was a daily occurrence. The severity of misery varied between what relatives felt was moderate, in 38% of cases, and quite serious in 52% of patient members. Forty-four percent of relatives attributed misery to the patient's condition, and for 17% misery was considered partly due to the condition and partly the patient's character.

Underactivity for just under 50% of relatives exposed to this behaviour (45%) found it difficult to cope with. At the same time underactivity was both frequent (i.e. present on a daily basis) and considered quite serious when it did occur. In most cases (72% of the 18 relatives) felt underactivity was primarily a result of the patients condition.

Worrying provoked slightly less concern for relatives when present in patient members. The majority of relatives occasionally felt concerned about this behaviour, but not to the extent that they were unable to tolerate it, even though it occurred very regularly, and in 40% (of the 22 patients) was considered quite serious. Again relatives largely attributed this to the patient's condition, but their were a certain percentage (27%) who claimed that worrying was due entirely to the patient's character and not to his/her condition.

Relatives exposed to fearfulness or anxiety in patient members (52.5% of the total sample) again one finds a group of relatives who are occasionally concerned (52%) and a group (43%) who consider it quite a problem. Similarly, fearfulness/anxiety took place fairly regularly and was perceived to be serious by over half the respondents identifying this behaviour. A large number of these relatives attributed fearfulness and anxiety to the patient member's condition.

Irritability proved to be dominant in patients diagnosed with depressive neurosis, as well as those with functional psychosis. Fifty percent of the 26 relatives reporting patients who were irritable described their difficulty in confronting this behaviour, which occurred frequently. The severity of irritability in the patient sample was considered quite a problem by 42% of the 26 relatives. In attributing what these relatives felt to be the cause of the patient's irritability roughly half assigned this to the patient's condition, and the other half considered irritability due entirely to the patient's character.

Withdrawal, as with misery, represented the second most common behaviour in the patient sample, affecting mainly those diagnosed with psychosis. A slightly higher percentage of relatives (52%) found withdrawal in their patient members very difficult to tolerate. A similar pattern emerges, as with the behaviours described above, whereby the regularity of withdrawal occurred on a weekly basis for most. Fifty-nine percent of these relatives considered withdrawal, when it occurred, to be serious, and exactly half of the 26 relatives attributed this to the patient's condition.

Indecision in patient members was recognised by 60% of all relatives in the sample. Many (54%) of the 24 relatives found their patient member's indecision quite problematic and were exposed to this behaviour quite frequently. Under half these 24 relatives felt this indecision serious, whereby the same number ascribed this to the patient's condition.

Nagging and grumbling, although reported by a sizable number of relatives, again did not appear to be as difficult to confront as some of the behaviours described above. Nagging and grumbling was recognised quite often, yet not perceived as particularly serious by relatives. For this reason, nagging/grumbling did not appear to present any major difficulties for relatives to accept. Again this behaviour was seen to be part of the patient's condition by just under half the 25 relatives recognising nagging and grumbling.

The least common social withdrawal behaviours included slowness, overdependency, self neglect, forgetfulness and attention seeking. Generally, these behaviours appeared less stressful for relatives, taking place less frequently and considered somewhat less serious, despite being viewed as part of the patient's condition.

Summary

Some of the more common social withdrawal behaviours identified in patients, (such as misery, withdrawal, irritability, nagging and grumbling, indecisiveness and so forth), were difficult for most relatives to accept, occurring either weekly, if not daily, and seen to be serious. Relatives largely attributed these particular behaviours to the patient's condition.

5.11.2 Somatic/Florid Behaviour

Many of the somatic/florid symptoms outlined in Table 5.8 above appeared to be distributed relatively evenly among each of the three diagnostic groups. Some however, like sleep disturbance, somatic complaints, obsessionality and excessive appetite were prominent in patients diagnosed with affective psychosis. Other somatic/florid behaviours, such as rudeness, destructive behaviour, and hallucinations, were identified amongst patients with a diagnosis of functional psychosis, and suicide threats or attempts were exclusive to those diagnosed with depressive neurosis. Compared to social withdrawal behaviours somatic/florid symptoms were far less common amongst patients in the month before relatives were interviewed. Indeed, the only behaviours of this type reported by a similar proportion of relatives describing social withdrawal behaviours in their patient members were somatic complaints, sleep disturbance and obsessionality.

Relatives appeared much more accepting of patient's somatic complaints, whereby some 72% identifying this behaviour either accepted it or only occasionally felt concerned. In 65% of cases patient members complaining of bodily aches and pains which were a daily occurrence. Fewer numbers of relatives (30%), however, felt these complaints were serious. Most relatives thus described these complaints as moderate or not serious, but nonetheless perceived to be part of the patient's condition.

Obsessionality, as with somatic complaints, was accepted by relatives in a very similar way. Most relatives, 57%, appeared comparatively complacent when the patient became obsessional, even though in 66.7% of cases this was a daily occurrence. Obsessionality however, was not regarded as particularly serious when present, and for this reason was accepted without much difficulty. Obsessionality was, as with somatic complaints, associated with the patient's condition.

Sleep disturbance in patient members for relatives usually meant the patient sleeping excessively and waking at odd hours, yet for most proved not to be problematic for relatives to deal with, despite being a daily event. This disturbance, however, was one of the few behaviours not associated with the patient's condition, and also not considered very serious. Appetite too, (i.e. overeating), like sleep disturbance, was not in most of the 10 cases difficult to tolerate for relatives, even though it was a regular occurrence. Again, relatives encountering this behaviour did not consider it serious in any way and did not link it to the patient's condition.

Overactivity and elated mood were also comparatively easy for the 25% of relatives affected to accept, apart from a small minority who experienced some difficulties with these. Overactivity was marginally more frequent amongst half of the 10 relatives reporting it, but otherwise both behaviours were quite infrequent and considered not serious, and largely associated with the patient's character.

Unpredictability was a difficult behaviour for the 70% of relatives who had confronted this, despite however its infrequency. It was perhaps for this reason the same percentage of relatives regarded unpredictability as serious when present, linking it also to the patient's condition. This was also true of the 15% of patient's who drank heavily.

If a patient had odd ideas relatives who encountered this found it a problem to confront. For most of these relatives the occurrence of odd ideas in patients were comparatively infrequent, sometimes not evident for a month or more. Again, odd ideas, were considered serious by relatives and almost exclusively assigned to the patient's condition.

Rudeness, offensive, destructive, odd and violent behaviour, suicide threats or attempts and hallucinations were particularly difficult for all relatives concerned, given the particularly distressing nature of these behaviours. The general pattern of these behaviours for the patient sample were there relative infrequency, (except for odd behaviour and hallucinations which were quite regular), and the seriousness with which it was regarded for many of the relatives concerned. The patient's condition was perceived to be the main cause of these behaviours.

Summary

Somatic/florid behaviour in patients were less evident in patient members, largely because many were not experiencing an episode of illness. Where present, however, relatives were able to accept without much difficulty behaviours such as sleep disturbance, somatic complaints, obsessionality and excessive appetite and overactivity, despite their frequency in some cases. Rudeness, destructive and offensive behaviour, odd and violent behaviour, hallucinations and unpredictability were very difficult for relatives to confront, even though they were seen to be part of the patient's condition.

5.12 Overall Summary

Most families consisted of 3 or 4 members. Of the three kinship groups included in the study spouse relatives formed the largest, followed by parent and child relatives, with this very few relatives were single. In gender terms the relative sample consisted mainly of women: wives, mothers and daughters. Of the male relatives many were husbands, fathers, and a minority of sons. Parents therefore represented the oldest of the kinship groups, some above the age of retirement.

The largest diagnostic group were patient members who had received a diagnosis of functional psychosis, followed by those diagnosed with depressive neurosis. Amongst patient members there existed a predominance of children, followed by spouses and then parents. Male patient members formed the larger of the two gender groups, who were mainly of sons of relatives diagnosed with one of the two psychoses. Females patient members were mostly wives diagnosed with depressive neurosis. The age of patients, as with relatives was associated with kinship, whereby parents represented the eldest group, then spouses and lastly child patients being the youngest.

The patient group varied in terms of their length of illness and clinical background, in which patients with both long- and short-term contacts with services had been included in the sample. Over half the patient sample had been admitted to the psychiatric ward at Borgo Roma's general hospital, although the most common form of service contact was individual consultations with a psychiatrist. The patient sample also included a number of those who had ceased contact with South Verona's psychiatric services. Not all patients were unwell during the time of the relatives' interview.

Just under half the relative sample was employed. The majority held unskilled jobs, the remainder were either homemakers or retired. Similarly, just over half the patient sample was also employed. Most relatives and patient members were thus financially quite stable, yet there where those who experienced financial difficulties. Domestic, social and leisure activities, and interpersonal relationship revealed a split amongst those relatives not experiencing any great hardship in these areas to those who encountered great difficulties. Many relatives had physical and/or problems with their psychological health.

Patient members' own activities in managing their finances and dealing with domestic responsibilities largely applied to spouse or parent patient members. Most were able to perform these. In leisure and social pursuits many patients were not socially active. Most respondents mentioned at least one socially withdrawn behaviour in the patient, misery representing the most common of these. Fewer reported somatic/florid symptoms in patient members. Patient member's in the sample varied according to their psychiatric status.

The diversity of socio-demographic groups and patient diagnostic categories offers scope to explore the difference potential in impact on relatives. The second results chapter that follows attempts to compare these groups to establish precisely how impact differed amongst South Verona relatives.

Chapter 6

Impact of Care Amongst South Verona Relatives: Determining Who Had the Most Difficulties

This chapter seeks to explore how factors such as kinship, gender and patient diagnosis shape the impact of care on relatives of the mentally ill. Each aspect is examined by comparing two groups within these characteristics. The section on kinship compares spouses and parent supporters. Aspects of gender are then assessed to identify the differing impact between male and female relatives as a consequence of their sex and their roles family roles. The final section examines patient diagnosis evaluating how psychosis[1] and depressive neurosis determines the different changes relatives made. These groups were chosen primarily because of the important role they can play in shaping the impact of care on relatives, (see Chapter 3). Other areas such as relatives' age and their social support networks are equally important in determining impact of care, although were not included in the following analysis. This was mostly due to sample limitations. The difficulty was in attempting to create, in any satisfactory way, groups to compare. In terms of relatives' ages it was difficult to form groups of elderly supporters and younger caregivers to compare. This was also the case for relatives' social support networks. The majority of relatives had either social contacts or pursued leisure activities (see Chapter 5, section 5.12.8). There were however, a small number of cases which showed the importance of two these factors. An elderly female supporter, for example, caring for her son was finding this progressively harder because of her age. Similarly, one relative without a sufficient

---

[1] The category of psychosis included patient members with both affective and functional psychosis. These two groups were combined to provide sufficient numbers to compare with people diagnosed with depressive neurosis.

social outlet found her situation hard to cope with given the lack of outside support.

In separating kinship, gender and diagnostic factors for the purposes of analysis risks overlooking any overlap between these groups. The purpose of this chapter is to look specifically at how impact is shaped depending on relatives' kinship role, their gender and the diagnosis of their patient member. Any strong overlap between these groups, however, was taken into account. Each aspect of impact is considered in this analysis, including the effects on relatives' employment and financial activities, domestic and social activities, personal relationships and physical and psychological health. These were largely objective factors relating to the changes made to relatives' material and physical routines. To a lesser degree factors relating to subjective impact are dealt with in sections concerning coping with behaviour and other stresses relatives encountered with the patient members' condition. A separate section examines patient members' own performance and activity according to their diagnosis. Here the areas included for analysis are patient's employment and financial, domestic and social activities.

This is proceeded by an in-depth look at the input from South Verona's community psychiatric services. Details of what relatives know about the patient's condition, both in terms of diagnosis and the nature of illness, and knowledge on the patient's medication and potential side effects is described. The need for more information on these issues is considered, occasionally making reference to kinship, gender and diagnostic factors explained above. The amount of knowledge relatives have is then explored in terms of whether it enables them to cope more effectively in living with the patient member. Relatives satisfaction with the services provides the final theme of analysis. Here, contact with services and relations with professionals are recounted and examined. Needs for services, for both relatives and patients are then assessed.

6.1 Kinship

Previous studies that found no differences in impact according to kin relationship have generally used overall assessments of impact rather than look precisely at the areas where kinship can differentiate impact of care (Perring et al, 1990). Alternatively, some studies have applied measures to examine variables such as distress and health in relation to kinship and have found differing concerns amongst spouses and parent supporters (Thompson and Doll, 1982; McCreadie et al, 1987, for example). In taking into account the findings of earlier work the following analysis attempts to identify some of the areas of impact likely to be specific to kinship. Those selected are employment and financial activity, and physical and psychological health, partly because of the strong relationships found, and partly because of what might have been expected.

6.1.1 Employment and Financial Activity

Employment and financial activity illustrate clearly the potential role changes of spouse supporters. Difficulties with employment and financial circumstances are by no means exclusive to spouse caregivers. Parent relatives in this area, however, are less likely to be affected by having to make major changes to their family role in the same way as spouse carers, (i.e. by having to compensate for a loss in family earnings). Parent supporters can be affected by having to take time off work or adjust their work shifts. There could also be financial difficulties arising from certain debts that a patient member may have accumulated or arrears with domestic repayments. Which kinship group thus has been most affected in the areas of employment and financial activity?

In taking employment first, adjustments to relatives' work routine did indeed, affect mainly spouse relatives, both in terms of the actual changes made to their employment situation and the stresses they experienced. A quarter of the twenty spouse relatives in the sample had made changes to their employment which involved giving up their jobs or retiring early to stay at home either to care for the patient member or any children. The majority of these particular spouses (4) were the wives of patient members and one male spouse relative. It became evident that the demands of each of these relatives' home life had intensified to the extent that they were unable to continue working. There was often a reluctance on the part of these particular relatives to disclose information about having given up work in order to cope more effectively with their situation at home and the patient member him/herself. One female spouse supporter, for example, during the interview talked about her job and expressed how it had become more of a strain working and coping with her domestic life, yet when asked if she had made any changes to her existing employment she gave the impression this had not been necessary. It was only at the end of the interview that this spouse relative talked more openly about her situation she revealed she had left her job the day before because of the difficulty she had in maintaining the household, looking after the three young children and seeing to her husband's needs.

There were other areas regarding employment that spouse relatives in particular experienced difficulty with. Twenty-five percent of spouse relatives who continued working found it stressful. Spouse supporters directly associated this stress with the concern they felt for the patient member spouse and this differed significantly when compared to parent relatives (t=-3.39, df33, p=.002). Spouse relatives noticed too a decline in the standard of work performed and this again differed substantially from parent relatives (t=-2.48, df33, p=.018).

There is little doubt that spouse relatives experience more pressure in maintaining their work routines and home environment compared to parent relatives. The quality of this particular pressure or strain differs for spouse carers in that they become largely responsible for the smooth functioning of family life, of which their employment circumstances form one part. The other part included the family's financial activity and it can follow that any changes to a family member's employment leads to difficulties with the family income. Financial difficulties, when they did occur, were more likely to affect spouse relatives, particularly if the spouse patient member is the main breadwinner, and subsequently impeded by his/her condition (MacCarthy, 1988). Parents, on the other hand, if they had always supported their child financially had less difficulty adjusting materially with the onset of the patient member's condition (MacCarthy, 1988). What then were financial circumstances like for relatives and were financial difficulties specific to kinship or were other factors involved?

The effects of a patient member's condition on financial activity applied to both spouses and parents, although there were specific effects for each kinship group. Spouse relatives who had made changes to their employment, namely those who had given up their jobs, inevitably experienced a 50% drop in family income. The drop in family income of this size was virtually exclusive to spouse relatives in the sample, except in one case where a patient member's salary, (the son of a parent relative), contributed to the household income the loss of which had the same effect on the family's finances as with spouses. Parent relatives, on the other hand, did experience some effects of the patient member's condition on the family's expenditure. In 33.3% of cases parent relatives had to reduce their spending. However, these effects were often in the context of already tight financial resources, and exacerbated if the patient member had become unemployed.

Most spouses and parent relatives were able to maintain their jobs, if working, and remain reasonably secure financially. Only a handful of relatives overall experienced difficulties in both these areas, the latter being a consequence of the first. How then does this compare with other findings? The few changes relatives of this sample made to their employment routine accords with that of Fadden et al's (1987b) findings. Financial difficulties for South Verona relatives were minimal and other work on impact of care has found a more consistent pattern of financial difficulties amongst carers (see Chapter 3). Spouses in the current study where the main targets for any severe financial problems, although the percentage was very low. In general, South Verona families did not experience any formidable financial hardship. The employment percentages amongst both relatives and patient members were high, (as Chapter 5 showed), and it was not uncommon for them to hold down two jobs simultaneously.

Summary

Spouse relatives in sample were more susceptible, compared to parent relatives, in making changes to their employment activities. This was particularly so for female spouse relatives who also may have to care for children. Financial difficulties were minimal overall. Those however, with the more severe difficulties in this area were spouses. Other impact areas closely associated with kinship status were relatives' physical and psychological health.

6.1.2 Physical and Psychological Health

Identifying a decline in relatives' physical health as a consequence of their caring role is much harder to correlate than problems relating to psychological health.

As Parker (1990) notes, age is more likely to be the correlate in the decline of physical health. The present study confirms this finding, and also shows quite marked kinship differences where impact is concerned.

Forty-seven percent of all relatives described having serious problems with their physical health. Just over half of this percentage were parent relatives between the ages of 56 and 75, compared to spouse relatives who were in a younger age group between 36 and 55. Only a small percentage of these relatives attributed their physical health problems to the patient member's condition. Despite the lack of direct relationship between most relatives' physical health problems and the patient members' condition it was clear in many cases that relatives' poor physical health often them made them less able to deal with their situation effectively. In some cases a relative's existing health problems would be exacerbated when the patient was unwell. A husband of a patient member who had substantial problems with his back, although not directly related to his wife's condition (depressive neurosis) mentioned that his symptoms became much worse when she was unwell.

Psychological health problems, on the other hand, were more directly associated with the patient member's condition, as relatives themselves viewed it. The percentage of relatives reporting significant psychological problems were slightly less than those with physical ill health, 30% in all. However, a much higher percentage of relatives attributed these problems to the patient member's condition, and quite distinct kinship differences were also to be found. Parent relatives were clearly more affected by psychological difficulties compared to spouses, 46.6% and 15% respectively. The significance of which was high (t=3.14, df33, p=.004). Parent relatives were more likely to ascribe their psychological difficulties to the patient member's condition, much more so than spouses. This particular difference between kinship groups was again highly significant (t=3.60, df33, p=.001). The psychological distress shown by both mothers and fathers interviewed was apparent in the concern they expressed about the patient member's condition and what was to become of them.

What sorts of reasons accounted for these psychological difficulties in which parent relatives appeared more susceptible towards? The patient's diagnosis is a strong possibility as previous studies have suggested. Impact of a patient's clinical status can indeed affect the carers psychological well being. Fadden et al (1987b) found differences in the way psychiatric symptoms affected carers in their study. Over a long period of time, as Perring et al (1990) argued, caring for a relative with mental illness can induce higher levels of psychiatric distress compared to the population in general. More than this, the authors add that patient's psychiatric status is also more commonly linked to this form of distress amongst families of the mentally ill.

This draws up a number of issues that can be examined, which involve both kinship and patient diagnosis. All parent relatives had patient members with a diagnosis of psychosis. The majority of spouse relatives lived with spouses who had a diagnosis of depressive neurosis. The distinction thus between kinship and diagnostic groups is reasonably clear cut. How then does patient diagnosis affect relatives' physical and psychological health?

Relatives physical health problems according to patient diagnosis did not appear to be related in any significant way (t=.31, df38, p=.758), and again suggested that other factors were more likely to cause health problems. The decline in relatives' psychological health, on the other hand, could be associated with patient diagnosis. Thirty-two percent of relatives with patients diagnosed with psychosis had notable problems with their psychological health compared to 13% of those with patients diagnosed with depression. This was not however statistically significant (t=1.95, df38, p=.058). The association appears to be slightly weaker compared to direct comparisons between kinship and relatives' psychological health examined above.

Summary

A substantial number of relatives overall had physical health difficulties, which although were related to factors, like age, would nevertheless aggravate the impact of care, particularly on parent relatives. Problems with psychological health were much more associated with the patient member's condition. Parent relatives, whose patient members had been diagnosed with psychosis, experienced these difficulties more so than spouses.

6.1.3 Summary of Kin Relationship and Impact

In the areas selected, employment and financial activity, and physical and psychological health of relatives revealed quite strong differences between spouse and parent relatives. With employment and finances spouses tended to experience the greater difficulties. Yet, in overall terms South Verona relatives had few problems concerning employment and financial activities.

Relatives' physical health problems were difficult to associate with the patient's condition in any direct sense. There was a much more convincing relationship between relatives' psychological health and the patient members' condition and highly specific to kinship. Parents compared to spouses appeared much more vulnerable to psychological problems in response to the patient members' condition, particularly if diagnosed with psychosis.

6.2 Gender

Gender of relative and impact of care is often a primary focus of analysis, particularly in studies on caring for elderly relatives. The issue of gender and caring has been discussed at great length by feminists in Social Policy (see Chapter 2). The concern is that a greater number of women assume the caring responsibility of a relative in need, and in the decision to care often falls on women (Land and Rose, 1985; Ungerson, 1985). Men as carers often become neglected or receive less attention in some of the literature, yet their part is no less important and can be just as distressing (Arber and Gilbert, 1989).

The following analysis concentrates primarily on relatives' gender and the impact of care in four areas: domestic activity; leisure pursuits and social contact; reaction and coping with behaviour; and, coping responses to behaviour. Kinship aspects will be included but only secondary to gender. These particular areas were chosen because of the strong gender differences found in other studies, and the aim here is establish if these same gender differences apply to South Verona relatives or if other factors are involved.

6.2.1 Domestic Activity

The area of domestic activity is a potential source of gender difference even if the family/household does not have a relative with mental illness. The likelihood of women performing much of the housework and having to deal with most of the other domestic responsibilities is far greater than it would be for male members of the household. This is very likely within the Italian context given the strong tradition of family roles. In the sample 95% of female relatives did most if not all of the housework whereby 62% of male relatives performed the same amount. Only 7% of relatives associated the amount of housework they did with the patient's condition, and the differences in gender were extremely slight.

Few relatives noticed an increase in housework as a consequence of the patient member's condition. Despite housework showing a notable gender difference it was virtually unaffected by the patient member's condition. If a disruption did occur it was either minor or short lived for most. In one example however, a male spouse relative, whose wife had a diagnosis of chronic depressive neurosis having spanned over a period of 20 years, found it difficult to maintain a reasonable level of housework while he continued to work. He found physically demanding jobs, such as washing floors, cleaning windows, etc the hardest due to a back problem. But somehow the housework had become shared between this relative and the two children who would do certain household chores, although he admitted that on several occasions the housework would be neglected.

Taken further, to establish the possible extent of other domestic disruptions, can it be assumed that female carers will be at the receiving end of impact in this area? Are household disruptions thus an inevitable consequence when a family member becomes mentally ill, and do male and female relatives respond to them differently? Do male or female carers take on more of the household responsibility in view of the patient members' condition and any changes occurring?

A quarter of all relatives had noticed that the amount of household responsibilities they had increased after the patient member became unwell. A gender difference in impact was found in the amount of household responsibility assumed. Fifty percent of these particular relatives, virtually all women, found the increase in this responsibility had almost doubled. The other 50%, mostly male spouse relatives, experiencing this increase assumed responsibility only when the patient member was unwell. In the management of household affairs male relatives experienced more severe impact. Of the 20% of relatives expressing problems in managing domestic affairs during the patient's illness, 75% were male relatives, half of whom were spouses. The gender difference here was significant (t=2.33, df38, p=.025). One illustration was of a son, whose mother had been diagnosed with affective psychosis. This particular relative, although did not directly provide care for his mother, had taken on a number of responsibilities. The son himself was in his early twenties and worked during the day and studied in the evenings. The tension between the patient member (the mother) and her spouse was considerable and often resulted in familial conflicts. This partly explains why the father virtually absolved himself of either caring for the children or assuming the mother's responsibilities. He did not regard it as his role and his perception of his wife's condition was that she was lazy. He often would say that his wife should make an effort to get over this 'thing' she had. The son was also concerned for his younger sister's welfare making sure she attended school and cooked her meals. This relative had clearly assumed nearly all the responsibilities his mother was unable to maintain.

In cases where fathers of the patient member came forward for interview, where the mother was unavailable, a common theme to emerge was the concern they showed for their sons when unwell. Many did not assume any of the domestic responsibilities, like the housework and so forth, but were nevertheless involved with their son's welfare in other ways (i.e. in providing financial support, etc).

Summary

Gender differences in each realm of domesticity varied for each of the sexes. Housework in itself seemed mostly unaffected by the patient's condition, yet it was evident that female relatives largely conducted this activity. Impact on domestic affairs occurred more in terms other household responsibilities and in the management of household affairs. Female relatives appeared to experience impact on household responsibility over a longer period of time, compared to male relatives who took on this responsibility only when the patient member was unwell, which suggested a much shorter time span. Male relatives, invariably spouses however, suffered more impact when dealing with problems concerning household management which were a consequence of the patient's illness. Overall impact in the area of domestic activity was again minimal for South Verona relatives, but revealed some gender differences where it did occur. This was also the case concerning relatives' leisure and social activities.

6.2.2 Leisure Activity and Social Contact

A restriction of leisure and social activities outside the home when caring for a family member with mental illness is almost perceived as an inevitable consequence (see Chapter 3). It is suggested that male relatives may be less inclined to give up or reduce their leisure activities, or feel less inhibited about leaving the patient member at home, compared to female carers (Gilhooly, 1984).

Maintaining social networks outside the home is also viewed as important in alleviating some of the detrimental effects that impact of care may have. Having friends or other relatives to confide in, for example, can act as a release of pent up tension or protect against emotional distress (Broadhead et al, 1983; Wallston et al, 1983). How often therefore did South Verona relatives pursue leisure and social activities? Were there any gender differences in the pursuit of these interests?

In examining first the extent of relatives' leisure pursuits a large percentage, (55%), never went out or did so very infrequently. Even at this stage of the analysis gender differences are notable. Forty-two percent of this figure were female relatives, and when compared to male relatives proved significant (t=-2.50, df38, p=.017). Female relatives were less inclined to be involved in leisure activities. Were their any reductions then made to these activities, and were they gender specific?

The degree to which relatives had reduced their social activities did indeed vary according to gender. For male relatives the reduction in these activities was either slight or only when the patient member became unwell. For females, on the other hand, the degree of reduction was much more considerable, 33% compared to 12.5% for male relatives in the same category. It also appeared that female relatives were much more reluctant to leave the patient unattended. All of the five relatives who never left the patient alone at home were women. Severe restrictions to relatives' social lives due to caring for the patient member on a continual basis affected only 3 relatives. Social contact with friends and other relatives was very high amongst South Verona relatives, particularly amongst the women. Ninety-two percent of relatives maintained contact with friends and family outside the home and 72% could confide in someone during times of difficulty. The percentage of female relatives who had someone to confide in was higher for females, 79% compared to 62.5% for male relatives. The impact on this particularly social activity was experienced by 32% of these relatives, who had noticed a decline in the number of friends coming over to visit. In 15% of these cases the drop in visits was considerable. This decline in friends visiting inevitably affected more female relatives, 37% compared to 25% males. The difference however, was not significant (t=-.75, df38, p=.460). There was little social isolation amongst South Verona relatives. Having someone to confide in was common for relatives. Very few had no one to talk to (17.5%) and similarly few felt isolated in their situation because of not knowing anyone else with the same circumstances. The difference in gender was marginal.

Summary

A large percentage of relatives in the sample never pursued leisure activities. Most relatives however, continued to maintain social contacts with either friends or relatives outside the home. Reductions in these activities as a consequence of the patient member's condition, appeared to affect more female relatives. The next section looks at how relatives reacted to and coped with the patient members' behaviour and whether gender differences were also apparent here.

6.2.3 Reaction to Behaviour and Coping Responses

Confronting a patient member's disturbed behaviour is one of the primary sources of distress for families. The way a carer reacts to difficult behaviour, according to previous studies reviewed in Chapter 3, vary depending on the type of symptoms. It appears that symptoms such as strange ideas, hallucinations and other florid behaviour, although distressing when they appear, are comparatively easier for carers to deal with than negative symptoms like withdrawal, irritability, apathy and so forth.

Gender factors and the differences in how relatives react serve as an interesting adjunct to coping responses. For the purposes here, while incorporating gender, relatives' reaction to behaviour was assessed using the two categories of behaviour: negative symptoms or social withdrawal, and florid/somatic behaviour. How then did relatives react to patient behaviour and what sorts of gender differences emerged?

Table 6.1 below lists both the number and percentage of relatives, according to gender, who found various behaviours very difficult to accept when exhibited by the patient member.

Table 6.1
Patient Behaviour Relatives Found Difficult to Confront

Social Withdrawal Behaviour	Male	Female
Misery	3 (18%)	11 (45%)
Underactivity	1 (6%)	10 (41%)
Worrying	2 (12%)	3 (12.5%)
Fearful/anxiety	2 (12%)	7 (29%)
Irritability	2 (12%)	11 (45%)
Withdrawal	2 (12%)	12 (50%)
Slowness	1 (6%)	3 (12.5%)
Overdependency	2 (12%)	3 (12.5%)
Self neglect	1 (6%)	3 (12.5%)
Indecisive	3 (18%)	10 (41%)
Forgetful	1 (6%)	6 (25%)
Attention seeking	2 (12%)	5 (20%)
Nagging/grumbling	2 (12%)	8 (33%)
Somatic/Florid Behaviour		
Sleep disturbance	1 (6%)	3 (12.5%)
Unpredictability	3 (18%)	4 (16%)
Somatic complaints	1 (6%)	4 (16%)
Odd ideas	1 (6%)	5 (20%)
Appetite	2 (12%)	2 (8%)
Rudeness	3 (18%)	8 (33%)
Offensive behaviour	1 (6%)	4 (16%)
Suicide threat/ attempt	3 (18%)	-
Overactivity	1 (6%)	3 (12.5%)
Odd behaviour	1 (6%)	2 (8%)
Obsessionality	2 (12%)	7 (7%)
Elated mood	2 (12%)	-
Destructive behaviour	1 (6%)	1 (4%)
Hallucinations	1 (6%)	3 (12.5%)
Violent	1 (6%)	3 (12.5%)
Drink heavily	1 (6%)	5 (20%)

Social withdrawal behaviour was far more frequent than florid symptoms and much more evident over a longer period of time. Female relatives reported the greatest difficulty when encountering social withdrawal behaviour. Misery, underactivity, irritability, withdrawal, indecisiveness and forgetfulness were noticeably more difficult for female relatives. Even with somatic/florid behaviour more female relatives found this very troublesome to tolerate. This was particularly apparent where rudeness and obsessionality were concerned.

With coping responses to behaviour previous work suggested that women would tended to use less effective coping techniques compared to men (Pearlin and Schooler, 1978), and were more likely to use 'avoidance coping' which was felt to be maladaptive (Billings and Moos, 1981). Barusch and Spaid (1989) found no significant differences between the sexes in terms of specific coping styles. They did find however, gender differences in the use of coping styles for particular problems.

In the current study, relatives were asked to identify a particular incident of patient behaviour (in the month prior to interview) that had distressed them. Using a 17 item coping schedule (see Appendix), listing both practical and cognitive responses, could any gender differences in the type of coping responses used by relatives be identified? Were women more likely to internalise their coping responses (i.e. respond at a more subjective or emotional level) when compared to men?

In the sample of relatives females tended to use both practical and cognitive coping responses. There was no distinction between men, for example, using more practical coping responses and women using mostly cognitive ways of dealing with the patient member's behaviour. Table 6.2 below lists the coping responses, both practical and cognitive, according to relative's gender. The most popular response for women would be to 'wish the situation away' (46%), and at a more practical level 'knew what had to be done' (41%), and accepted 'these things happen in life' (41%). Common responses for male relatives included 'seeing things from the other person's point of view' (37%) and 'accepting sympathy or understanding' (37%). No relatives coped with the patient member by considering him/her to be unimportant.

Table 6.2
Coping Responses to Behaviour by Relatives' Gender

Practical Coping Responses	**Male**	**Female**
Knew what had to be done	4 (25%)	10 (41%)
See things from the other person's viewpoint	6 (37%)	9 (37%)
Draw on past experiences	3 (18%)	5 (21%)
These things happen in life; have to take the good with the bad	4 (25%)	10 (41%)
Try not to act too hastily	3 (18%)	8 (33%)
Go over what to say or do	3 (18%)	9 (37%)
Talk to someone to find out more	5 (31%)	7 (29%)
Come up with a number of solutions	4 (25%)	5 (21%)
Cognitive Coping Responses		
Feel better by eating, drinking, etc	2 (12%)	8 (33%)
Think S is not so important	-	-
Accept sympathy or understanding from someone	6 (37%)	8 (33%)
Keep feelings to oneself	4 (25%)	8 (33%)
Criticise or lecture oneself	4 (25%)	8 (33%)
Wish the situation would go away	5 (31%)	11 (46%)
Go along with fate	5 (31%)	6 (25%)
Look for a silver lining	3 (18%)	6 (25%)
Think things could be worse	2 (12%)	3 (12%)

Nearly all relatives had their own method of accepting or resigning themselves to the patient member's behaviour and condition in general. This often this depended on their individual set of circumstances. One husband relative, for example, would ignore his wife's behaviour, because it helped his wife feel less guilty about her condition and the duties it prevented her from doing, especially for the children. This relative had become accustomed to not making any demands on his wife, and in this way managed to accept much of what his wife's condition entailed. Many of this husband's coping responses lead him to perceive his wife's behaviour as 'moderate' and not particularly strange or hard to accept. He had become resigned to his wife's condition, in which she had been hospitalised twenty times over the past 15 years. This type of acceptance however, took its toll on the husband. His own physical health suffered and he often felt the strain of having to keep things going. Towards the end of the interview this carer summed up his despair by exclaiming, 'I sometimes wish the situation and my wife's condition would just disappear'.

Another relative, a wife of a patient member diagnosed with functional psychosis, was very articulate in the way she talked about her husband's condition and how she coped. During the interview this relative stressed not so much the practical changes she has had to make given her husband's illness, instead she considered it far more important to discuss the difficulties that had arisen at a personal level between them. She summed up her situation when she said:

> It's not that the illness is upsetting ... , that is, it's not that I have a husband who, for example, still hears voices, that is, the crisis has passed and slowly but surely we are seeking to return to normality. I thought for a moment that you would give more space to the problem in the family, ... [instead you ask] ... how he [the husband] can be a burden, but for us it is difficult to carry on, which has nothing to do with the fact that one carries on all the same.

It was this type of resignation that most of the relatives in the sample adopted and these were primarily relatives whose patient member had been unwell for a number of years. They had developed a certain familiarity with the patient member's illness making it much easier to accept. This, combined with the skill of knowing how to deal with a crisis made relatives much less frightened of what the patient member was experiencing. In this way these relatives (i.e. those with patient member's whose illness had become more long-term) coped, even during times of great difficulty.

Relatives whose patient member had been unwell only for a short period of time or had suffered only a single acute crisis, on the other hand, would describe in great detail the shock of seeing how strangely the patient member behaved during the episode itself. Often these relatives seemed unaware of any build up towards the crisis or simply did not realise that any mounting tensions might have been stressing the patient to the point of crisis. Once the patient member recovered these families would resume their normal activities, but would still remain baffled as to why it happened. In some cases parent relatives would blame themselves for what the patient member went through, either by feeling guilty or questioned their parenting of the patient member.

The sorts of strains and difficulties relatives experienced was not uniform or standard, but often unique given the differences in relationships and circumstances in each individual family. Quite often the distress relatives experienced depended upon how they perceived their own situation and the importance they attached to the emerging problems.

Summary

With these observations in mind searching for gender differences in coping styles seems secondary to understanding the coping mechanisms each family assumed. This subsequently emerged when distinguishing between gender and assessing the coping responses listed above. Coping responses were mixed between the sexes, both male and female relatives used a combination of practical and cognitive coping styles in response to patient behaviour. What seemed significant was how each relative adopted their own techniques for dealing with the patient's behaviour and any episodes of illness.

6.2.4 Summary of Gender and Impact

In the few cases where domestic impact occurred female relatives assumed the household responsibilities over a longer period of time compared to male relatives in the sample. These latter relatives, usually spouses, took on more household responsibility only when the patient became unwell, suggesting much briefer periods of impact compared to female relatives. The greatest difficulty for male relatives was the management any of household activities when disruptions took place.

Virtually all South Verona relatives had some form of social life and when assessing any gender differences in the restrictions that have occurred female relatives suffered more impact compared to male relatives. The differences in gender here were not staggering but sufficient enough for a discrepancy to be evident.

Similarly, with reaction to behaviour more female relatives found both social withdrawal behaviours and florid symptoms very difficult to confront. However, coping responses to behaviour revealed no notable differences and individual coping mechanisms appeared to be more relevant than gender factors.

Gender differences and the impact of care thus operated in very specific ways. In many cases female relatives would experience more impact in certain areas compared to males and vice versa, yet overall it appeared that women are more vulnerable to impact than men. The theme of the next section is to identify the extent of impact on relatives according to the patient member's diagnosis.

6.3 Patient Diagnosis and Impact

This section looks at how a patient member's clinical diagnosis determines impact of care. Previous studies, detailed in Chapter 3, have found patients psychiatric status, demonstrated by his/her behaviour, an important indicator of stress on carers. Very few studies have made direct comparisons with different diagnoses to examine any variation in impact on carers. Most studies have largely researched carers of people diagnosed with schizophrenia. Fadden et al's (1987b) study was one of the few exceptions, in which she examined spouses of depressed patients. Does a patient's clinical diagnosis thus play some part in determining the type of impact relatives experience? The two main diagnostic groups used for comparison here are psychosis (functional and affective) and depressive neurosis.

The type of impact on relatives associated with patient diagnosis pin-pointed specific aspects of stress relatives had experienced. These were encountered in several areas, namely employment and financial, leisure, personal relations and psychological health. Patient behaviour was also used to assess the impact on the interpersonal relationship with the relative and impact on their psychological health. Much of these explorations overlap substantially with relatives' kinship and gender examined in the above sections. To recap briefly, most patient members with a diagnosis of functional psychosis were sons of parent relatives. Patient members who had received a diagnosis of affective psychosis were predominantly male spouses. Patient members in the depressive neurosis group were largely female spouses. How then does patient diagnosis (or type of condition) affect the impact on relatives?

6.3.1 Employment, Financial and General Activity

In focusing on the stress provoked by employment, financial and general activities together with patient diagnosis highlighted some significant findings. Relatives of patient's diagnosed with depression, found work a great deal more stressful, and this was significant when compared to relatives of patients with a diagnosis of psychosis (t=-2.23, df38, p=.032). Not all relatives found work stressful because of the patient member's condition. Only 20% of relatives who reported being stressed at work associated it directly with concern over the patient member. This result ties in with kinship factors. The majority of these relatives were spouses, who were more likely to experience work difficulties. Worries about financial circumstances however, were unexpectedly confined to relatives of patients diagnosed with psychosis, more often than not parents of patient members.

At a more general level, for the same diagnostic group (psychosis), relatives experienced greater difficulty in keeping things going in the family in view of the patient member's condition. This hardship differed substantially when compared to relatives with depressed patient members (t=2.45, df38, p=.019). There was also a high percentage of relatives of patients with a diagnosis of psychosis (56%) who felt the strain of keeping things going so great they worried about not being able to continue.

Summary

Financial and general activity both showed the magnitude with which relatives of patients diagnosed with psychosis experience the stress of their situation. Generally trying to keep things going for relatives of this particular patient diagnosis (psychosis) appeared stressful than for relatives of patients diagnosed with depressive neurosis.

6.3.2 Leisure and Social Activities

A similar picture emerges for relatives of patients diagnosed with psychosis and the reduction in leisure activities. The difference when compared to relatives with patients diagnosed with depressive neurosis was however, not significant (t=2.00, df38, p=.053). A strong indicator explaining this reduction was linked to the concern or stress relatives of patients with a diagnosis of psychosis felt and expressed not feeling much like going out, and was significant (t=2.36, df38, p=.024). There were no significant differences between the two main diagnostic groups where social contacts were concerned. Maintaining contact with friends and relatives were, on the whole, quite high for most relatives, (see also section 6.2.3 above).

Summary

Reduction in leisure activities largely affected relatives whose patient members were diagnosed with psychosis. This trend in impact continues into personal relations between relatives and patient members.

6.3.3 Interpersonal Relationship

Personal relationships, for the purposes here, were examined at two stages. The first looks at the state of relations between relatives and patient members in both diagnostic groups. The second attempts to determine if patient behaviour affected these relationships, and also includes aspects of kinship.

Where relations between relative and patient member were problematic there was a higher percentage of relatives of patients diagnosed with psychosis who expressed greater difficulties in this area, 48% compared to 33% of relatives of patients diagnosed with depression. This difference in percentage however, was not significant (t=.84, df38, p=.408). This sort of result also reflected other aspects of personal relations between the relative and patient member. These included, for example, the number of arguments, how stressful the relative was finding relations with the patient, and if they had deteriorated with the onset of the patient's condition.

It was then interesting to see whether patient behaviour influenced how patients and relatives got along. Indeed, the way relatives responded to patient behaviour appeared to have some bearing on how relations between them were, and kinship factors were also highly relevant. There was a significant difference between parents who got on well with the patient member and those who found relations very difficult, and this depended on how they reacted to patient behaviour (t=-2.25, df13, p=.043). If parents found it difficult to confront challenging behaviour this created tension between them. The association with reaction to behaviour and how relations between patient and relative were affected spouses to a much lesser degree. In diagnostic terms all parents in the sample had sons who had been diagnosed with psychosis. The difficulties again affected relatives of patients with a diagnosis of psychosis.

Summary

The overall level of stress and the general difficulties involving interpersonal relations were concerned tended to be higher for relatives with patient members diagnosed with psychosis, but statistically were not significant. Patient behaviour to some extent determined how relatives and patient got on. Again, relatives (mostly parents) of patients diagnosed with psychosis experienced greater difficulties with this than spouses whose patient members were largely diagnosed with depression.

6.3.4 Psychological Health

Whether a patient member's diagnosis is likely to affect relatives' psychological health was another important issue to assess. The analysis above on relatives' psychological health according to kinship suggested that parent relatives in the sample had more problems with their mental health compared to spouses. Indeed, more relatives of patients with a diagnosis of psychosis reported having mental health problems compared to those of patients diagnosed with depression, although not statistically significant (t=1.95, df38, p=.058). Similarly, more relatives with patient members diagnosed with psychosis attributed their psychological problems to the patient members' condition. When compared to spouse relatives the statistical significance was apparent (t=2.13, df38, p=.039).

This particular finding might be explained by comparing relatives' psychological health with patient behaviour. Patient behaviour of both social withdrawal and somatic/florid symptoms were more frequent and more severe in patients diagnosed with psychosis. Two groups of relatives were compared, one having minor psychological difficulties with those who had substantial psychological problems and the exposure to patient behaviour they had encountered in the past month. There was a higher mean score of patients who were more socially withdrawn (mean 48.2) reported by relatives with substantial psychological problems compared to relatives with minor psychological problems (mean 33.2). The difference however, was not significant (t=-1.48, df 25, p=.150). When examining relatives' psychological health in relation to patients who displayed somatic/florid symptoms in the same period there was an even stronger suggestion that relatives may experience notable psychological problems (t=-2.07, df 25, p=.049).

Summary

The pattern thus emerging seems to suggest that patient behaviour may provide some indication of the degree to which relatives' psychological health is affected, particularly where somatic forms of behaviour are concerned. The likelihood of relatives of patients diagnosed with psychosis having more problems with their psychological health was greater than for relatives of depressed patients.

6.3.5 Summary of Patient Diagnosis and Impact

Two previous studies, MacCarthy et al (1989b) and Fadden et al (1987b), found no association between patient diagnosis and overall level of burden. However, in each of the four areas examined in conjunction with patient diagnosis there was an overwhelming indication that relatives of patients diagnosed with psychosis suffer more subjective impact compared to the group diagnosed with depressive neurosis. The strain of keeping things going in general, not feeling much like going out, tense personal relations and significant psychological problems were more frequently detected in relatives of patients with psychosis. This does not suggest however, that relatives of patients diagnosed with depressive neurosis escape these difficulties, but when compared to the former group the difference is striking.

Patient behaviour and its affect on the relationship between relative and patient and relatives' psychological problems show quite conclusively how it heightens the difficulties in these areas, if not directly attributing to them. Again, the pattern to emerge suggested that patients diagnosed with psychosis are more likely to display both social withdrawal and somatic symptoms of behaviour, in which their relatives were more susceptible to certain forms of impact.

The following section examines how well patient members were able to continue performing there usual activities, and the extent of impact on relatives this might have invoked.

6.4 Patient Performance and Impact

In MacCarthy et al's study (1989b) two thirds of the patient sample could perform most of the basic daily tasks necessary, such as maintaining personal hygiene and dressing, but managing household affairs or pursuing leisure activities were far less common. The purpose of this section is to examine the extent to which South Verona patient members were able to carry out their daily routine, or if this had become disrupted as a consequence of their condition. The same two diagnostic groups formed above, psychosis and depressive neurosis, were employed to investigate any differences in patient performance. The areas considered are employment and financial, domestic and social activities.

6.4.1 Employment and Financial Activities

A number of factors in this analysis pointed to the importance of employment for patient members. Fifty-two percent of the patient sample were employed at the time of relatives' interview. A high percentage of these patients had received a diagnosis of psychosis (71%). A number of these patients had only short-term episodes of illness and recovered fairly quickly to resume their usual activities. There were however, a few patient members with chronic conditions (diagnosed with psychosis) who somehow managed to continue working despite their illness. There were many positive benefits as a consequence. Indeed, this was perhaps one of the main reasons why South Verona relatives in general experienced little objective impact. But what of the patients out of work, was this due to their condition?

Twenty-two percent of patients, 78% of whom with a diagnosis of psychosis, were out of work and 2 were retired[2]. Relatives of patients who were out of work directly attributed this to the patient's condition. Does a patient's occupational status influence the type of impact a relative experiences? Whether the patient was employed or not had some consequence on the relative's own employment circumstances and the family's finances. For most relatives the effects of a patient member's job status were not, however, in terms of relatives having to make changes to their own work or in taking time off to care for the patient. Relatives whose patient members were unemployed found their own work more stressful than those whose patient members worked, although this was not significant (t=-1.97, df 30, p=0.058). This stress was further reflected in the decline of relatives' work standards with unemployed patient members, and differed significantly from relatives whose patient members worked (t=-2.41, df30, p=0.022).

As expected the consequences of a patient member becoming unemployed, whose income was relied upon, subsequently lead to financial difficulties, (see section 6.1.1 above). In comparing relatives who reported having to reduce family spending with relatives whose patient members worked the difference was indeed notable (t=-2.64, df28, p=0.014). Using the same two groups for comparison, there was also a significant difference between relatives whose patient members were unemployed and their financial arrears, compared to those whose patient members worked (t=-2.14, df27, p=0.042).

Summary

Impact thus concerning a patient members' employment status on relatives own

---

[2] There were missing data in eight cases.

job is clearly shown in the stress provoked and the subsequent difficultly in maintaining standards. When a patient member is out of work their families also appear more likely to suffer financial difficulties. Most of the patients who were out of work had a diagnosis of psychosis, although this should be interpreted with some caution given the numbers involved are small. It is likely that either of the diagnoses, psychosis or neurotic depression, if severe enough will have disabling effects. It does seem however, that patients with psychosis are perhaps more likely to be out of work compared to those with depressive.

6.4.2 Domestic Activity of the Patient Member

As with domestic activity examined under the section on relatives' gender and impact cultural factors play quite an important part in determining who performs the housework. In some cases this even appeared to outweigh the effects of the patient's condition, especially if the patient was female. Sixty-seven percent of female patient members, all of whom spouses, were very active with the housework, compared to only 12% of male patient members. This also in part explains the lack of impact on housework for relatives (see section 6.2.1 above). If the patient member, especially if female, was completely incapacitated during her condition male relatives would sometimes obtain outside help with domestic chores. On one occasion when a relative's wife became unwell and clearly unable to perform domestic activities his mother, who lived locally, would regularly come to do them.

6.4.3 Summary of Patient Performance

There was some association between patients who were out of work and the stress relatives felt in maintaining their own standards at work. A large percentage of female patient members conducted the household chores, and in some cases even when unwell. The final main section assesses the impact of formal services on relatives of patients diagnosed with mental distress.

Relatives and South Verona's Community Psychiatric Services

When given the choice between whether the patient member should be provided with hospital or community care many carers choose the latter. Many are usually willing to support the patient, and despite the difficulties carers often face they still prefer the patient to be at home. This is the general conclusion reached by a number of studies (Johnstone et al, 1984; Hoult, 1986, for example). Some researchers have attempted to study the effects of different care programmes for patients with psychiatric illness and the subsequent impact on families (Brown et al, 1966; Washburn et al, 1976; Braun et al, 1981). Their findings however, have been somewhat contradictory ranging from community services producing less family distress to greater family burden only where community services existed. Much of the impact work and services have looked at relatives' knowledge about the situation and the patient member's condition and relatives' satisfaction with services. Information about a patient member's condition can help to assist families cope more effectively and help improve the patient's prognosis (see Chapter 3). Relatives' satisfaction with services, has also been studied quite extensively covering a range of issues asking relatives about the quality of services received and involvement with staff (Johnstone et al, 1984); the timing of service intervention for families (MacCarthy et al, 1989a); the cooperation of professionals (Thompson and Doll, 1982); and the needs of relatives from services (Creer et al, 1982; MacCarthy et al, 1989b). Services are, more often than not, oriented towards the patient and any benefit derived for relatives is usually indirect. Within this framework it therefore comes as no surprise that dissatisfaction with services, on the part of relatives, and the recognition of unmet need is frequently cited in the literature. The following analysis seeks to explore, in the first instance, the knowledge relatives in South Verona had about the patient member's condition, their future prospects and medication, and whether they required more of this type of information. The second seeks to evaluate how satisfied relatives were with South Verona services, including the contact relatives had with professionals, and their needs for services.

6.5 Relatives Knowledge of the Patient's Condition and Medication

The community psychiatric service in South Verona, during interviews with relatives, had no formal way of providing information to families of patients through psychoeducation or family support groups. Information of this sort was often obtained by relatives when accompanying patient members to the psychiatric ward or the Community Mental Health Centre during visits. The only formal provision to include patients' relatives was family therapy. The following, using kinship, relative's gender and patient diagnosis where relevant, assesses whether the amount of information relatives had received on patient diagnosis, the nature of the condition and future prospects, and medication was sufficient. Several questions are then explored to examine how useful this information was for other areas, such as interpersonal relationships, and relatives' own psychological health.

6.5.1 Patient Diagnosis, Nature and Future Prospects of the Condition and Medication

Information about patient diagnosis had been received by just over half the relative sample. More parents compared to spouse relatives, for example, had received information on patient diagnosis. The need for additional knowledge on diagnosis was expressed by the majority of relatives, 35% of whom felt their need was considerable. Relatives whose patient members received a diagnosis of psychosis had more need for information on the diagnosis itself.

The nature of the patient's condition and what this implied in terms of future prospects was an uppermost concern for relatives. This was evident in the high percentage of relatives who had no information on these aspects of the patient's condition, 77.5% in all. There was a greater need for information on these areas issues compared to patient diagnosis. Forty seven percent of relatives, many of whom mothers of sons diagnosed with psychosis, felt a considerable need for more information on the nature and future prospects of the patient's illness.

Compared to diagnosis and the nature of the condition many more relatives felt they had received ample information and fully understood what the patient's medication entailed and the potential side effects were. Thirty-two percent of relatives however had no information of this sort, yet only a moderate number required more of this information. The need for this information was comparatively less overall.

6.5.2 Does Knowledge About the Patient's Condition Make a Difference in How Relatives Cope with their Situation?

The type of knowledge South Verona relatives had received about the patient's condition and medication was not as detailed or instructive as that of psychoeducation. The transfer of knowledge was likely to be brief, informal and accumulated only after a series of regular contacts with services and staff. Did the knowledge relatives have about the patient member's condition and medication enable them deal with their situation better? Two groups of relatives were compared, those who had received what they felt to be sufficient information about the patient member's diagnosis, nature of condition and medication, and those who had a considerable need for more of this information. This was then examined with how they were finding things generally, their personal relationship with the patient member, their psychological health, and how they reacted to the patient's behaviour.

In some cases there were some striking differences between these groups. Relatives who felt they needed more information differed substantially, compared to relatives who did not, particularly in how they were generally finding things and in their relationship with the patient member, and significant at the $p< 0.05$ level. This was not the case for relatives' psychological health ($t=-1.87$, df23, $p=.074$). There were further marked differences to be found when assessing relative's reaction to behaviour and more information. The type of challenging behaviour included reaction to miserableness, overdependency, indecisiveness, overactivity, withdrawal, underactivity, worrying, and fearfulness. It is difficult to draw any firm conclusions from these results. There does appear, however, to be some link between relatives' general circumstances, their personal relationship with the patient, and they way relatives react to challenging behaviour and the knowledge they have on the patient's diagnosis and nature of condition.

Summary

The level of knowledge South Verona relatives gathered from services scarcely made any impact on how they generally coped with their situation, their personal relationship with the patient member, and how they reacted to challenging behaviour. Yet, relatives who lacked information on diagnosis and the nature of condition had greater difficulties in the above areas compared to those who did not require it.

The following section deals with how satisfied relatives were with services, what the patient member had received and what they felt was required.

6.6 Relatives' Satisfaction with Services

One of the major themes of dissatisfaction by relatives of services included poor involvement with professionals, particularly over a long-term period, often a result of high staff turnovers (Johnstone et al, 1984). Other criticisms by relatives of services included a disregard of their concerns until the situation reached a crisis point (Creer, Sturt and Wykes, 1982); unsympathetic attitudes by staff towards carers difficulties; and, poor communication between staff and carers (Creer, Sturt and Wykes, 1982). Relatives' unmet need is another area of investigation some studies (Creer et al, 1982; MacCarthy et al, 1989b). This was recognised by the low expectations relatives had of services and the low demands made from them. More often than not, relatives do not complain about services. Creer et al's, for example, study highlighted that most of their 52 interviewees wanted some form of change in the service, and a third of them had a minimum of one unmet need. Practical help, particularly with financial advice, was a frequent request by relatives. The type of unmet need found in MacCarthy et al's (1989b) study ranged from involvement in planning treatment programmes, advice about managing challenging behaviour, respite from caring and emotional support. Similarly, they also found few relatives expressing dissatisfaction with services, most were resigned to their situation, yet had substantial unmet needs.

The following section seeks to examine the issues discussed above and divided into three main parts: contact relatives have had with South Verona services and relations with professionals; what relatives need from services; and, what relatives feel the patient member requires from services. Some reference, where relevant, is made to relatives kinship and gender status, and patient diagnosis.

6.6.1 Contact with Psychiatric Services and Relations with Staff

At least half the relative sample had been in contact with services within the 3 months prior to interview. Contact with the patient member's psychiatrist was the most common service agent seen by relatives. Contact with other psychiatric professionals, such a nurses (either on the admissions ward or the CMHC), psychologists and social workers were much less routine. How easily could relatives approach services when they felt it necessary? Forty-five percent felt it possible to contact services in this way, although none of them had done so. Twenty-seven percent of relatives had contacted services and received help when concerned about their patient member. Hence over 70% of relatives were satisfied with knowing they could contact services and obtain help when they felt it necessary. A quarter of the sample, however, did not feel they could approach services when worried. These were mostly relatives whose patient member had a diagnosis of psychosis.

How satisfied then were relatives with service staff? This was examined in terms of how supportive/cooperative relatives felt service staff were towards them. Relatives were not directly asked how satisfied they were with professionals, but talked of this in response to what they felt services should be offering them in their situation. Thirty-five percent of relatives mentioned wanting more support from staff in the form of either general advice or reassurance. A large percentage (71%) of these relatives had patient member's with a diagnosis of neurotic depression. Nearly all of these relatives were male spouses. Many of whom expressed not being particularly pleased with staff attitudes towards them. It was here that relatives felt neglected by professionals which gave rise to much of the dissatisfaction reported. One relative felt staff viewed him as insignificant in his role as the patient's son and were unaware of the responsibility he had to assume. Very often he was concerned about his mother's condition and would try to relay this to staff at the CMHC, or try to get feedback from them. He was usually ignored or given very little time by professionals, and he found this lack of communication with staff distressing. Similarly, one wife expressed how she was unhappy with the way the nurses at South Verona would be evasive when she asked them about why her husband would get so ill. Sometimes they were quite rude and not very reassuring or sympathetic. These comments represented the range of dissatisfaction South Verona relatives had with professionals.

An additional grievance was expressed by relatives involved in family therapy. As part of South Verona services the provision of family therapy represented the only formal service to include families in its treatment of the patient. Just under 25% of relatives and patients obtained family therapy. The concern these relatives voiced included feeling that in these sessions the patient's condition was in some way attributable to them. Almost all relatives receiving family therapy felt some hostility from staff, which created even more dissatisfaction. This sort of attitude appeared to affect general visits to the psychiatrist too. In one case both the husband (the relative) and the wife (the patient member) felt little was gained and the husband felt as though he was being treated as the 'sick person' and the wife would feel 'left out'.

Attitudes like these can have detrimental effects on patients, as Appleton (1974) explains. Relatives become less willing to tolerate any problems created by the patient if they themselves are treated badly by professionals. No doubt relatives become resentful of being viewed as the aetiology of the patient's illness, which hamper the patient's recovery. In turn, not only do relatives feel less tolerant towards the patient but also quite dejected about their situation. This was true for South Verona relatives who expressed dissatisfaction with staff.

Summary

Most relatives appeared satisfied knowing they could contact services if they wished to. Some felt the service unapproachable if they wanted to express any concerns they had about the patient member. Interactions with staff were more problematic for relatives. Professionals appeared much less approachable and many relatives were unhappy with how they were perceived and ignored when concerned. Family therapy also created dissatisfaction with professionals who relatives felt were sometimes quite hostile towards them. It was inevitable that relatives thus expressed the need for staff to be more supportive and cooperative. This seemed particularly relevant for male spouse relatives whose patient member had been diagnosed with depressive neurosis.

6.7 What Do Relatives Require From Services?

It was rare for relatives, when asked a general question about what they felt they needed from services or how services could be improved, to say what was required. This was partly related to relatives being resigned to their situation, as MacCarthy et al (1989b) found. It was more revealing to ask relatives specific questions about service provision and whether they needed more. Within this section several areas of need, (according to what earlier work has unveiled), are considered. These include crisis intervention, respite and alternative accommodation, home visits and a forum for relatives to discuss any psychological problems of their own.

6.7.1 Need for Crisis Intervention

Crisis intervention services for patients was either through the casualty department of South Verona's general hospital, a home visit, or an appointment within 24 hours of contacting the service. For the most part relatives were satisfied with what had been received and felt intervention services had responded adequately during times of crisis with the patient member. Just over half the sample did not experience any difficulty in obtaining crisis intervention when needed. However, a quarter of relatives, mostly spouses, said they had not obtained emergency services easily. Twelve percent of these relatives reported not having received any help within 24 hours and felt they required more immediate intervention, rather than simply being given an appointment for a later date.

6.7.2 Need for Alternative Accommodation and Respite Care

Despite the many difficulties relatives face when living with a member who suffers from mental illness very few feel these members should live elsewhere. In Johnstone et al's (1984) study, for example, of the 42 relatives interviewed only 6 felt the patient should have alternative accommodation. Similar findings were found in the present study. When asked if the patient member should live in alternative dwellings South Verona relatives were quite often offended at the question, regardless of the intensity of their difficulties. Subsequently, nearly all relatives, including those experiencing severe impact, did not feel that alternative accommodation for the patient member would have been a more suitable arrangement, either for them or the patient.

There was however, some need for respite care among South Verona relatives. Twenty percent of relatives expressed this, half of whom said the need for this was considerable. These latter relatives were female whose patient member had been diagnosed with psychosis. There general situation revealed severe impact in areas concerning the patient members own performance, relatives' domestic and social activities, and their relationship with the patient member. Curiously, none of these particular relatives, however, had significant problems with their physical or psychological health, nor did they appear to have difficulty in coping with the patient member's challenging behaviour.

6.7.3 Need for Home Visits

The demand for more home visits was again requested by only a small minority of relatives. Thirty-five percent of South Verona relatives received home visits on a regular basis. For 22% only a slight to moderate need for more home visits was expressed, and these were largely relatives whose patient member received a diagnosis of functional psychosis. Considerable need for this service was requested by just 2 relatives. Regular home visits to families seemed quite extensive and appeared to satisfy most of those in need of them, relatives with patient members diagnosed with psychosis.

6.7.4 Need to Discuss Psychological Problems

The need for emotional support from services is one of the primary requests by relatives caring for a patient member with mental illness (MacCarthy, 1989b). Relatives were asked if they had been invited to discuss any psychological problems they might have. This is pertinent considering the percentage of relatives in the sample expressing significant problems with their psychological health (see section 6.1.2 above).

Just over half of South Verona relatives (55%) mentioned a slight to moderate need to discuss their own psychological problems with a professional. Most of these had patient members with a diagnosis of psychosis. There were however, 15% of relatives who felt a considerable need to discuss their psychological problems. No other differences between groups appeared to exist. Being able to discuss any psychological difficulties for relatives appeared to be the most requested service by them.

6.7.5 Summary of Relatives' Need for Services

The need for extra services appeared to apply to only a minority of relatives in the sample. Most relatives were satisfied with the service provision, (i.e. in what had been received and what they felt they could obtain). Crisis intervention services on the whole appeared effective in dealing with any emergencies arising. Relatives who expressed there dissatisfaction with the way services responded to their crisis were few and predominantly spouses. Alternative accommodation for the patient member and the need for respite care for the relative was a minimal need, and corroborates with the findings of other impact studies. Similarly, home visits also showed a minimal need. The minority of relatives who did request this type of service, especially those with considerable need for this, experienced severe impact in some areas. The most requested service by relatives was the opportunity to discuss their own psychological difficulties. Overall, relatives who were in need of additional assistance from services were usually those whose patient member had been diagnosed with psychosis. The final part of this section looks at what relatives felt services should be offering the patient member.

6.8 Services for Patient Members

The manner in which services operate and what is offered to patients will invariably have an indirect effect on their relatives. This section is concerned with the type of services relatives felt the patient member could benefit from. It includes whether patient members were in need of sheltered work or any social activities provided by services. A series of other issues ranging from the patient member's relationship with staff and their overall satisfaction with the services are also included.

6.8.1 Sheltered Work, Social Activity and Satisfaction with Services for Patient Members

Of the patient sample only two had been offered sheltered work at the day centre in South Verona. In total 35% of relatives reported some degree of need for patient members to be offered more of this type of work in which to occupy their time. For over half of these patients relatives felt the need for this work was considerable and in some cases even urgent, many of these patient members were unemployed.

Relatives were also asked if the patient member needed to be offered any social activities organised by services. A marginal number of patient members in the sample had been offered this service and none of them attended any social outings or activities arranged by services. Forty percent of relatives, 17% whose need was considerable, requested more of this particular service for their patient members, similar to the percentage of relatives requesting sheltered work for patients. In this area one could see the difficulty relatives had, often parents with sons diagnosed with psychosis, in motivating patients to find employment or become more socially active and expressed the need for services to assist with this. Assistance with matters concerning welfare support was reported by 17.5% of relatives.

It was evident from relatives requests for specific services for patient members that a core number of patients needed to occupy their time either vocationally and/or socially. What of other services for patient members? How satisfied were relatives with what patient members had received? From what relatives had conveyed over half (25%) had said that staff could make themselves more available to patients. Many of these patients were spouses diagnosed with depressive neurosis. Twenty-two percent of relatives, predominantly spouses, expressed how patients should be given more regular appointments to see professionals. This also included suitable follow-ups by services to avoid losing contact with the patient when still in need of professional help. In 30% of cases relatives questioned how suitable an environment the psychiatric ward was for patient members during their stay there. Some relatives were distressed that the patient member was admitted to a psychiatric ward where the other people appeared to be much worse.

Summary

The most common form of service help requested by relatives concerning their patients was sheltered work for those who were largely out of work. Relatives were aware that patient members needed some form of work and social activity to occupy their time during the day. In general, just over half the sample of relatives were satisfied with the services the patient had received. Only a small minority of relatives appeared completely dissatisfied with the way services had responded to the needs of the patient. There were some objections by relatives about staff, the admission ward and the system of appointments, yet felt satisfied with what the patient had received.

6.9 Overall Summary

In differentiating relatives according to the groups chosen - kinship, gender, and patient diagnosis - revealed in quite precise ways relatives who were more vulnerable to impact than others. Some of the findings here coincided with that of previous work. Other findings of the current study, in examining relatives according to these groups to compare revealed some new aspects of vulnerability.

In terms of kinship spouse relatives were the main group to encounter the greater difficulties concerning employment and financial changes with the onset of the patient member's condition. A finding that is in line with previous impact work. The patient member's own performance, particularly whether employed or not, also influenced how relatives coped with their own work activities. Yet, in overall terms there was a high percentage of relatives who managed to maintain their jobs and not run into financial difficulties, despite the patient member's condition. Parent relatives were more likely to suffer problems with their physical health, particularly as they were older, which again corroborates with what was found in previous research. Relatives' psychological health represents one of the most significant areas of impact according to other impact work. The present study found no exception to this. In addition, the present study also found that parent relatives were far more susceptible to problems with their psychological health as a consequence of the patient member's condition, who in the majority of cases had a diagnosis of psychosis.

Gender differences and impact on domestic and social activities were also similar to other findings. Women in the sample appeared to experience more impact in these areas compared to men. Women had greater difficulties in confronting patient behaviours relating to the patient's condition, although unlike some previous findings there were no gender differences in how they coped with them. There were also however, very specific areas in domestic activities, for example, household management and during disruptions, where male relatives had more difficulties.

Patient diagnosis was found to be a very important indicator of impact on relatives in several areas: relatives' employment, financial and leisure activities, their interpersonal relationship with the patient member, and their own psychological health. There was consistent evidence to suggest that relatives of patients diagnosed with psychosis, compared to those with depressive neurosis, suffered more subjective impact. Previous findings have underlined the importance of patients psychiatric status on the impact of care, although this study represents one of the few attempts to compare diagnostic categories in establishing levels of impact.

South Verona community psychiatric services appeared fairly extensive for many relatives and patient members in the sample. Some of the shortfalls found however, was the failure of professionals to acknowledge the importance of relatives in their services practices. No formal service provisions for relatives existed in the period relatives were being interviewed. Professionals' attitudes towards relatives represented perhaps one of the main criticisms of services by relatives, and where improvements could be made. This significantly aggravated relatives' situations, which is also a common finding in other studies. Only a minority of relatives however, felt the need for extra services for the patient member, but there was a notable need for relatives to discuss their own psychological problems, which again confirms previous findings.

The following chapter draws on these main findings to discuss them in more detail within the context of previous work. The implications of the current study are located at two levels. Firstly, the significance of the current findings and the extent of impact on relatives in South Verona within the context of community psychiatric services. Secondly, the broader policy implications and the application of Italy's 1978 mental health reform.

Chapter Seven

Discussion and Conclusions

Several main interests formed the basis of the present study. The increasing interest generated by policy makers and academics in the movement towards community care represented one of the first. Community mental health care in Italy, with the enactment of the 1978 reform and the sudden reduction in mental hospital beds, provoked both intrigue and astonishment amongst academics and professionals alike. Within the Italian setting little was known about the extent of impact on relatives living with someone diagnosed mentally ill. The many anecdotal accounts and outcome studies carried out on Italy's mental health care system after the reform have offered only speculation about the possible impact on relatives of the mentally ill. Nothing empirical had been conducted to understand the exact effects of community mental health in Italy on families of the mentally ill.

The shift towards community care in Italy and what this implied for families of the mentally ill provided the main impetus for the present study. The current research study took both the themes and issues feminists and researchers on the impact of care had raised in Britain to explore the effects of community care in Italy in the 1978 post reform era, and to consider the efficacy of community care. Each of the theoretical and practical issues such as the debate on community mental health care in Italy, the implications community care and feminist thinking, and the impact of care in itself on the relatives of the mentally ill, cover much of the mainstream thinking to have emerged on the topic. The stance underpinning the basis of the present study supports the shift to community alternatives in mental health care, coming out in favour of what Italy sought to achieve, at the same time giving credence to the implications these policies have on the people who then care for relatives with mental illness. Indeed, the primary aim of the study was to establish the degree of impact on relatives within the context of the 1978 mental health reform in Italy. The study also sought to determine the varying intensities of impact amongst differing groups of relatives, to show what factors made caring more difficult for some and not for others. It is worth at this stage reiterating some of the main theoretical issues and other domains of discussion to lay the framework for discussing the main findings of the study.

7.1 Theories and Thinking Behind Community Care Policies in Britain and Italy

In Italy the move towards community care, at least as far as the 1978 reform is concerned, was based on a different set of principles and circumstances to that of Britain. The two countries are culturally very different in terms of their postwar welfarism, their status of science, and their psychiatric professionalisation (Rogers and Pilgrim, 1987). Basaglia's ideological condemnation of asylum-based care, the creation of a political movement to oppose its very rudiments, and the push for social reforms in general were collectively important in bringing about the current mental health policy in Italy. The model of reform during this time operated within a cultural framework that endeavoured to close the gap between society and the socially marginalised. Mental institutions were perceived as oppressive towards those marginalised within them. It was within this framework of thinking that the speedy closure of asylum beds came about, and imperative that psychiatric hospitals be replaced quickly with new community services (Fasolo and Frisanco, 1991). This ideology, together with the knowledge gained from previous experiments in mental hospital closures conducted by Basaglia and colleagues, became later consolidated in the 1978 mental health reform.

Attempts to implement this law brought about a new set of difficulties. Little thought had been given to how community services would be distributed, set up around the country, and exactly what the consequences of the reform would be. Fierce criticism of deinstitutionalisation policies, such as that in Italy, feared the abandonment of ex-mental hospital patients, the increase in homelessness and the possibility of suicide as a consequence (Jones, 1988). The battery of outcome studies and the polemic to emerge since the reform's enactment have been plagued by 'wildly for' or 'wildly against' opinions on Italy's mental health system. This, together with the lack of reliable information, has clouded any clear understanding of what has happened overall. The patchy distribution of community services around the country however, certainly represents one of the most formidable problems. Understanding the effects of the reform therefore has been stifled by these events and the current situation. Locations where community mental health care has been considered successful have tended to be those who had implemented community alternatives and supported Basaglia's cause long before 1978. South Verona is a good example of this. Even with its own success in administering a comprehensive community psychiatric service little attention has been given to what the families of the mentally ill may be experiencing.

In Britain, on the other hand, the move towards community care has been slower and seemingly more cautious compared to Italy's bold advancement. There was increasing pressure to close down mental hospitals in Britain for a variety of reasons, ranging from the uncovering of institutional scandals to the socio-economic climate over the last three decades (Goodwin, 1993). Part of the ideology underpinning many community care policies in Britain is the perception, based on conservative and neo-liberal social and political thought, which emphasised the family as the locus of care, rather than statutory agencies (Twigg et al, 1990). The approach, therefore, towards community care in both countries differed quite substantially. Italy was keen to do away with institutions because of the restrictions on mental patients' civil rights. In Britain economic priorities became one of the chief motivating factors for seeking community alternatives. In both countries thus the main consequence of these policies was to posit the family as the major provider of care. Italy did so without much due thought and attention to this and many of the other implications. In Britain the concern was to cut expenditure and thus the burden of care came to rest on the family.

Simon Goodwin (1993) in his analysis of the move towards community care identifies two key periods, 1948-1963 and 1975-1993, in the development of community care policy in Britain. In latter he shows how policy formulations were affected by costs. Expenditure on social services had risen considerably between 1951-1981. Social expenditure accounted for 75% of the growth in public expenditure during this time (Judge, 1982). In overall terms the amount spent by the state on the National Health Service (NHS) since its inception quadrupled in real terms (Ham, 1992). Internationally, however, Britain spends proportionately less of its GNP on health care than other advanced industrial countries. The percentage increase in expenditure for hospital services for was indeed greater for the mentally ill than for acute patients, rising by 7% compared to 4.4% for acute in-patients. Despite this the increasing emphasis on community care did not result in increased funding for mental health services outside the hospital (Goodwin, 1993). In 1981-82 local authority personal social services in England spent £27.8 million on community care for the mentally ill, compared with £857 million which was spent by the health service in the same period on hospital services (DHSS, 1983). It was not, however, that the absolute cost of mental health services was becoming a serious burden for the state, but rather there was pressure placed upon it about the escalation of costs, rather than the scale of what was being spent. It became increasingly apparent that, despite previous beliefs that mental illness could be treated like any other illness, the mentally ill required care which was being provided to only a minimal degree (DHSS, 1975). The more practical issues of tending had scarcely been addressed. Only recently has there been more policy recognition of the reliance on families to care for mentally ill relatives.

7.1.1 The Feminists

The ensuing reliance on informal carers in Britain provoked increasing criticism from feminist academics, critiques that have been developed over the past decade (Finch and Groves, 1982; Ungerson, 1987; Dalley 1989). These critiques were coupled with an emerging series of studies on carers of the elderly and physically disabled. These showed that care of a dependant relative tended to fall on the shoulders of one person, usually someone close, and very often a female member of the family. Feminists in Britain were avid in uncovering the inherent gender-bias in community care policies. Their chief argument is simply that as an inevitable consequence of community care policies the bulk of caring is often performed by women. For the feminists these policies therefore are a source of women's oppression. In retortion to this state of affairs some feminists have gone so far as to argue for a return of residential care (Finch and Groves 1980; Dalley, 1989). The focus and arguments by feminists and policy makers, have repeatedly overlooked what families and their adult dependants would like. Feminists have generally failed to consider that families might not wish clients to be in residential care, or that the clients themselves might prefer being at home. In the debate put forward by feminists male carers have been seriously underestimated.

7.1.2 Impact of Care Studies

A parallel series of studies on the impact of care sought to identify the precise effects of caring for someone with mental illness (Thompson and Doll, 1982; Gibbons et al, 1984; Fadden et al, 1987b). These studies provided some understanding of what was involved when living with someone diagnosed with mental illness. Many studies in this area set parameters of impact largely relating to the changes relatives (significant others) made to numerous activities in their everyday lives. Impact studies, however, lack any concrete theoretical basis, although there are various factors used as a framework in which to analyse the potential effects. The distinction between objective and subjective impact in early studies (Hoenig and Hamilton, 1967; Hoenig, 1968), although represented an advancement in defining impact, was nevertheless limited in scope. The measurement of impact was also subject to difficulties. The distinction between the two facets of impact are fairly well established, although attempts to measure these, particularly subjective responses remains dubious (Platt, 1985; Noh and Avison, 1988).

How impact differed for some depending on certain socio-demographic factors also became a subject of interest. The way in which impact took shape and why some people experienced more impact compared to others has only been marginally explored in previous work. Relatives' kinship, gender, age, and the patient's psychiatric status are all factors that have been implicated in determining levels of impact. Other factors such as coping responses and social support networks were also seen to affect impact, but could act in ways to alleviate impact rather than augment it.

Summary

The issues drawn from the three areas of debate, (community care, the rebuttal by feminist academics of its implications, and the studies dealing precisely with the impact of care and the mentally ill), formed the basis of the present study. The study itself was carried out using a similar framework to that employed in impact studies and the mentally ill (Fadden et al, 1987b). The results of which later provided the context in which to discuss the issues raised and the points of interest.

7.2 Main Findings of the Study

Judging from what previous impact studies found and the arguments expressing concern about the consequences of community care, there appeared to be sufficient reason to expect a similar sort of situation in South Verona, particularly in view of some previous accounts of the reform's effects (Crepet and Pirella, 1985; Jones and Poletti, 1985; Crepet, 1988). Anticipating a high percentage of South Verona patients living with families was a certainty given the way the community psychiatric services were organised and the minimal reliance on hospitals. Indeed, this was the case. In Italian society too, the family is culturally and economically important. Despite the dramatic socio-economic changes in the past century - the move away from extended family networks (Golini, 1988), the decrease in family size (Livi Bacci, 1977), and the changing position of women - the importance and centrality of the family in Italy remains remarkably intact (New and Benigni, 1987). The contemporary role of women in Italy is now one of a *doppia presenza* (double presence) in managing both major responsibilities at home and in the work place (Balbo, 1978). It seemed feasible to assume therefore, that women may well find themselves responsible for the care of patient members under the Italian system of community mental health, and if the feminists' analysis community care is correct. It was a little more difficult to predict the likely extent of impact on families within this system of mental health care. It certainly represented one of the foremost questions on the 1978 mental health reform, with the rapid reduction of mental hospital beds (Jones, 1988).

The situation in South Verona, contrary to many of these expectations, yielded a number of surprises. Before examining these with some of the main findings of the current study it is appropriate at this point to outline briefly South Verona in the context of the 1978 reform. By the time the 1978 mental health reform had been enacted South Verona had already established a fully comprehensive community psychiatric service. The service therefore, was not undergoing any form of transition from the mental hospital to the community when the current study was carried out. None of the patients included the current sample had been discharged from the mental hospital, situated on the outskirts of South Verona. Despite being an interesting phenomenon, it was inappropriate to look at the impact on families using a before and after type of inquiry, where a patient member had been discharged from the asylum and returned home. Even the long-term patients of South Verona's service, included in the sample, had been treated in the community. South Verona, with its tradition of community mental health care, in keeping with the reform's principles, was an ideal location to assess the level of impact on relatives.

The extent of impact overall appeared low for the majority of relatives in the study. This was particularly apparent where objective impact was concerned. At the time interviews were taking place most relatives did not have problems with their employment. The majority of relatives who worked managed to continue doing so without much disruption, despite the patient member's condition. Some studies have reported quite major disruptions to relatives' employment (Johnstone et al, 1984; Gibbons et al, 1984), although it is not as frequent as difficulties with financial activities. It must, however, be borne in mind that not all patient members were unwell at the time of relatives' interview, and not all had long-term illnesses. This partly explains some the lack of disruption. For most relatives in the sample effects on their employment usually meant taking some time off work when the patient was unwell. In more extreme cases relatives stopped work altogether, yet these cases were few and far between. Relatives affected by the patient's condition in this way were predominantly women, wives of patient members.

Perhaps one of the most remarkable findings was the number of patients who continued to be employed, even those still in contact with South Verona psychiatric services. Verona's economic prosperity and low unemployment figure at 6.5% during 1988 provides some explanation for this finding. It also demonstrated that a high employment situation can indeed reduce the potential impact on relatives caring for a mentally ill family member. This had a knock on effect in other areas of impact, such as the family's financial activities. Indeed, families in the study were, for the most part, financially secure. Financial problems appeared virtually non-existent for most. A minimal number of relatives had some difficulties with their financial circumstances which were heighten by the patient members condition. An even smaller percentage of relatives (all spouses) experienced sudden falls in family income due to the patient member's condition. On the whole however, relatives were financially quite comfortable and in most cases the onset of the patient member's condition did not affect the family's income at all. This is not a particularly common finding in impact studies, in which households were adversely affected financially

(Thompson and Doll, 1982; Gibbons et al, 1984; Fadden et al, 1987b). When one considers also that the sample of relatives mostly consisted of spouses, who are theoretically more likely to encounter difficulties in either financial and employment activities, the present study's findings appear exceptional.

Domestic activities and the running of household affairs also presented few major impact difficulties for relatives. There was a strong gender difference in those performing the housework, yet this in itself was largely unaffected by the patient's condition. Managing other household affairs revealed some impact on relatives, particularly in terms relatives having to adopt new responsibilities following the onset of the patient's mental illness. As other work has shown spouses were mainly affected by these sorts of changes in responsibilities (Fadden, et al, 1987b). The current study however also found gender differences in specific areas of household activities. Women seemed to experience a greater level of impact in household responsibilities over a longer period of time. Male relatives found managing household and domestic activities, when the patient member was unwell, significantly more difficult than female relatives. This could have something to do with male relatives not being accustomed to managing the household, and as a consequence experienced more disruption. It was notably evident that some male relatives in the sample were particularly hard hit in the area of household management due to the patient member's condition.

There was an even clearer distinction of gender differences and impact found in the area of social and leisure activities. Despite not pursuing leisure activities outside the home as frequently as male relatives female relatives nevertheless, appeared to experience more impact in their social activities compared to men. They were also much less likely to leave the patient member unattended when unwell. This, however, was counterbalanced by the large percentage of South Verona relatives, particularly women, who had regular contact with friends and relatives, and people to confide in. South Verona relatives in the study maintained fairly good social contacts outside the home. Feeling socially isolated because of their situation was a comparatively rare phenomenon for almost all these relatives. This, as with the lack of employment and financial impact on South Verona relatives, in theory may have either alleviated or prevented some of the potentially more harmful effects of impact. As some authors have suggested social networks can act to protect against emotional distress (Broadhead et al, 1983; Wallston et al, 1983), and some close relationships are particularly beneficial to women's mental health (Cohen and Wills, 1985). However, whether these benefits applied to South Verona relatives was doubtful. Indeed, this also accords with Zimmerman-Tansella et al's (1993) study in which they found no substantial direct protective effect on emotional distress in an Italian community sample. For example, this situation did not protect relatives from experiencing significant psychological impact. Neither were there any striking gender differences in this latter area. This was a somewhat unexpected finding given the focus of studies on the differences in gender regarding coping styles (Fadden et al, 1987b; Barusch and Spaid, 1989).

Similarly, when examining how relatives reacted to patient behaviour many who confronted social withdrawal behaviour found it very difficult, particularly female relatives. Yet, there were no gender differences when comparing both practical and cognitive coping responses to patient behaviour. A finding similar to that of Fadden (1984). Individual coping mechanisms were much more telling of how relatives perceived their situation and how they subsequently dealt with it, and seemed more pertinent than the need to identify gender differences in coping styles. Some common coping responses adopted by relatives in their situation was to 'wish the situation would go away', which also provides an indication of the difficulty relatives had. Another common response, also found by Creer et al (1982), was a resigned attitude of 'these things happen in life' and 'taking the good with the bad'. In both cases there was a slightly higher percentage of women who perceived their situation in these ways.

In overall terms women did appear more vulnerable to impact than men, which confirms much of what feminist theory on carers contend. This was not, however, a particularly outstanding finding in the current. Many men in the sample too had experienced quite substantial impact on their lives when the patient member was unwell. For most men the impact encountered was not related to the effects on their working or social lives. All relatives expressed concern for their spouse, their child, or their parent patient member. The definition of caring, described in Chapter 2, is positively distinct from the concern shown towards someone. Amongst South Verona relatives impact of care was very difficult to separate in this way. In some cases both appeared inextricably linked. In many cases, however, the concern expressed for the patient member often outweighed any caring for. In the strict sense of the definition many relatives in the sample did not directly care for patient members. Some allowance has been given to this particular situation. As Chapter 3 explains caring for someone with mental illness is different, often more sporadic or episodic, to that of caring for someone who is elderly, or someone with a physical and mental handicap. The concept of caring is, in essence, a mixed one and clearly still in need of an analytic definition (Twigg et al, 1990). There were several occasions where relatives, particularly male relatives (fathers and husbands), whose concern for the patient member was akin to subjective distress. It is this form of distress that has been overlooked in the impact literature, or set apart from the process of caring in the caring literature. There are also methodological reasons for this type of neglect, and indeed there is a need to assess certain strains that may be specific to particular kin relationships (Perring et al, 1990). The same might also be true where gender factors are concerned.

In again highlighting kinship factors and the strain experienced the current study found a definite association between parent relatives' poor psychological health and the patient member's condition. Parents experienced far more difficulties as a result, compared to spouse relatives in the sample. There was clearly a great deal of concern by parent relatives, expressed during interviews, with regards to their child's own mental illness. This too coincided with patient diagnosis. Relatives with patient members diagnosed with one of the two psychoses (functional or affective) had much more impact on their psychological health. These relatives experienced a much greater strain in generally keeping things going and also in tense personal relations with the patient member. The extent of subjective impact therefore, amongst relatives with patient members diagnosed with psychosis was undeniable. The effects of the patient members' condition on relatives' own psychological health represented thus one of the more notable areas of impact for South Verona relatives. This in itself, does not constitute a new finding and is in keeping with what previous impact studies have found (Gilhooly, 1984; Fadden et al, 1987b; Falloon et al, 1993). The recognition that parent relatives may well be more vulnerable to emotional distress compared to spouse relatives was, however, a comparatively new finding.

The knowledge relative's had regarding the patient member's condition and the medication they took was sufficient for at least half of those interviewed. Relatives were less well informed on the nature of the patient's condition and their future prospects. The need for more information in these areas was clearly required by a fair number of relatives. The present study however, was not aimed at determining whether the amount of information relatives had could improve the patient member's prognosis, as with studies aiming to reduce Expressed Emotion (Leff et al, 1982; 1985). There was, however, an interest to assess whether this form of information could indeed have some effect on helping relatives with their situation. It is difficult to say in any conclusive way whether knowledge of the patient's condition helped reduce impact on relatives. There was some indication that relatives without this information appeared to have more difficulties with their interpersonal relationship with the patient member, and with how they reacted to the patient's challenging behaviour.

Support for relatives by South Verona community psychiatric services was primarily an indirect consequence of what the patient member had received in terms of treatment and intervention. The lack of formal services aimed solely for the benefit of relatives who support patient members would have been welcomed by relatives in the sample, particularly those whose patient members suffered long-term mental illness. The majority of relatives were satisfied with the services the patient member had received. Many also felt they could contact services and receive help if necessary, particularly in times of crisis.

The most common dissatisfaction of services amongst South Verona relatives concerned staff attitudes towards them. Many complained of being ignored or treated with hostility. In general relatives perceived staff to be unhelpful when they themselves needed to be comforted or reassured about the patient member or their situation. This too is a consistent finding in many other impact studies (Creer, 1975; Creer et al, 1982; Johnstone et al, 1984).

Relatives were not always able to express in precise terms what they required from services or if any improvements could be made. When asked about specific services, either for their own benefit or the patient member's, relatives mostly requested the opportunity to discuss their own psychological problems. This was particularly so for relatives with patient member diagnosed with psychosis. Despite the difficulties relatives might have confronted, in view of the patient member's illness, there was an overwhelming preference amongst South Verona relatives for their patient members to be at home. This is similar to Johnstone et al's (1984) findings, but more so amongst South Verona relatives. None felt their patient member required alternative accommodation, accept for one elderly mother who was unable to look after her son due to her age. This particular finding puts in doubt the feminist argument for a return to residential care. In South Verona's context it is largely inappropriate to talk in these terms. There is a strong commitment towards community mental health care which is favoured by the relatives of the mentally ill themselves, despite the difficulties. It is nevertheless, important to take count of the difficulties relatives often face.

7.3 Difficulties and Positive Encounters in South Verona

The present study's overall findings point to specific groups of relatives identified as being much more susceptible to impact than other groups. Parents, particularly mothers, of patient members diagnosed with psychosis were certainly more predisposed to subjective forms of impact. They were also more likely to have other difficulties not directly related to the patient member's condition, such as problems with their physical health. Parents were older in age, and for some who were elderly it was clear they were less able to withstand the difficult aspects of living with someone with mental illness. Spouse relatives in the sample also experienced some difficulties which were more in terms of objective impact such as the changes made to their employment or financial activities. Wives of patient members in this familial setting were more affected than husbands. Subjective impact on South Verona relatives was far more apparent, in particular psychological distress, notably in relatives with a patient diagnosed with psychosis. The sheer strain of keeping things going was at times too much for some relatives of patient members with this diagnosis.

For the majority of South Verona relatives in the sample the extent of impact, particularly objective impact, was minimal overall. This was partly due to the sample included in the study, whereby many patient members did not suffer from long-term mental illness. Not all relatives whose patient member suffered long term mental necessarily experienced objective impact. The economic context at the time interviews were taking place certainly helped to keep patient members employed, despite their condition. The benefits derived were invaluable for both the patient and his/her family. The patient's quality of life was far better than it would have been had they been unemployed. This context might have even acted to prevent any decline in the patient member's condition, or even improved their prognosis. For the family the patient's employment prevented the possible material difficulties that can often arise. Stalling any potential objective impact was certainly a great benefactor for both relatives and their patient members.

Cultural factors represented another reason for the minimal amount of impact in the area of domestic activities. Men, whether spouses, children or parents were not always expected to perform the housework, cook, clean or go shopping, either for themselves or the rest of the family. Most of these activities were performed by female relatives even before the patient member became unwell. As a result of this most remained remarkably unscathed by any domestic disruptions when the patient member was unwell, given they knew how to perform them. Male relatives in the sample experienced more difficulties in managing household affairs, and in some cases this was simply because they were unaccustomed to dealing with these activities.

It seemed however, that little prevented the subjective impact many relatives experienced. Extensive social contacts and someone to confide in, although did not appear to buffer relatives against their emotional distress, were probably beneficial anyway. It certainly prevented relatives becoming isolated in their situation, which could have given rise to other problems and perhaps added to their strain. South Verona's community psychiatric services however, played little part in offering relatives any direct formal support. What was notably lacking in these services was a forum for relatives to discuss their own stresses and strains in their situation, as well as the psychological or emotional difficulties they might have been experiencing.

7.4 Strengths and Weaknesses of the Study

One of the main strengths of the study was the variety of characteristics in both relative and patient groups. The spectrum of families included in the study was fairly broad. Relatives varied in terms of kinship, gender, family composition, age, residence, and so forth. Most came from similar social classes, occupying mainly unskilled, blue collar or clerical jobs, which reflected fairly accurately the occupational makeup of South Verona. Most people were employed either in industry or the service sector (Mosher and Burti, 1989). The diversity in socio-demographic factors and family composition enabled an analysis to determine which group appeared more vulnerable to impact. Generally, this is confounded in the literature (Perring et al, 1990). Similarly, most studies on impact and the mentally ill have concentrated on people with schizophrenia (Perring et al, 1990). The present study attempted comparisons between two groups of diagnoses: psychoses and neurotic depression. Some of the strengths therefore lay in the comparisons made between groups of relatives and patients to identify how impact differed. The patients themselves also varied socio-demographically and in their clinical backgrounds. The inclusion of patients with both short- and long-term illnesses was advantageous, and useful in gaining some understanding of how impact can change over time. Often, the very sporadic nature of mental illnesses does not always have long lasting effects on families. Not focusing simply on the long term mentally ill, as other studies have tended to do (MacCarthy, 1989; Fadden et al, 1987), perhaps presented a more accurate picture of impact generally. In doing so a more balanced idea of what happens to relatives when a family member becomes mentally ill could be seen.

The study has a number of limitations, many of which are methodological. The high refusal rate of relatives and patients perhaps led to slightly skewed patient samples in the main diagnostic category in terms of male/female ratios[1]. The psychoses categories tended to be dominated either by male patients and female patient were more prominent in the neurotic depressive group. However, this also reflects the tendency anyway for young adult males, for example, to be diagnosed with schizophrenia (Iacono and Beiser, 1992), and women who largely have diagnoses of depression (Ernst and Angst, 1992). Every effort had be made to either persuade patients or relatives who refused initially to be interviewed, or to trace those who could not be found at the addresses provided. There were also certain restrictions on who could be interviewed. The consultant psychiatrists involved with some of the

---

[1] How representative both samples were of South Verona's catchment area is uncertain because of the high refusal rate.

patient members listed by the Case Register were often reluctant do allow access in some cases.

It would have also been more preferable to have more information on patient's current psychiatric status. Other impact studies (ie. Fadden et al, 1987) have used the Present State Examination (PSE) to determine a patient's current mental state. This however, would have been difficult to implement given the training required. The lack of resources and time restraints, particularly as the study was mostly self funded, prevented asking someone trained to administer the PSE for the purposes of the present study. This was compensated slightly by the series of questions on patient behaviors included in the schedule employed on relatives. These provided some details on patients' symptoms in the month prior to interview.

An interesting factor to emerge from the study was that the patient's condition was not always the focal point of the family's difficulties. Often, the patient's condition was part of a wider context of family tensions or problems existing prior to the patient becoming unwell. There were sometimes deep-rooted problems with other members of the family which distressed relatives a great deal. The schedule was not always extensive enough to measure this type of distress or other aspects of subjective impact directly associated with the patient member's condition. It nevertheless, provided enough scope for relatives to express them during the course of the interview. On some occasions, also when answering questions, relatives would sometimes become quite emotional, particularly those experiencing quite severe impact. It became apparent during interviews like these that an overlap might exist between what relatives express as impact and what is also measured as Expressed Emotion. In other words, can what is measured as Expressed Emotion be a reflection of impact on the relative and their situation?

7.4.1 In an Ideal Research World!

Conducting some form of comparative study to look at how impact might vary under different community mental health service settings in Italy might have yielded some interesting contrasts. A comparison, for example, of a service like South Verona with that of catchment area in a larger city, perhaps Rome, struggling to develop its community psychiatric services and the heavy demands made upon them.

Psychological impact on relatives is an obvious point for expansion. A more indepth look at this using a schedule sensitive to measuring subjective impact would have provided more precise estimates of its significance

7.5 The Current Findings in the Broader Context

There are no simple answers to questions concerning the success or failure of community psychiatric care in Italy following the 1978 reform. Variations in the way the reform has been implemented and the lack of reliable information on its outcome inhibit any conclusive answers. What is undoubtedly clear however, is that the families of the mentally ill are pivotal to the reform's functioning. The reform has failed to take account of this. Even in good practice areas where the reform has been successfully implemented many patients live with their families. This is true of South Verona's community mental health services. Relying on families and relatives in this way broadens the discussion into the efficacy of community care and the feminist arguments against it. Within the context of the present study South Verona community services provide a comprehensive service in the community for people with mental illness. The service is committed to the reform's ideals and has been highly successful in operating without the need for a mental hospital. What have been identified as new long-stay patients have adapted to community-based services, and are not in need of long-term residential care in South Verona (Mignolli et al, 1984).

These are some of the many positive achievements in community mental health in Italy both prior to and after the 1978 reform. It is important not to lose sight of these achievements and what Basaglia and his supporters sought to accomplish. His reason for doing so was principly ideological and political, whose underlying philosophy was to give credence to the mentally ill, who were otherwise marginalised from society. This ideological basis contrasts the pursuit of community care policies in Britain whose underlying concerns have more to do with cost-effectiveness. What good practice areas in Italy, such as South Verona, Lomest, Portogrugaro and Trieste showed is a commitment to community mental health care. They have shown that community mental health care can be feasibly implemented without the devastating consequences many feared, such as an increase in suicides rates and homelessness (Williams and Tansella, 1987). What, however, are the costs to families of the mentally ill?

It is difficult to generalise the findings of the current study to Italy as a whole given the vast differences in service provision. As many impact studies in Britain have shown that relatives can suffer detrimental effects to their material, social and psychological well-being when caring for a someone with mental illness (Creer et al, 1982; Fadden et al, 1987b). The present findings, although similar in many respects to previous studies, showed that impact occurred to a much lesser degree amongst South Verona relatives. For many, the impact of the patient member's condition was short-lived. Only a small number of cases could more prolonged effects on relatives be identified. Even in the majority of these situations impact on relatives' material circumstances was comparatively minimal. Yet, the effects however, on relatives psychological health, and other areas of subjective impact, were unmistakable. It was this cost to relatives which caused most concern. The group of relatives most affected by the patients condition as parents with patients diagnosed with one of the two psychoses, either functional or affective. Females too tended to experience slightly higher levels of impact compared to men. Prominent levels of impact, however, appeared confined to a minority of relatives in the current sample. This minority of relatives typically characterised the sort of impact found in previous studies conducted in Britain.

The comparatively low degree of objective impact had much to do South Verona's broader economic context. This perhaps represented one of the most illuminating findings of the present study. Economic and demographic circumstances in South Verona acted favourably towards the system of community mental health care, both informally (for the relatives of the mentally ill) and formally (in terms of the smooth functioning of services). As a medium-sized city Verona does not suffer many of the social problems found in larger, urban cities (ie. homelessness, high unemployment). Neither does it have organisational problems or problems in coordinating services often seen in large cities (Donnelly, 1992). This situation implies that resources, if provided adequately in terms of demand and not stretched beyond its capacity, can indeed, work very well.

Favourable economic, social and cultural factors (ie. high employment, a strong tradition of family solidarity and the traditional role of women, etc) found in South Verona appeared to actively reduce the burden on families that might have otherwise been created. Low levels of unemployment are to some extent significant. If a patient member is able to continue working and carry on with their everyday activities, pressures on the family are reduced. The future success of the reform will also be dependent on their ability to adapt to changing economic, social and cultural contexts, in which the state and mental health services may have to assume more of the caring responsibility if families are not able to care for dependants.

Even the most comprehensive community psychiatric service, like South Verona, cannot in itself prevent relatives experiencing some of the more harmful effects of living with someone with mental illness. It seems, however, that relatives are supportive of community-based services despite the difficulties they often face (Vicente et al, 1993), and the majority of South Verona relatives were satisfied with services. At most, relatives wished to see a change in staff attitudes, and support for their own emotional distress, rather than see a return to asylum-based care. Relatives were not always able to express how South Verona's community psychiatric services could be improved. On some occasions during the course of the interview relatives talked about what they had expected from it. This usually reflected what was needed in their particular situation. A wife of a patient member diagnosed with psychosis mentioned at the end of the interview that she had expected some form of marital therapy. Her relationship with her husband was clearly deteriorating and her sense of loss was overwhelming. This was heightened by the fact the husband could no longer work, nor look after their young child. All the familial responsibilities therefore lay with the wife, the strain of which was formidable.

Some relatives openly expressed relief when approached for an interview. Comments, such as, 'at last, someone is taking an interest in what we have to say', were common amongst relatives experiencing quite intense levels of impact. Other needs included simply obtaining practical advice, sitting with a professional to discuss the patient's condition, why the patient member had become ill, if they (the relative) was in any to blame or if there was anything that could be done to help the patient member recover, were all questions raised at interviews. The exasperation of some relatives in their contact with services and staff was exemplified by another wife, whose husband's condition of psychosis had spanned over a period of 15 years. She said:

> For me it's not that my husband's illness is a burden, even when it can be, but what burden's me is the way that I have to find treatment for him.

This relative needed to know whether her husband's illness was curable, or whether she would somehow always have to contain whatever he said or did when he was unwell. Even after such a long period of time this particular relative still needed practical advice about her husband's illness, and that if nothing could be done what was the best approach towards his condition. These examples represented some of the hard core cases of relatives who experienced quite severe impact generally. Many of the requests, particularly from relatives whose impact was intense, was for staff to be more supportive towards them, to answer any queries or concerns, rather than specific services such as respite care or alternative accommodation for the patient member. Each family's experience of their situation is qualitatively different in terms of their perceptions and expectations. In part, this explains why some relatives experience more impact than others.

The rigid distinction also between patients and carers is another theme that needs to be clarified and expanded upon. The findings from the current study suggest that relatives did not always 'care for' patients in the strict sense of the term, particularly where gender issues are concerned. There are two implications from this that are worth exploring. The first suggests that the term 'caring for' or even defining a relative as carer and the patient as the dependant are sometimes inappropriate given the present findings. Often patient members contributed to various domestic and familial responsibilities, and in many cases this was linked to the episodic nature of their condition. More often than not, therefore, patients in the sample were not necessarily dependant on someone to look after them, even when unwell.

The second implication concerns the carers own difficulties, particularly their psychological well-being and sometimes material difficulties, (such as a loss of income). Both these issues suggest that the definition of caring used in the caring literature, either requires some expansion to include these points or needs to be made less rigid where the field of mental health is concerned.

The approach used by South Verona services did not appear to acknowledge many of these issues. Their focus was essentially patient-centred. Only occasionally would the family as a whole would be seen; during sessions of family therapy, for example. The sample of patients in the current study appeared to receive quite traditional methods of professional input, whereby many had individual consultations with a psychiatrist and were given medication. For what is regarded as a progressive and reformed type of psychiatric service, South Verona has retained some of the more conventional methods used in treating people diagnosed with mental illness. The progressive nature of South Verona psychiatric services lies in its location which is community-, rather than asylum-based. By comparison community psychiatric services in Trieste are much less traditional and conservative in this approach to both patients and their families, involving them much more in the way services are determined and the type of treatment received (Vicente et al, 1993).

Moving onto gender issues and impact, the current study found a slightly higher proportion of female relatives experiencing quite intense impact compared to men. More female relatives appeared to be caring for patient members with long-term conditions, particularly wives. Drawing any reliable conclusions on this alone, however, requires a certain amount of caution. The extent of care given by relatives in the sample varied enormously. Men provided care for patient members too, even if they were fewer in number, and their experiences less intense in some cases. Their contribution however, was larger than was thought. The arguments put forward by feminists have some relevance to South Verona's community mental health care, and to the Italian context in general. Cultural definitions and stereotypes play a prominent part in designating womens' roles at home and in the family, as British feminists have argued which have extended into caring tasks (Dalley, 1978; Finch and Groves, 1980; Ungerson, 1983). These are similarly relevant to Italy, although Italian feminists have not, as yet, explored these precise issues. There are no figures to illustrate whether there are proportionately more female carers compared to males. We can only assume this may be the case given family associations in Italy comprise mainly of women (Giannichedda, 1989), and from what studies conducted in Britain have found. The question of whether policies advocating community care should rely on informal care, opposed by the feminists, has mixed views in the Italy. This issue forms part of an ongoing debate in the Italian parliament where the future of the 1978 reform is still to be decided.

7.6 Future Dilemmas and Possible Directions

Seeing a return to residential or institutional care endorsed by feminists and other opponents to community care, is unlikely to take place in Italy, at least not in the immediate future. Italian family associations lobby for a more efficient distribution and functioning of community services, and at the most call for beds to be made available in community mental health centres (CMHC's) or residential homes. None, however, demand a re-opening of the asylum (Giannichedda, 1989; Donnelly, 1992). To some extent families of the mentally ill have gained more attention at the service level. Community psychiatric services in Trieste, for example, now offer extensive support for families of the mentally ill (Mezzina et al, 1992).

Discussions seeking to remedy the limitations of law 180 have taken place in parliament over the last few years. The bills presented have, in essence, urged an increase in the creation of community services. Suggested amendments to law 180 have focused on using beds in previous psychiatric institutions. Ongaro-Basaglia (1989; 1992), however, argued that a more viable solution would be to create a model of mental health care based on a 24 hour service, open seven days a week, covering the population in a given catchment area and providing full-time care for patients, if necessary, both day and night. Treatment would take place at home or in the surgery and the provision of residential solutions of a therapeutic nature, and economic and social support provided by liaising social services. Ongaro-Basaglia also stressed that a mental health service of this type should not replicate the hospital structure with the additional attachments of surgeries and social services. The need for small residential units as an alternative to both hospitals and the family has been recognised. Ongaro-Basaglia maintained that this not only prevents chronicity, but gives families the opportunity to take on another role in support of their members and not be just the sole carers bearing much of the responsibility, instead be more involved in therapeutic plans.

A very recent new bill has considered revoking the 1978 reform's clause concerning the prohibition of compulsory admissions to hospital. The bill wants to give doctors the right to admit patients to hospital against their will. If patients refuse to go to hospitals it also allows doctors to call in the police. Local authorities too are to provide day centres, clinics, and community housing (Endean, 1993). The new bill also seeks to sanction local authorities who fail to implement the services required by the mentally ill. The fears, generated by the media, on the scandals of community care and the inadequate nature of these policies on meeting the needs of severely mentally ill, also gaining ground in Britain, are perhaps contributing to such amendments in policy. In Italy, as Donnelly (1992) explained, there has been less of an ideological polemic regarding law 180. Mental health professionals have adopted a more pragmatic approach and are more willing to accept the reform's limitations for whatever reason.

What the future holds for mental health care in Italy is determined not simply by potential amendments to the reform act itself, but also the availability of financial resources allocated to mental health care and the willingness of regions to provide community mental health services. It is no longer useful to discuss Italy in terms of the current discharge of patients from psychiatric institutions, but more of how alternative community services are being developed across the country and the limitations involved. Whether the system of community psychiatric care in Italy becomes more homogeneous or gains the necessary expenditure to develop alternative services remains uncertain. How best to generalise the successes of community mental health services like Trieste and South Verona to areas lacking these services still needs to be understood in terms of how far that success is dependent upon favourable, exceptional or specific local circumstances (Donnelly, 1992). The situation at present, as a recent paper described, showed that the largest type of psychiatric services in Italy is that lacking in community facilities (Fasolo and Frisanco, 1991). At the same time Fasolo and Frisanco (1991) are positive in their assessment of psychiatric services around the country. They explained:

> We thus have to cope with a sector that is still developing and which is seeking an identity to be used as a model for the years to come. However what seems certain is that the

> spirit underlying the reform has in general been assimilated by the psychiatric services. This means that its ideology is gradually being incorporated in the professional and social culture of the country, despite difficulties apparent in its implementation ... we now find that the services are stronger and psychiatric care more efficient (pp.224-225).

There are still however, structural problems that block the transfer of successful community care experiences into those areas without these alternatives, even putting aside any political resistance to the reform in these areas (Donnelly, 1992).

Obtaining the financial backing to increase the number of community psychiatric services is another factor stalling any further progress in this direction. The concentration of mental health expenditure on existing psychiatric hospitals, leaving only 20% for alternative developments in services continues to act as a hinderance (Ongaro-Basaglia, 1987). In the broader welfare context too proposed changes to other welfare policies in Italy - reforms in the health care, pension, voluntary associations and local authority systems - show a trend towards the state's partial withdrawal of its responsibilities, in particular its financial obligations (Ponzini, 1993). In Britain a similar withdrawal has meant a move towards a mixed or pluralist economy of welfare in which both the public sector and the private market provide services (Graham, 1991; Pinker, 1992).

The problems of community care in Britain include not only financial and funding arrangements but also policy and practical difficulties. Problems in these areas have gained increasing attention in the literature over recent years (Dalley, 1998; Jones, 1988; Hudson, 1991). Goodwin (1989) provided an alternative explanation of why mental health services are failing to meet the needs of the mentally ill and community care is in crisis. His argument points to some of the mistaken assumptions and myths surrounding the development of community care policies[2]. Goodwin's assessment of community care highlights other, more real, problems. Within the context in which central government has retained the responsibility to treat the mentally ill, but has surrendered the provision of care to local authorities, the informal sector and involuntary organisations there have arisen numerous administrative difficulties and tensions. The present economic climate, leaving little or no scope for additional expenditure on health and personal social services, and the need to expand local authority provisions to enable the mentally ill to live in the community culminated in a major reorganisation of policy at the beginning of the 1990's with the passage of the 1990 NHS and Community Care Act. How far this act will in practice improve the provision of community care remains to be seen.

Another barrier to effective community mental health care is the resistance or lack of faith in the current changes in community care. As Kingsley (1993) argued, 'whilst much attention has been directed towards creating new visions of mental health services very little has been devoted to the forces that militate against achieving these aspirations' (p.299). These forces come from both inside and outside mental health services. Often there is scepticism about the capacities of various service delivery systems which are expressed either in terms of direct disbelief or uncertainty about their effectiveness. As Kingsley continues, these uncertainties from within services are mirrored outside them in doubts about the efficacy of community care and its ability to meet the needs of the mentally ill. There is, to some extent, a failure amongst the

---

[2] These include whether community care was a product of the development in drug treatments; the development of a consensus of opinion about how the mentally ill should be looked after; whether the 1959 Mental Health Act was a social reform or that institutional care was in decline; whether there was a change in policy or practice; whether the mentally ill have been abandoned; and whether community care was an opportunity to provide mental health services cheaply.

sceptics to acknowledge the mounting successes of various projects and reforms (see Lavender and Holloway, 1988; Ramon and Giannichedda, 1988). The lack of progress, and the failure to acknowledge success, often lead to over pessimistic conclusions about the future of community care in Britain and tend to overlook what can be learnt from past mistakes.

Conclusions

7.7 The Lessons of Community Care - Some Comparative Comments Between Italy and Britain

The strong legacy behind the movement of community mental health care in Italy will always retain a sense of uniqueness in terms of the build up, enactment and implementation of the 1978 mental health reform. Some authors have written about the lessons for Britain of the Italian experience (Ramon, 1984; Jones, 1988).

Britain can learn from the successes of community mental health care in Italy. Sufficient commitment and adequate resources have proved to be important ingredients in a community psychiatric service that functions well. The successes are similarly relevant for other areas in Italy who have yet to develop community services. Attempts to reduce or fail to expand community mental health services, in an effort to curb spending, may well threaten any further successes. The trend however, towards reducing resources committed to mental health care in both countries will aggravate problems of community mental health even further.

Britain can also take heed of the problems encountered in implementing the 1978 reform. The more negative experiences of the Italian mental health policy in some ways have offered a warning of what could happen if deinstitutionalisation too rapid. Fortunately, Italy escaped any major catastrophe. The lessons for Italy had more to do with thinking carefully about the implications of a new reform and ensuring that some of the primary consequences have been accounted for. The 1978 reform could have benefitted from some pre-planning and thought on the ramifications, and subsequent outcome. On the other hand, it was precisely because policy makers were more focused on other issues (ie. civil rights, the threat of a referendum, and so forth) that such an extraordinary law was passed to begin with.

The humanitarian nature and ideological impetus underlying the 1978 reform is something British policy makers could also learn from. The pragmatic approach often forming the basis of community care policies in Britain (Ramon, 1984), and the need to cut expenditure, sometimes stifles any recognition of the mentally ill's own needs. Cultural differences (ie. norms and values) in the two countries have played a significant part in the way community mental health care has been employed. Cultural factors too do not allow any direct transmission of policies from one country to another and it would be foolhardy to think otherwise. There are however, some policy recommendations that can be borne in mind.

7.8 Policy Implications and Service Recommendations in Light of the Present Study

The feminist policy recommendation of reintroducing residential care on a scale large enough to avoid the reliance on women to provide care is perhaps too rash in view of the current findings. The majority of relatives and patients tend to prefer to stay at home. A certain level of residential care is necessary for a hard core number of patients who either have no place to stay nor family to care for them. These however should not be the only options where community care is concerned. The primary reliance on the family or relatives of the mentally ill is not something policy makers should take for granted without due support. Aiming towards expanding formal support for families is certainly a step in the right direction for community care in Italy. This starts with staff making themselves more accessible to relatives and perhaps training to provide formal support groups for relatives. A forum for relatives to at least express themselves and the difficulties they might be experiencing would represent a substantial improvement in services for South Verona relatives. Using a forum, such as this, also enables the transfer of information about the patient's diagnosis and give relatives the opportunity to discuss what might be concerning them about the patient and their situation. It is also important for services to identify the differing needs of individual relatives depending on their kinship status, in order that the right kind of support be given to relatives whose experiences may be more intense than others.

Offering families and patients a choice of what would best suit them in their situation is again something services could strive towards. This may mean providing enough alternative accommodation or to offer families respite care. There does not appear to be, however, a large demand for these sorts of services in South Verona. It seems existing community services are extensive enough not to warrant an introduction of alternative residential facilities.

Perhaps one of the most important considerations is the need to keep patients occupied. The importance of maintaining patients in employment had numerous benefits for both them and the relatives they lived with. The implications of this also meant that there was less reliance on formal services to provide facilities, such as day care centres and occupational therapy. South Verona's favourable economic situation at the time the study was taking place enabled this. Economic prosperity, however, tends to run in cycles. It is not a phenomena that is ever-lasting and there will be times, such as during a recession, that unemployment rises and jobs become scarce. With this in mind it is crucial therefore to ensure that provisions can be made to keep patients occupied in some way.

Additional policy considerations, relevant to both Britain and Italy, point to how the distinction between carers and patients may need reconceptualising. Relatives' needs in the study occasionally overlapped with those of the patient members, particularly where carers' own psychological distress was concerned or where the family experienced material hardship through a loss of the patient's income. Policy implications thus need to take account of these sorts of difficulties which relatives living with patient members can sometimes face. Support for the family as a whole, rather than simply a patient-centred approach could be much more beneficial in the long run for all those involved.

The favourable conditions, discussed earlier, of the wider economic, social and cultural context again should not be taken for granted or used as an excuse to withdraw much needed services of support for both patients and the relatives they live with. These conditions can enhance the success of reforms, like law 180, but cannot act as a substitute to essential services.

7.9 Implications for Future Research

Expanding on the theme of how the economy acts to protect relatives and patients from experiencing some of the worst features of objective impact is worth exploring further. What impact the economy has on the type of welfare and mental health services that are required, might depend on the availability of employment opportunities.

Given the psychological distress present in many relatives living with someone diagnosed mentally ill it is important to start researching and identifying ways in which this can be reduced. It would also be interesting to explore the relationship between impact on relatives and their expressed emotion. Would it be possible to apply psychoeducation and relatives' support groups used in reducing expressed emotion to also decrease some of the strain, tension and distress relatives can experience as impact?

These two themes perhaps represent some of the most important considerations from the current study that could be pursued in further research.

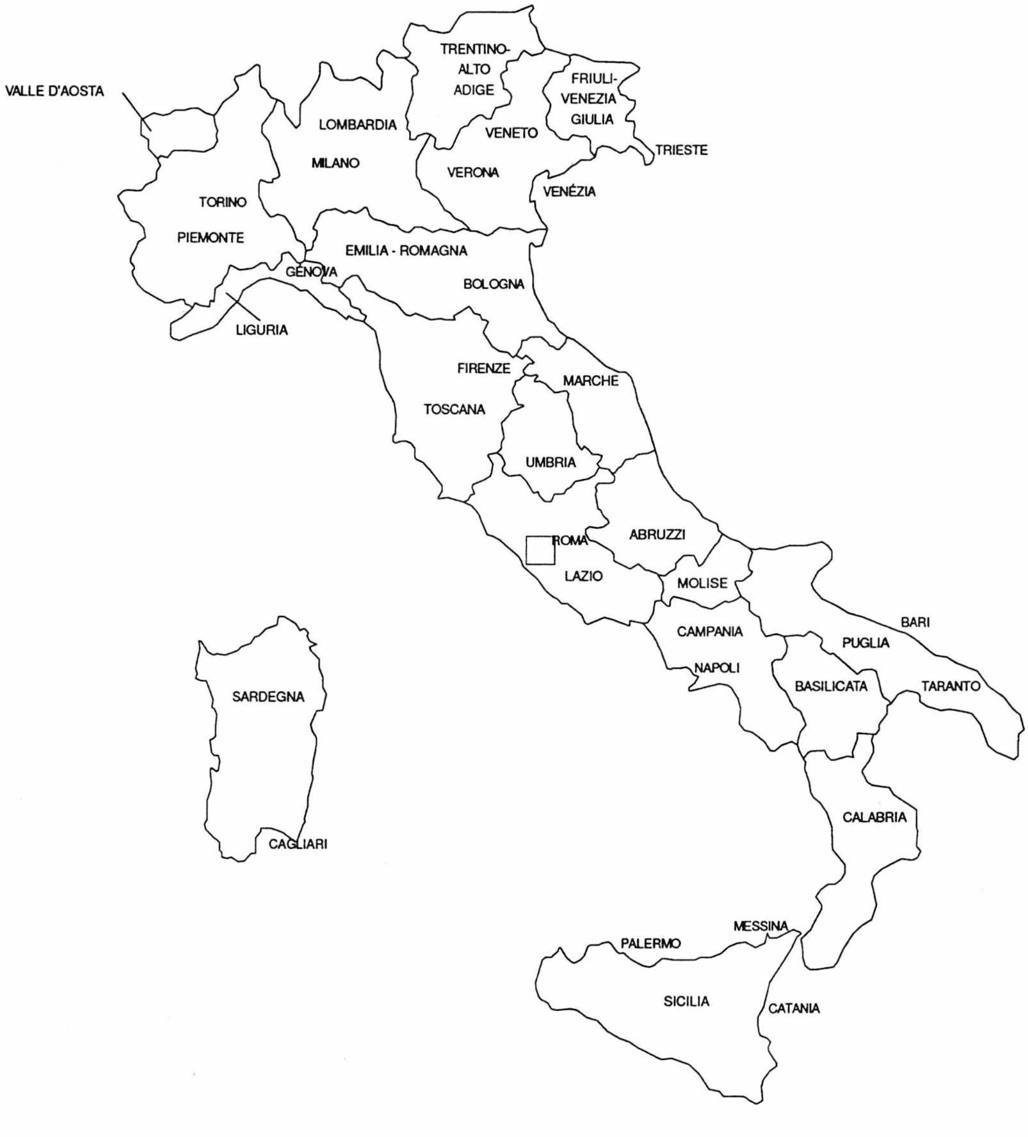
7.10 Final Comments on Italy

Italy is currently undergoing a number of changes following the exposure of the deeply embedded corruption in both its political and commercial ranks. This has coincided with a series of amendments in welfare policies shortly taking place. It is still too early to predict the outcome of these changes but there is now a definite push to improve the existing situation. The 1978 mental health reform has, it seems, been drawn into what may turn out to be another era of change.

It would be misleading to think however, that any amendments to the 1978 reform are a retreat from community mental health care, or even an acceptance of its failure. Contrary to this idea, policy makers and professionals are aiming to extend the implementation of the 1978 reform and correct some of the limitations encountered. Recognising the shortcomings of the 1978 reform and the difficulties of implementation have more to do with learning from past mistakes. This does not necessarily mean resorting back to the asylum because community care does not work. It is unlikely that this will occur, given there is still a commitment to community mental health care. Progress in Italy's mental health care system means not disregarding the achievements made since Basaglia and the 1978 reform. Adopting a sober approach to existing problems, including those faced by relatives of the mentally ill, whilst retaining the essence of what Basaglia and his colleagues sought to achieve, can only add to the successes already accomplished. It appears futile to now abandon them.

Appendices

Major Cities and Regions of Italy



Studio delle Famiglie di Pazienti Psichiatrici a Verona-Sud
Scheda della Intervista

Intervistatore: .... Data: ....

Inizio, ore: .... Fine, ore: ....

Luogo dell'intervista:
1 Casa del informante
2 Casa del paziente ( )
3 Casa del informante e paziente
4 Altro (specificare): ....

Paziente presente durante l'intervista

0 No ( )
1 Si

Altre persone presenti durante l'intervista (specificare):

....

Paziente: ....

Indirizzo:................................

....

Telefono: ....

Parente: ....

Indirizzo:................................

....

Telefono: ....
(Se diverso da sopra)

1. Presentatevi. Spiegate lo scopo dello studio ponendo l'accento sul vostro interesse nei confronti delle famiglie che hanno dei parenti con disturbi psichiatrici a casa.

2. Cercate di usare un tono confidenziale.

3. Se e' il caso, chiedere il permesso di accendere il registratore.

Dati socio-demografici del paziente

Sesso:
1 Maschio ( )
2 Femmina

Eta': ( )

Stato civile:
1 Celibe/nubile
2 Sposato/a/convivente
3 Separato/a ( )
4 Divorziato/a
5 Vedovo/a

Dati socio-demografici del parente

Sesso:
1 Maschio ( )
2 Femmina

Eta: ( )

Stato civile:
1 Celibe/nubile
2 Sposato/a/convivente
3 Separato/a ( )
4 Divorziato/a
5 Vedovo/a

Grado di parentela (del parente) col paziente

1 Madre
2 Padre
3 Moglie o fidanzata
4 Marito o fidanzato
5 Figlia ( )
6 Figlio
7 Sorella
8 Fratello
9 Altri parenti
10 Altri non parenti

Familiari

Quante persone, Lei compreso/a, vivono nella sua famiglia?
Scrivere qui: ( )

Se la famiglia consiste solo del parente e/o del Soggetto, segnate qui e andate all'inizio del questionario: ( )

Indicatele in ordine di eta' a partire dal piu' anziano. Scrivere N/C se non si conosce la risposta esatta.

Il no. di persone e': (il piu' anziano prima)	1	2	3	4	5	6	7	8
Sesso: Maschio	1	1	1	1	1	1	1	1
Femmina	2	2	2	2	2	2	2	2
Grado di parentela con chi da supporto (Scrivere qui):								
Eta' (Scrivere qui):								
La persona e': Occupata (a tempo pieno)	1	1	1	1	1	1	1	1
Occupata (a tempo parziale)	2	2	2	2	2	2	2	2
Pensionata	3	3	3	3	3	3	3	3
Disoccupata	4	4	4	4	4	4	4	4
Frequenta la scuola (a tempo pieno)	5	5	5	5	5	5	5	5
Frequenta la scuola (a tempo parziale)	6	6	6	6	6	6	6	6

Storia dei ricoveri in reparto psichiatrico o O.P.

S e' mai stato ricoverato in un ospedale psichiatrico (O.P.) o in un reparto psichiatrico?
(Se si, chiedere):
Quando e' avvenuto il primo ricovero di S?

(Specificare) ....

Quante volte e' stato ricoverato?

(Specificare) ....

E' mai stato ricoverato per piu' di un anno?

0 No ( )
1 Si

(Se si, chiedere):
Quante volte e' stato ricoverato per piu' di un anno?

(Specificare) ....

Quale e' stato il piu' lungo periodo di ricovero?

(Specificare) ....

Storia del problema

"Vorrei possibilmente sapere come sono andate in generale le cose con S quest'ultimo anno."

Quali sono le cose che vi fanno pensare che ci sia ancora qualcosa che non va'?
(Indicare per esteso):

Distribuzione del tempo del soggetto (Bilancio del tempo)

"Vorrei avere un quadro di come S passa di solito un giorno della settimana."
Come ha trascorso la giornata di ieri; e' stata una giornata abbastanza tipica?

A che ora S si e alzato/a: ....

Ed e' andato a letto: ....

S ha avuto delle difficolta' a dormire?
(Fino a che ora):

- -(Segnare le risposte):

Tempo passato a letto (di notte) nelle 24 ore	( )
Tempo passato a letto (di giorno) nelle 24 ore S come passa normalmente il tempo a casa?	( )
Tempo passato a casa a non fare nulla (definire dettagliatomente, es. guardando nel vuoto, passeggiando su e giu')	( )
Ore in contatto faccia-a-faccia (tra parente e paziente) durante la settimana.	( )

Parte 1 - Attivita' dell'Informante (Carer)

"Desiderei sapere se Lei ha un lavoro retribuito o quale lavoro faceva in passato".

Ha un lavoro al momento?
0 No ( )
1 Si

Cosa fa/faceva di preciso ?
(Scrivere la risposta):

(Se l'informante non lavora fuori di casa, andate alla Parte Ia): Lavoro di S (p.8)

(Se l'informante lavora/lavorava, chiedere):

Ha fatto/ha dovuto fare di recente dei cambiamenti nel suo lavoro a causa della malattia di S? (Se l'intervistato dice che i cambiamenti sono stati causati da altre ragioni, controllare se tali ragioni non sanno state causate indirettamente dalla malattia di S).

0 No ( )
1 Si

(Se la risposta e' NO, andate all'item segnato (1).
Se si, chiedere):

Perche' e' stato necessario per Lei fare questi cambiamenti?

1 Ha lasciato il lavoro a tempo-pieno per prendersi cura di S
2 Ha lasciato il lavoro a tempo-parziale per prendersi cura di S
3 Ha cambiato un lavoro a tempo-pieno con uno a tempo-parziale (cioe' meno di 30 ore la settimana) per badare a S
4 Ha lasciato il lavoro a tempo-pieno per badare ai bambini in quanto S non era in grado di farlo
5 Ha cambiato un lavoro a tempo-pieno con uno a tempo-parziale per badare ai bambini come S non avrebbe potuto fare ( )
6 Ha lasciato il lavoro perche' era diventato troppo oneroso reggere contemporaneamente il lavoro le preoccupazioni e/o le esigenze determinate dalla malattia di S
7 E stato licenziato perche non manteneva i consueti standards/lavorativi a causa delle preoccupazione per S
8 Ha dovuto cambiare turno/ore di lavoro/ridurre lo straodinario

INFORMATEVI DEI FAMILIARI CON LAVORO RETRIBUITO

Lei o chiunque altro della famiglia ha mai dovuto cercare un impiego o fare straordinari per motivi legati alla malattia di S?

0 No
1 Ha preso un posto a tempo pieno
2 Ha preso un posto a tempo parziale
3 Ha cambiato da un lavoro a tempo
  parziale con uno a tempo pieno ( )
4 Gia lavorava ed ha cominciato a fare
  straordinari
5 Ha lasciato l'universita' o la scuola
  per intraprendere un lavoro

(Se e' stata scelta una delle risposte 1-5, chiedere):
Quali sono state le ragioni per tale cambiamento nel lavoro?

1 Finanziarie - bisogno di piu' soldi per mantenere
  la famiglia a causa della perdita dello stipendio di
  S o delle spese extra necessarie per l'assistenza a S
2 Sociale/emotive - bisogno di avere contatti ( )
  extrafamiliari o di avere una pausa da S e dall'
  ambiente domestico

Lei o chiunque altro della famglia ha duvuto prendere dei periodi di ferie per la malattia di S? Se si, quanto tempo l'anno scorso?

0 Nessun periodo
1 Meno d'una settimana
2 1-3 settimane ( )
3 3-5 settimane
4 Piu' di 6 settimane

(1) Se la risposta alla domanda di cambiamento nel lavoro e' stato NO, chiedere:

Come trovate il lavoro al momento? Qualche volta ha un po' di difficolta' a concentrarsi e far procedere le cose come al solito? Tutto cio' e' legato alla malattia di S?

0 Lavorare non e' un problema
1 Lavorare e' stressante ma non c'entra la
  malattia di S ( )
2 Lavorare e' stressante per le preocupazioni/
  le difficolta' pratiche legate alla malattia di S
3 Lavorare e' stressante solo quando S sta molto male

(Se e' stata scelta la risposta 1, chiedere):
Recentemente che difficolta' ha trovato nel lavoro?

1 E' un po' stressante ma si va avanti
2 E' abbastanza duro mantenere il normale
  ritmo nel lavoro ( )
3 E' estremamente difficile per il timore che
  l'informante ha di dover lasciare completamente

il lavoro

(Se l'informante sta avendo difficolta' al lavoro, dire):
"Il lavoro Le ha procurato un po' di stress, recentemente". Poi chiedere:

Pensa che ci sia stato un certo calo nel suo rendimento al lavoro? E' un calo notevole? Quanto? C'e qualcuno che L'ha notato?

0 Nessun calo di rendimento
1 C'e' stato un calo ma nessuno l'ha notato
2 C'e' stato un forte calo che i colleghi hanno notato ( )
3 Calo molto serio, con possibile rischio di essere licenziato o con licenziamento gia' minacciato

Ha qualche altra difficolta' nel campo del lavoro/impiego di cui non abbiamo parlato?
(Se si, indicare per esteso):

<u>Parte Ia - Dettagli sull'impiego del paziente</u>

"Vorrei chiederle brevemente del lavoro di S."
S ha mai avuto un impiego retribuito?

0 No ( )
1 Si

Se no, chiedere perche'?
(Indicare per esteso):

(Se si, chiedere):
Qual'e'/era la sua mansione specifica?

Parte 2 - Questioni Economiche

(Non chiedere se il paziente lavora)
S, al momento, ha qualche introito - sussidi, pensioni, etc?

0 No ( )
1 Si

S amministra da solo i suoi soldi? E' capace di organizzarsi le spese di una settimana?

0 S non e' capace di amministrarsi il denaro
1 Riesce ad amministrare il denaro ma non a pianificare
  le sue spese per una settimana ( )
2 Riesce ad amministrasi i soldi e ad organizzarseli
  per la settimana

(Se S non si amministra ed organizza i soldi, chiedere):
Questo fatto e' in qualche misura legato alle condizioni di S?

0 No
1 Probabilmente ( )
2 Senz'altro

C'e' stata qualche variazione negli introiti della famiglia da quando S si e' ammalato? Se si, come direbbe che e', adesso, il vostro tenore di vita dall'inizio della malattia di S?

1 Migliore
2 Uguale ( )
3 Un po'peggio
4 Molto peggio

(Se sono state scelte le risposte 3-4, chiedere):
Di quanto e' calato l'introito della famiglia?

1 Calo di meno del 10%
2 Calo di meno del 25% (fino al 10%) ( )
3 Calo fino al 50%
4 Calo di piu' del 50%

Qual'e' il motivo di questo calo degli introiti?

1 Perdita dello stipendio di S
2 Perdita dello stipendio di un altro familiare
  a causa della malattia di S ( )
3 S ha buttato via dei soldi in un periodo di
  crisi della sua malattia

"Da quando S e' ammalato":
Avete dovuto ridurre qualche spesa - per esempio, su cose come il mangiare, il vestirsi, i divertimenti o altre cose simili?

0 No ( )

1 Si

Vi e' capitato di restare indietro con pagamenti, affitto, conti, rate, ecc.?

0 No ( )
1 Si

(Se la risposta e' si, chiedere):
Da quanto tempo avete difficolta' nei pagamenti?

1 Meno di una settimana
2 Piu' di una settimana, meno di 3 mesi
3 Piu' di 3 mesi, ma meno di 1 anno ( )
4 Piu' d'un anno
5 Sempre
6 Altro (specificare) ....

Pensa che questi problemi economici siano legati alle difficolta' di S? Per esempio S ha lasciato dei debiti che avete dovuto pagare?

0 No
1 Probabilmente ( )
2 Senz'altro

Chi e' il principale responsabile della gestione dei soldi in famiglia? - Chi decide per cosa spendere i soldi e si preoccupa di controllare che vengono pagati i conti?

1 Informante
2 Paziente
3 Altri familiari
4 La responsibilita de divisa tra l'
  informante e S o tra familiari compreso S ( )
5 La responsibilita' e' divisa tra l'informante e
  i familiari escluso S
6 L'informante ha la responsibilita completa solo
  quando S sta male

Tale situazione e' come prima che S si ammalasse?

1 Uguale
2 Qualcun'altro ha dovuto prendersi la
  responsabilita' a causa della malattia di S ( )
3 L'informante si prende la responisibilita quando
  S sta male ma non le altre volte

Ci sono discordie familiari per problemi di soldi? Se si, quante volte capita?

0 Mai
1 Una volta al mese
2 2-3 volte al mese ( )
3 Una volta la settimana
4 Ogni giorno
5 Altro (specificare) ....

Lei e' mai preoccupato per problemi di soldi? Quante volte le capita di avere in mente il problema dei soldi?

0 Mai
1 Qualche volta ( )
2 Piu' di qualche volta
3 Quasi sempre

Sentite di avere difficolta' a controllare i soldi? Sono sotto il vostro controllo?

Sfuggono completamente al controllo ______________________ Completamente sotto controllo
1 2 3 4 5 6 7

Fino a che punto S ha voce in capitolo per quel che riguarda problemi di soldi?

Nessuna voce in capitolo ______________________ Le decisioni dipendono da S
1 2 3 4 5 6 7

Parte 3 - Compiti/Mansioni Familiari

S riesce a fare i lavori di casa piu' semplici, come pulire, prendersi cura dei vestiti, senza che nessuno gli dia una mano? Se si, con quale frequenza S lo fa?

0 Non fa mai nessuna faccenda di casa
1 Qualche volta prende parte alla faccende di casa o esegue regolarmente solo mansioni di poco conto, ma deve esservi spinto ( )
2 Fa qualche volta le faccende di casa o regolarmente mansioni di poco conto regolarmente senza esservi spinto
3 Prende parte in modo molto attivo alle faccende domestiche

(Se mai o con l'aiuto di qualcuno (0-1), chiedere):
Questo fatto e' causato dalle condizione di S?

0 No
1 Probabilmente ( )
2 Senz'altro

S riesce a fare piccole commissioni per la famiglia da solo? - per esempio, fare la spesa? Se si, con quale frequenza S lo fa?

0 Mai
1 Ha parte nelle incombenze familiari ma deve esservi spinto
2 Fa qualche incombenza per la famiglia senza esservi spinto ( )
3 E molto partecipe delle incombenze familiari

(Se Mai o Non da Solo (0-1), chiedere):
Questo fatto dipende dalle condizioni di S?

0 No
1 Probabilmente ( )
2 Senz'altro

S riesce a cucinare o comprarsi da mangiare da solo? Se si, con quale frequenza S lo fa?

0 Mai
1 Non riesce a cucinare o comprarsi da mangiare senza aiuto
2 Riesce a cucinare ed a comprarsi da mangiare senza aiuto e lo fa di tanto in tanto ( )
3 Per lo piu' cucina/si compra da mangiare da solo

(Se Mai o Non da Solo, chiedere):
Questo fatto dipende in qualche modo dalle condizioni di S?

0 No
1 Probabilmente ( )
2 Senz'altro

Quanto lavoro fa in casa attualmente? (rispetto agli altri familiari?)

0 Niente
1 Un po'
2 La maggior parte ( )
3 Tutto
4 Varia a seconda delle condizioni di S

Se l'informante fa la maggior parte o tutto il lavoro (2-3) che c'e' da sbrigare in casa, chiedere: Dipende dal fatto che S non si occupa di quelle faccende di casa di cui dovrebbe invece occuparsi?

1 Dipende dal fatto che S non si occupa di quelle
  faccende di casa di cui dovrebbe invece occuparsi ( )
2 Non dipende da S

Cosa mi sa dire delle altre mansioni di cui ci si deve occupare in una casa? Che responsabilita' ha nelle mansioni domestiche?

0 Nessuna
1 Un po'
2 La maggior parte ( )
3 Tutta
4 Varia a seconda delle condizioni di S

S si occupa al momento delle comuni mansioni di casa - per esempio controllare che i conti vengano pagati, preoccuparsi che vengano fatte le riparazioni che servono?

0 Per niente
1 Un po'
2 Per la maggior parte ( )
3 Completamente
4 Varia a seconda delle condizioni di S

E' sempre stato cosi' o le responsabilita' che ha adesso per la gestione della casa sono aumentate da quando S si e' ammalato?

0 Nessun cambiamento nel carico di
  responsabilita' o comunque non dovuto a S
1 Deve avere piu' responsabilita' perche'
  S non fa la sua parte di lavoro in casa ( )
2 Si prende tutte le responsabilita' di casa
3 Si prende tutte le responsibilita' solo quando
  S sta male

Da quando S ha cominciato ad ammalarsi ci sono stati problemi nella gestione della casa? Se si, di che importanza?

0 Nessun problema
1 Qualche problema
2 Completa disorganizzazione nelle faccende
  di casa ( )
3 Le faccende di casa sono risultate
  disorganizzate solo nei momenti in

cui S e' stato male

In generale come pensa che stiano andando le cose in famiglia? Pensa che sia piu' difficile far andare avanti le cose, dato che S e' malato?

0 Nessun problema
1 C'e un po' di stress ma si va avanti
2 Trova piuttosto difficile fare andare tutto come si deve ( )
3 Trova molto difficile - ha paura di non farcela piu' tra non molto

Cos'e' che e' piu' difficile fare?
(Scrivere):

Cos'e che e' piu' scombussolante (disturbante) fare?
(Scrivere):

(Se l'informante trova difficolta' a far andare avanti le cose, dire):
"Cosi' trovate difficile far andare avanti le cose". (Poi chiedere):
In che modo pensate che questa vostra difficolta' influenzi la gestione della casa?

0 Le cose non vanno esattamente come dovrebbero ma nessuno si e' lamentato di questo
1 Qualcuno ha notato che certe cose non vengono fatte ( )
2 La casa e' completamente disorganizzata ed anche le cose piu' essenziali non si fanno

Pensa di avere la capacita' di controllare tutti i problemi che capitano in casa e che abbiamo appena visto?

Non ho il controllo di nulla ______ Posso senz'altro controllare quello che succede
1 2 3 4 5 6 7

Quanto pensa che S riesca a influenzare le cose che capitano?

S non ha nessuna influenza ______ Tutto quello che succede dipende da lui/lei
1 2 3 4 5 6 7

Ci sono altre difficolta' nella gestione della casa di cui non abbiamo parlato? Se si, (Scrivere):

Parte 4 - Problemi (Mansioni/Compiti Domestici)

"Quello che adesso vorrei fare e' parlare di un problema specifico o di una particolare situazione nell'andamento della casa che avete dovuto affrontare in quest'ultimo mese - qualcosa che vi ha provocato difficolta' o noie. Le viene in mente qualcosa?"

Chi vi era coinvolto?

Cos'e' accaduto? (brevemente)

Quali sono state le cause di quello che e' accaduto?

Cosa l'ha reso importante per lei?

"Ci sono molti modi usati per far fronte ai problemi. Pensando alla situazione appena descritta, Lei ha usato qualcuna dei modi qui indicati per affrontare quella particolare situazione/ problema?"

Andare al <u>Questionario sulla Soluzione dei Problemi</u>

Questionario sulla Soluzione dei Problemi

Chiedere: Lei:-	No	Qualche volta	Abbastanza spesso	Molto spesso
Cerca di sentirsi meglio mangiando, bevendo, fumando, predendo droghe o farmaci, etc	3	2	1	0
Pensa che _____ non sia in fondo cosi' importante	3	2	1	0
Sa che cosa deve essere fatto e cosi' raddoppia i suoi sforzi per far funzionare le cose	3	2	1	0
Accetta la compassione/ simpatia e la comprensione di qualcuno	3	2	1	0
Cerca di vedere i lati positivi della cosa	3	2	1	0
Cerca di tenere i propri sentimenti per se'	3	2	1	0
Cerca di vedere le cose dal punto di vista dell' altro	3	2	1	0
Critica e censura se stesso/a	3	2	1	0
Pensa che le cose potrebbero essere peggio di quanto sono. Siamo tutti nella stessa barca	3	2	1	0
Pensa alla sua esperienza passata; si e' trovato altre volte in questa situazione	3	2	1	0
Pensa che queste siano cose che succedono nella vita; deve accettare il buono e il cattivo	3	2	1	0
Cerca di non agire senza pensare e di non seguire il suo primo impulso	3	2	1	0

Vorrebbe che la situazione spiacevole fosse scomparsa o che in qualche modo lei l'avesse superata	3	2	1	0
Ripete tra se' e se' quello che dira' o fara'	3	2	1	0
Parla a qualcuno per chiarirsi meglio la situazione	3	2	1	0
E' fatalista: a volte capita di avere sfortuna	3	2	1	0
Trova diverse soluzioni al problema	3	2	1	0

Parte 5 - Attivita' Sociali e Ricreative

Lei ha del tempo libero?

0 Neanche un po'
1 Ha del tempo libero qualche giorno ( )
2 Ha del tempo libero ogni giorno

Prende parte a qualche attivita' sociale/ricreativa? Ed eventualmente, con che frequenza?

0 Mai
1 Va fuori meno di una volta al mese
2 Una volta al mese ( )
3 2-3 volte al mese
4 Una volta al mese o piu'

Si sentirebbe sicura ad andar fuori e lasciare S in casa da solo/a?

0 Nessun problema
1 E' un po' riluttante ma lascia S da solo/a ( )
2 Raramente o mai lascia S da solo

S prende parte ad attivita' sociali/ricreative? Ed eventualmente, con che frequenza?

0 Mai
1 Va fuori meno d'una volta al mese
2 Una volta al mese
3 2-3 volte al mese ( )
4 Una volta al mese o piu'
5 Altri (specificare) ....

Lei e S prendete mai parte insieme ad attivita' sociali/ricreative? Ed eventualmente, con che frequenza?

0 Mai
1 Vanno fuori insieme meno di una volta al mese
2 Vanno fuori insieme una volta al mese
3 Vanno fuori insieme 2-3 volte al mese ( )
4 Vanno fuori insieme una volta alla settimana o piu'
5 Altri (specificare) ....

Da quando S si e' ammalato ha dovuto ridurre il numero di volte che usciva di casa per svagarsi con altre persone?

0 No
1 Lieve riduzione
2 Considerevole riduzione
3 Da quando S e' ammalato l'intervistato e raramente uscito ( )
4 Non va fuori quando S sta male ma esce quando S sta meglio

Non si sente piu' di uscire a causa delle preoccupazioni/ difficolta' legate ai problemi creati da S?

0 Mai
1 Qualche volta ( )
2 Sempre

Sente che badare a S prende cosi' tanto tempo che non c'e' piu' spazio per attivita' di svago con altre persone?

0 Mai
1 Qualche volta ( )
2 Sempre

La malattia di S ha fatto si che gli amici vengano a far visita piu' rarmente o non chiamino piu'?

0 Nessun cambiamento
1 Chiamano meno amici ( )
2 Evidente calo del numero di amici che chiamano oppure gli amici non chiamano piu'

Quanti amici/parenti sente vicino a lei? Per esempio, con quanti amici e' stato/a in contatto la scorsa settimana?

0 Nessuno
1 1 o 2
2 2 - 5 ( )
3 Piu' di 5

Prima che S si ammalasse vi frequentavate piu' spesso con i vostri amici?

1 Piu' contatti da quando S si e' ammalato
2 Nessuna variazione ( )
3 Meno contatti

Se trova le cose particolarmente difficili, ha qualcuno (amico o parente) a cui rivolgersi per ricevere un aiuto o un sostegno?

1 C'e' un certo numero di persone che posso sentire
2 1 o 2 persone
3 Non c'e' nessuno a cui possa rivolgermi ( )

4 Ho qualcuno a cui potermi rivolgere ma preferisco
fare da solo/a

Si sente mai isolato/a come se lei fosse l'unico/a in una simile situazione o invece ha contatti con qualcun altro che sia in una posizione simile alla sua?

1 Conosco/ho contatti con persone
nella stessa situazione
2 Ci conosciamo con persone in una
simile situazione ( )
3 Non so di nessun altro in tale condizione
ma non mi sento isolato
4 Non so di nessuno in questa condizione, e
per cio' mi sento isolato

Parte 6 - Relazione dei Parenti con S

Quando S e' a casa con lei come passate il tempo insieme?

1 S e l'informante non condividono nessuna attivita
2 S e l'informante fanno qualcosa insieme ( )
3 S e l'informante per lo piu' condividono tutte le loro attivita

In generale, come direste che stiamo andando le cose tra lei ed S, al momento?

1 Molto bene
2 Abbastanza bene
3 Qualche problema ad andare d'accordo ( )
4 Al momento e' molto difficile andare d'accordo

Com'e' la situazione rispetto al rapporto che avevate con S prima che lui/lei s'ammalasse?

1 Il rapporto e' diventato piu' stretto
2 Va all'incirca come prima ( )
3 Va molto peggio da quando e' iniziata la malattia di S

(Se e' stata scelta la risposta 3, chiedere):

Pensa che le volte che ha litigato con S siano aumentate da quando S e' ammalato? Se si, ogni quanto litigate?

1 Meno d'una volta al mese
2 Una volta al mese
3 Una volta ogni 2 settimane ( )
4 Una volta alla settimana
5 Ogni giorno
6 Altro (specificare) ....

Nel complesso trovate che avere a che fare con S, al momento, sia un po' stressante?

0 No
1 Un po', ma me la cavo bene
2 Molto difficile andare avanti con S ( )
3 E' cosi' difficile che l'informante sente che non riuscira' piu' a farcela per molto

Nel suo rapporto con S quanta influenza crede di avere su cio' che accade tra di voi?

Nessun controllo sul vostro rapporto					Cio' che succede dipende soprattutto da me	
1	2	3	4	5	6	7

Fino a che punto lei pensa che S controlli il rapporto che avete?

S non ha nessun influenza sul rapporto					Cio' che succede dipende soprattutto da S	
1	2	3	4	5	6	7

Parte 7 - Effetti sulla Salute Fisica/Emozionale del Parente

Com'e' andata recentemente (di mese scorso) la sua salute fisica? Ha sofferto di qualche malattia, s'e' sentito male o ha avuto dolori?

0 No
1 Qualche problema ma niente di serio ( )
2 Abbastaza problemi

(Se le risposte 1-2 sono stati scelti, chiedere):
Ha dovuto andare dal medico? Se si, le ha dato delle medicine? Le sta ancora prendendo?

0 No
1 Sono stato/a dal medico ma non mi ha ordinato niente ( )
2 Sono stato/a dal medico e mi ha ordinato una cura e la sto ancora facendo

Per quanto tempo ha avuto queste difficolta'?

1 Da meno di una settimana
2 Da piu' di una ma meno di 3 ( )
3 Da piu' di 3 mesi ma da meno di un anno
4 Da piu' di un anno
5 Quasi sempre

Questa condizioni dipende in qualche modo dalla malattia di S?

0 No
1 Probabilmente dipende dalla malattia di S ( )
2 Senz'altro dipende dalla malattia di S

Recentemente ha avuto qualche difficolta' emotive? Ha avuto problemi a concentrarsi, si e' preoccupato/a molto, si e' sentito/a irrequieto, depresso o ansioso?

0 No
1 Qualche problemi, ma niente di serio ( )
2 Abbastanza problemi

(Se sono stati scelti 1-2 chiedere):
Ha visto un medico o qualcun altro per questi problemi? Se si, segue una qualche cura o prende una terpia per questi motivi?

0 Nessun problema
1 Qualche problema ma non ho preso niente ( )
2 Abbastanza problemi: sono stato/a in cura o lo sono ancora

(Se le risposte 1-2 sono stati scelti chiedere):
Da quanto tempo ha avuto queste difficolta'?

1 Da meno di una settimana
2 Da piu' di una ma meno di 3 ( )
3 Da piu' di 3 mesi ma da meno di un anno
4 Da piu' di un anno
5 Quasi sempre

Queste difficolta' sono in qualche modo collegabile alla malattia/dal comportamento di S?

0 No
1 Probabilmente ( )
2 Senz'altro

Parte 8 - Comportamenti Difficili

"Vorrei ora sapere qualcosa su come S si e' comportato di recente - **il mese scorso**. Adesso le leggero' una lista dei comportamenti che possono osservarsi in alcune persone in queste condizioni e forse lei mi puo' dire se S e' mai stato cosi'."

Approccio col comportamento mostrato - segnare nel primo riquadro
Chiedere: In passato S e' stato _______ (tipo di comportamento). Se si, come ha reagito a questo comportamento?

0 L'informante lo accetta o non se ne preoccupa
1 A volte preoccupa l'informante, a volte no
2 E' abbastanza un problema - l'informante trova sempre difficolta' ad affrontarlo
3 E' molto difficile tollerarlo e spesso l'informante non riesce ad adfrontarlo
9 S non si comporta cosi'

Frequenza di comportamenti - segnare nel secondo riquadro
Chiedere: Quante volte S si comporta cosi'?

0 Mai
1 Meno d'una volta al mese
2 Una volta al mese
3 Una volta alla settimana
4 Ogni giorno
5 Altro (specificare) ....

Gravita' del comportamento - segnare nel terzo riquadro
Chiedere: Qual'e' la gravita' di questo comportamento?

0 Non grave
1 Moderato
2 Abbastanza grave
3 Molto grave

Comportamento tenuto in relazione alla malattia - segnare nel quarto riquadro
Chiedere: In che proporzione questo comportamento e' dovuto alla malattia di S?

1 Il comportamento e' dovuto alla malattia
2 Il comportamento e' in parte causato dalla malattia ma S lo puo' in qualche modo controllare
3 Non ha niente a che fare con la malattia - e' proprio S che e' fatto cosi' - e' sempre stato/a cosi'
4 Il comportamento e' causato dai farmaci
9 L'informante non sa dire se il comportamento dipende o no dalla malattia

Triste (giu' di corda, cupo)	( )	( )	( )	( )
Chiuso/Ritirato (Taciturno, poco socievole)	( )	( )	( )	( )
Rallentato (nel fare cose/compiere mansioni)	( )	( )	( )	( )
Smemorato (difficolta' nel ricordare le cose di tutti i giorni)	( )	( )	( )	( )
Svogliato (passa il tempo a non far nulla)	( )	( )	( )	( )
Dorme troppo	( )	( )	( )	( )
Troppo dipendente (si attacca o la segue nei suoi spostamenti)	( )	( )	( )	( )
Preoccupato (per le cose quotidiane)	( )	( )	( )	( )
Timoroso/ansioso (paure strane)	( )	( )	( )	( )
Ossessivo (pignolo, puntiglioso, ripete continuamente determinate cose)	( )	( )	( )	( )
Indeciso, incerto (gli e' difficile prendere decisioni)	( )	( )	( )	( )
Strane idee (qualcuno complotta contro di lui, sente voci)	( )	( )	( )	( )
Troppo attivo (insolitamente rumoroso, agitato, pieno d'entusiasmo, loquace)	( )	( )	( )	( )
Allegro/felice (diversamente dal solito, senza motivi apparenti)	( )	( )	( )	( )
Imprevedibile (ha detto/fatto qualcosa di completamente inaspettato)	( )	( )	( )	( )

Irritabile (litigioso, perde subito la pazienza)	( )	( )	( )	( )
Brontola/si lamenta	( )	( )	( )	( )
Scortese (ha cattive maniere, non ha rispetto)	( )	( )	( )	( )
Violento (verso gli altri/ con le parole)	( )	( )	( )	( )
Spacca oggetti di casa, mobili, ecc.	( )	( )	( )	( )
Minaccia o cerca di suicidarsi	( )	( )	( )	( )
Si comporta in maniera offensiva verso (gli altri/lei)	( )	( )	( )	( )
Beve molto	( )	( )	( )	( )
Gioca d'azzardo	( )	( )	( )	( )
Non ha cura di se'	( )	( )	( )	( )
Appetito	( )	( )	( )	( )
Si lamenta di malesseri e dolori fisici (stanchezza, cerca di essere compatito)	( )	( )	( )	( )
Si comporta in modo strano (fa cose insolite, per es. si veste stranamente, borbotta per strada, ecc.)	( )	( )	( )	( )
Ha allucinazioni	( )	( )	( )	( )
Cerca attenzioni (e' molto esigente)	( )	( )	( )	( )

Parte 9 - Problemi (Comportamenti Difficili)

"Quello che vorrei fare adesso e parlare di un problema/situazione particolari riguardanti il comportamento di S che lei si e' trovato/a ad afrontare il mese scorso - qualcosa che sia stato difficile o problematico da affrontare. Le viene in mente qualcosa?"

Chi e' stato coinvolto?
(Scrivere):

Cos'e' accaduto (brevemente)?
(Scrivere):

Quale sono state le cause di quello che e' accaduto?
(Scrivere):

Cosa l'ha reso importante per lei?
(Scrivere):

"Ci sono molti modi usati per far fronte ai problemi. Pensando alla situazione appena descritta, Lei ha usato qualcuna dei modi qui indicati per affrontare quella particolare situazione/problema?"

Andare al Questionario sulla Soluzione dei Problemi

Questionario sulla Soluzione dei Problemi

Chiedere: Lei:-

	No	Qualche volta	Abbastanza spesso	Molto spesso
Cerca di sentirsi meglio mangiando, bevendo, fumando, predendo droghe o farmaci, etc	3	2	1	0
Pensa che ____ non sia in fondo cosi' importante	3	2	1	0
Sa che cosa deve essere fatto e cosi' raddoppia i suoi sforzi per far funzionare le cose	3	2	1	0
Accetta la compassione/ simpatia e la comprensione di qualcuno	3	2	1	0
Cerca di vedere i lati positivi della cosa	3	2	1	0
Cerca di tenere i propri sentimenti per se'	3	2	1	0
Cerca di vedere le cose dal punto di vista dell' altro	3	2	1	0
Critica e censura se stesso/a	3	2	1	0
Pensa che le cose potrebbero essere peggio di quanto sono. Siamo tutti nella stessa barca	3	2	1	0
Pensa alla sua esperienza passata; si e' trovato altre volte in questa situazione	3	2	1	0
Pensa che queste siano cose che succedono nella vita; deve accettare il buono e il cattivo	3	2	1	0
Cerca di non agire senza pensare e di non seguire il suo primo impulso	3	2	1	0

Vorrebbe che la situazione spiacevole fosse scomparsa o che in qualche modo lei l'avesse superata	3	2	1	0
Ripete tra se' e se' quello che dira' o fara'	3	2	1	0
Parla a qualcuno per chiarirsi meglio la situazione	3	2	1	0
E' fatalista: a volte capita di avere sfortuna	3	2	1	0
Trova diverse soluzioni al problema	3	2	1	0

Parte 10 - Soddisfazione per i Servizi - Parente e S

"Vorrei farle delle domande sulle esperienze che ha avuto con i servizi psichiatrici locali. Per servizi psichiatrici intendo i medici, gli psichiatri, le/gli infermiere/i, le psicologhe, le assistenti sociali, ecc. che lavorano in ospedale o al Centro di Salute Mentale: le visite che vi hanno fatto e che utilita' ne avete ricavato rispetto a S."

<u>Conoscenza della malattia da parte del parente</u>
<u>Contatti con personale specializzato/servizi da parte del parente</u>
<u>Bisogni del parente</u>

Tempo fa ha contattato qualcuno del personale specializzato qui sotto specificato, a causa delle condizioni di S? Quand'e' stata l'ultima volta che avete visto ______ e dove?

Profess.	Mai	Tempo fa 2 volte	< un anno > 3 mese	< un anno > 1 mese	> 1 mese
Medico di Famiglia					
Psichiatra					
Infermiere/i					
Psicologa					
Assisente Sociale					

<u>Sede</u>

1. Visita domiciliare (V.D.)
2. Ambulatoria (Amb.)
3. Reparto (R.)
4. Centro Salute Mentale (C.S.M.)

E' mai stato/a informato/a delle condizioni di S?
Se si, qual'e' stata la diagnosi?

(Specificare) ....

Sente il bisogno di sapere (di piu') sulle condizioni di S?

0 Nessun bisogno
1 Bisogno scarso
2 Bisogno moderato ( )
3 Bisogno considerevole
4 Bisogno urgente

E mai stato/a informato/a della natura delle condizioni di S e su cosa aspettarsi in futuro riguardo al suo comportamento o prospettive, ad esempio, di lavoro, etc.?

0 Nessuna informazione
1 Qualche informazione, ma sa ancora

poco della sua malattia/prospettive ( )
2 Abbastanza informazioni ma non quanto
avrebbe voluto
3 Sente di capire le condizioni di S e
le sue prospettive pienamente
4 Altro (specificare) ....

Sente il bisogno di sapere (di piu') su cosa aspettarsi dalle condizioni di S e sulle sue prospettive future?

0 Nessun bisogno
1 Bisogno scarso
2 Bisogno moderato ( )
3 Bisogno considerevole
4 Bisogno urgente

E' mai stato/a informato sulle medicine che S sta prendendo - sugli effetti clinici e gli effetti collaterali e sul perche' S deve assumerle?

0 Nessuna informazione
1 Qualche informazione ma sa ancora poco
sulle medicine
2 Abbastanza informazioni ma non quanto ( )
avrebbe voluto
3 Sente di conoscere pienamente le medicine di S
4 Altro (specificare) ....

Sente il bisogno di saperne di piu' sulle medicine che prende S?

0 Nessun bisogno
1 Bisogno scarso
2 Bisogno moderato ( )
3 Bisogno considerevole
4 Bisogno urgente

Si e' incontrata/o con qualcuno per discutere le sue reazioni emotive in relazione alle condizioni di S? Se si, con che frequenza l'ha fatto?

(Specificare) ....

Sente il bisogno che le vengano offerte (piu') opportunita' di discussione sulle sue reazioni emotive?

0 Nessun bisogno
1 Bisogno scarso
2 Bisogno moderato ( )
3 Bisogno considerevole
4 Bisogno urgente

Ha mai ricevuto visite domiciliari dal servizio? Se si, con che frequenza?

0 Nemmeno una
1 Meno d'una volta al mese
2 Una volta al mese ( )
3 Una volta alla settimana
4 Ogni giorno
5 Altro (specificare) ....

Sente il bisogno di un maggior numero di visite domiciliari?

0 Nessun bisogno
1 Bisogno scarso
2 Bisogno moderato ( )
3 Bisogno considerevole
4 Bisogno urgente

I servizi le hanno mai offerto l'opportunita' di portare S in ospedale o in un pensionato (o qualsiasi altra sistemazioni del genere) per avere una pausa o per le ferie? Se si, quante volte?

(Specificare) ....

Sente il bisogno che le venga data (un'altra) opportunita del genere per una pausa o per le ferie?

0 Nessun bisogno
1 Bisogno scarso
2 Bisogno moderato ( )
3 Bisogno considerevole
4 Bisogno urgente

Nei momenti di crisi con S trova che dal servizio si possa ricevere facilmente aiuto?

0 No
1 Nessun dubbio che ci sia la disponibilita' del servizio ( )
2 Altro (specificare) ....

Tempo fa con che prontezza i servizi hanno risposto alle crisi che sono sorte con S? E' stata fornita assistenza entro 24 ore dalla richiesta?

0 Nessuna assistenza entro le 24 ore
1 Assistenza entro le 24 ore su appuntamento ( )
2 Assistenza entro le 24 ore in forma di visita domiciliare
3 Altro (specificare) ....

Sente che cio' puo' essere migliorato in qualche modo? Se si, come? (Scrivere):

Sente che puo' contattare il centro/ospedale se e' preoccupata/o di qualcosa legato ad S o che puo' informarli dei cambiamenti delle condizioni/comportamento di S? Lo ha mai fatto?

0 L'informante non l'ha mai fatto e non pensa che potrebbe farlo
1 L'informante pensa che potrebbe farlo ma non l'ha mai fatto ( )
2 L'informante pensa di poter cercare aiuto ed informa il servizio dei cambiamenti delle condizioni di S quando ce n'e' bisogno ed ha fatto cosi' in passato

E' mai stata/o invitata/o a prender parte a discussioni su quali servizi potrebbero essere piu' adatti per S o essergli di beneficio in qualche modo? Se si, siete andati?

0 Mai invitata/o
1 Invitato ma mai andato ( )
2 Invitato e andato
3 Altro (specificare) ....

C'e' qualcosa che riguarda i servizi da cui potrebbe trarre beneficio? Cosa dovrebbe esserle offerto, nella sua situazione, da parte dei servizi/degli operatori?
(Scrivere):

Contatti con personale specializzato/servizi da parte di S
Bisogni di S

"Adesso vorrei chiederle su contatti di S col servizio e di come lui/lei li abbia trovati d'aiuto."

Qual'e' stata l'ultima volta che S ha visto (specificare l'operatore)

Profess.	Mai	Tempo fa 2 volte	< un anno > 3 mese	< un anno > 1 mese	> 1 mese
Medico di Famiglia					
Psichiatra					
Infermiere/i					
Psicologa					
Assisente Sociale					

Sede

1. Visita domiciliare (V.D)
2. Ambulatoria (Amb.)
3. Reparto (R.)
4. Centro Salute Mentale (C.S.M.)

S va al Centro di Salute Mentale? Se si, quante volte?

0 Mai
1 Meno d'una volta al mese
2 Una volta al mese
3 2-3 volte al mese ( )
4 Una volta alla settimana
5 2-3 volte ala settimana
6 Ogni giorno
7 Altro (specificare) ....

Ad S e' mai stata offerta un'attivita' riabilitativa o un posto in un laboratorio protetto o in un Centro Diurno dove potesse occupare il suo tempo? Se si, S e' mai andato?

0 Non e' stato offerto
1 E' stato offerto ma non c'e' andato ( )
2 E' stato offerto e c'e'andato

Pensa che S avrebbe bisogno di piu' opportunita' di lavore di questo tipo?

0 Nessun bisogno
1 Un bisogno scarso
2 Un bisogno moderato ( )
3 Bisogno considerevole
4 Bisogno urgente

E' mai stato offerto ad S di prender parte a qualche attivita' sociale o di svago organizzata dal servizio?

0 Non e' mai stato offerto
1 E' stato offerto ma non c'e' andato ( )
2 E' stato offerto e c'e'andato

Sente il bisogno che ad S vengano offerte (piu') opportunita' di questo tipo?

0 Nessun bisogno
1 Un bisogno scarso
2 Un bisogno moderato ( )
3 Bisogno considerevole
4 Bisogno urgente

E' mai stata offerta ad S una sistemazione alternativa e soluzioni abitative fuori di casa?

0 Mai offerta una sistemazioni alternativa
1 Offerta ma rifiutata ( )
2 Offerta e accolta

Sente che S avrebbe bisogno di un maggior numero di sistemazioni alternative?

0 Nessun bisogno
1 Un bisogno scarso
2 Un bisogno moderato ( )
3 Bisogno considerevole
4 Bisogno urgente

(Se sono state scelte le risposte 1-4, chiedere):
Se ad S fosse offerta una sistemazioni, accetterebbe
tale opportunita'?

0 No ( )
1 Si

C'e' nulla di quanto offerto dal servizio che Lei sente che potrebbe essere d'aiuto a S? Cosa pensa che il servizio/gli operatori dovrebbero poter offrire ad S?
(Scrivere):

Parte 11 - Situazione dell'Alloggio

"Come ultima cosa vorrei chiederle del suo appartamento/casa".

Paga l'affitto? Di chi e l'appartamento/casa? E suo?

0 Di proprieta'
1 In affitto da un privato
2 In affitto dal comune ( )
3 Camera ammobiliatata (vitto incluso)
4 Istituto/pensionato
5 Vive con amici/parenti
6 Altro (specificare) ....

Tipo di abitazione
Segnare:

1 Casa
2 Appartamento in un condominio
3 Stanza(e) in una casa ( )
4 Altro (specificare) ....

Quante stanza ha?

1 Una
2 2-3
3 3-4 ( )
4 5-6
5 7-9
6 Piu' di nove

Quante camere da letto?

1 Una
2 Due
3 Tre ( )
4 Quattro
5 Cinque o piu'

Ha una propria cucina o e' in comune ad altri?

1 In comune ( )
2 Propria

Ha il proprio bagno o e' in comune ad altri?

1 In comune ( )
2 Proprio

Densita'

Numero di persone diviso per il numero di stanza (escluse cucina e bagno)

Problemi domestici

0 Nessuno
1 C'e' qualche problema ma l'informante non
ha fatto nessun tentativo di traslocare ( )
2 Ci sono problemi gravi: il parente ha
cercato di traslocare

Da quanto vive in questa casa?

0 Non ci abita stabilmente
1 Da non piu' di 6 mesi
2 Da oltre 6 mesi fino ad un anno ( )
3 Da 1 anno fino a 5 anni
4 Da 5 anni fino a 10 anni
5 Da oltre 10 anni
6 Da sempre

"In questa intervista abbiamo parlato di lei e della sua famiglia e di alcuni problemi e difficolta che ci sono":-

C'e' qualcos'altro che non Le ho chiesto e che vorrebbe dirmi?
(Scrivere):

Commenti dell' Intervistatore

South Verona: Impact of Care Study
Interview Schedule and Coding Frame

Demographic Details CARD 1

VARI	COLUMN	IDENTIFICATION	CODE	
1	1,2	Series number:	01-99	
2	3,4	Card no:	01	
3	5	Client sex:		
		Male		1
		Female		2
4	6,7	Client age:	01-99	
5	8	Client marital status:		
		Single		1
		Married/cohab.		2
		Separated		3
		Divorced		4
		Widowed		5
		N/A		9
6	9	Area of residence:		
		Borgo Roma		1
		Castel d'Azzano		2
		Cadidavid		3
		Buttapietra		4
		Santa Lucia		5
		Golosine		6
		Other		7
		N/A		9
7	10	Client diagnosis:		
		Schizophrenic psychoses or other func. psychoses		1
		Affective psychoses		2
		Depressive neurosis		3
		Other		4
		N/A		9
8	11	Relative sex:		
		Male		1
		Female		2
9	12,13	Relative age:	01-99	
	10	14 Relative marital status:		
		Single		1
		Married/cohab.		2
		Separated		3
		Divorced		4

			Widowed	5
			Other	6
			N/A	9
11	15	Relation to client:		
			Mother	1
			Father	2
			Wife/cohab.	3
			Husband/cohab.	4
			Daughter	5
			Son	6
			Sister	7
			Brother	8
			N/A	9
12	16	Family size: (includes S)	2-9	
13	17	Other family members: relationship to relative (not children)		
			Mother	1
			Father	2
			Wife	3
			Husband	4
			Sister	5
			Brother	6
			Other	7
			N/A	9
14	18,19	Other family member's ages (apart from children):		
			Eldest: 01-98+	
			N/A 99	
15	20	Number of male children: 1-8+ (other than S and relative)		
			N/A	9
16	21	Number of female children: 1-8+ (other than S and relative)		
			N/A	9
17	22,23	Children's ages:		
		Eldest: 01-98+		
		N/A 99		
18	24	Occupational status of other family member: eldest:		
			Employed (full-time)	1
			Employed (part-time)	2
			Retired	3
			Unemployed	4
			In education (f-t)	5

		In education (p-t)	6
		Housewife	7
		Other	8
		N/A	9
19	25,26	First psychiatric contact:	
		MONTH (see 12 on Reg.form)	
		01-98+	
		N/A	99
20	27,28	YEAR of first psychiatric contact:	
		01-98+	
		N/A	99
		History of problem: things not quite right over the past year:	
			Yes No
21	29	Onset of client's illness	1 2
22	30	Crisis(ses) that have occurred	1 2
23	31	Deterioration of client's condition	1 2
24	32	Behaviour becoming more difficult/stranger	1 2
25	33	Problems with medication	1 2
26	34	Tense difficult relations between S and other family members	1 2
27	35	Improvement in client's condition	1 2
		Other	3
		N/A	9
28	36	Client have difficulty sleeping?:	
		Yes	1
		No	2

Working Activity CARD 2

VARI	COLUMN	IDENTIFICATION	CODE
29	1,2	Series no:	01-99
30	3,4	Card no:	02
31	5	Relative's occupational status: working now?:	
		Employed f-time	1
		Employed p-time	2
		Unemployed	3
		Retired	4
		Student	5
		Other	6
		N/A	9
32	6	Relative's current or past job:	
		Unskilled labour	1
		Blue collar (skilled or semi-skilled)	2
		Clerical/sales	3
		Semi-professional	4
		Managerial	5
		Professional/Exec.	6
		Homemaker/Housewife	7
		Other	8
		N/A	9
33	7	Relative made any changes to work?	
		Yes	1
		No	2
		N/A	9
34	8	If yes: reasons for changes?	
		Left f-t work to care for S	1
		Left p-t work to care for S	2
		Changed from f-t to p-t to care for S	3
		Left f-t work to care for children as S not able to	4
		Change from f-t to p-t to care for children as S not able to	5
		Left work as difficult maintain standards because of concern/demands	

			related to S	6
			Sacked because not maintaining standards due to S	7
			Change shifts (hours/days off)	8
			N/A	9
35	9	Relative or other family member had to seek work?		
			Found f-t work	1
			Found p-t work	2
			Changed from p-t to f-t work	3
			Already working, but doing overtime	4
			Left f-t education to start work	5
			Other	6
			N/A	9
		If 1-5 chosen: reasons for these changes?	Yes No	
36	10		Financial (need more money to maintain family because of loss of S's earnings) 1 2	
37	11		Social/psychological (need to have outside contact as a break from S and household) 1 2	
			Other	3
			N/A	9
38	12	Relative or other family member taken any holiday/time off work because of S's condition?		
			Less than a week	1
			1-3 weeks	2
			3-5 weeks	3
			More than 6 weeks	4
			Other	5
			N/A	9
39	13	How is relative finding work?		
			Not a problem	1
			Stressful, but not related to S	2
			Stressful because of difficulties related to S	3

		Stressful only when S unwell	4
		N/A (Not working)	9
40	14	If difficult, what are the difficulties?	
		Slightly stressful, but OK	1
		Fairly stressful, difficult to maintain normal standards	2
		Extremely stressful, fears not being able to continue	3
		Stressful only when S is unwell	4
		Other	5
		N/A	9
41	15	A decline in standard of work?	
		No	1
		Decline, but no one has noticed	2
		Sharp decline and others have noticed	3
		Serious decline, possible threat/risk of being sacked	4
		Other	5
		N/A	9
42	16	Relative have any other difficulty at work?:	
		No	1
		Difficulty in taking time off work, as not paid	2
		Difficulty in looking after children and S whilst working	3
		Other	4
		N/A	9
43	17	**Clients current occup. status:**	
		Never worked	1
		Unemployed	2
		Employed	3
		Retired	4
		Student	5
		Other	6
		N/A	9

44	18	Client's past or present occupation:		
			Unskilled labour	1
			Blue collar (skilled or semi-skilled)	2
			Clerical/sales	3
			Semi-professional	4
			Managerial	5
			Professional/Exec.	6
			Homemaker/Housewife	7
			Other	8
			N/A	9
45	19	If client is currently not working is this due to client's condition?:		
			Yes	1
			No	2
			D/K (Relative cannot say)	9

Financial Affairs CARD 3

VARI	CLMN	IDENT	CODE
46	1,2	Series no:	01-99
47	3,4	Card no.	03
48	5	Client have an income?	
		Yes	1
		No	2
49	6	Client administer own money?	
		Not able/does not	1
		Able, but doesn't plan weekly budget	2
		Able to and does so weekly	3
		Other	4
		N/A	9
50	7	If Not or Little: linked to condition?	
		Probably	1
		Definitely	2
		Other	3
		N/A	9
51	8	Change in family income since S became ill?	
		The same	1
		Improved	2
		Slightly worse	3
		Much worse	4
		Other	5
		N/A	9
52	9	If noticeable drop in income, by how much?	
		Drop of less than 10%	1
		Drop of < 25% > 10%	2
		Drop of up to 50%	3
		Drop of more than 50%	4
		Other	5
		N/A	9
53	10	If a drop in income occurred, for what reason?	
		Loss of client's	1

			earnings	
			Loss of other member's	2
			Client wasted money during a crisis	3
			Other	4
			N/A	9
54	11	Has family reduced spending since client became unwell?		
			Yes	1
			No	2
55	12	Fallen behind with bills/payments?		
			Yes	1
			No	2
56	13	If yes, for how long has there been difficulties with payments?		
			Less than a week	1
			> week, but > 3 months	2
			> 3 months, < a year	3
			> a year	4
			Always	5
			Other	6
			N/A	9
57	14	Are financial difficulties related to S's condition?		
			Probably	1
			Definitely	2
			S and other family members	3
			Other	4
			N/A	9
58	15	Main person responsible for family finances:		
			Informant	1
			Client	2
			Other family member(s)	3
			Shared between relative, S and others	4
			Relative and others, S not included	5
			Relative is responsible only when S unwell	6
			Other	7
			N/A	9
59	16	Has this always been like this, or has responsibility for finances changed?		

				The same1
			Another member had to take respon. due to S's condition	2
			Relative takes on respon. only when S is unwell	3
			Other	4
			N/A	9
60	17	Any family disagreements over money, if so, how often?:		
			Once a month	1
			2-3 times a month	2
			Once a week	3
			Every day	4
			Other	5
			N/A	9
61	18	Relative ever worried about money problems?		
			Sometimes	1
			More than occasionally	2
			Almost always	3
			Other	4
			N/A	9
62	19	Relative feel s/he has control over money problems?:		
			Completely out of control	1
				2
				3
				4
				5
				6
			Completely under control	7
			(D/K)	9
63	20	To what extent does S have a say in problems regarding money?:		
			S has no say	1
				2
				3
				4
				5
				6
			All decisions about money depend on S	7
			(D/K)	9

Household Affairs CARD 4

VARI	CLMN	IDENT	CODE	
64	1,2		Series no:	01-99
65	3,4		Card no.	04
66	5		Does S help with the housework?	
			Does none	1
			Occasionally, but needs pushing	2
			Occasionally, without being pushed	3
			Very active in doing housework	4
			Other	5
			N/A	9
67	6		If 1-2 chosen: related to S's condition?	
			Not related	1
			Probably	2
			Definitely	3
			Other	4
			N/A	9
68	7		S able/helps with shopping/errands on his/her own?	
			Does none	1
			Does some, needs pushing	2
			Does some on his/her own	3
			Very active in helping with this	4
			Other	5
			N/A	9
69	8		If 1-2 chosen: is this related to S's condition?	
			Not related	1
			Probably	2
			Definitely	3
			Other	4
			N/A	9
70	9		S cooks, etc, by his/herself?	
			Does none	1
			Not without help	2
			Can do so without help and does occasionally	3

			Does so regularly	4
			Other	5
			N/A	9
71	10	If none or little: is this related to S's condition?		
			Not related	1
			Probably	2
			Definitely	3
			Other	4
			N/A	9
72	11	How much housework does relative do at present?		
			Some	1
			Most	2
			All	3
			Depends on S's condi.	4
			Other	5
			N/A (None)	9
73	12	If 2-3 chosen: is this related to S's condition?		
			Not related to S	1
			S doesn't do his/her share when they should	2
			Other	3
			N/A	9
74	13	Relative other responsibilities in the household?:		
			Some	2
			Most	3
			All	4
			Depends on S's condi.	5
			Other	6
			N/A (None)	9
75	14	S involved in running of household affairs - bills, etc?:		
			Some	1
			Most	2
			All	3
			Depends on S's condi.	4
			Divided between S and relative	5
			Other	6
			N/A (None)	9
76	15	Relative's household responsibility increased since S became		

ill?:

No change/not related to S	1
Had to take on more responsibility as S not able to	2
Taken on all responsibility	3
Takes on responsibility only when S is unwell	4
Other	5
N/A	9

77 16 Since S became ill have there been problems in household management?:

No problem	1
Some problems	2
Completely disorganised	3
Disorganised only when S is unwell	4
Other	5
N/A	9

78 17 Generally, how are things going in the family?: More difficult to keep things going given S's condition?:

No problem	1
Slightly stressful, but OK	2
Finding it rather hard to make things go as they should	3
Finding it very difficult - worried about not being able to continue	4
Other	5
N/A	9

79 18 If 2-4 chosen: how does this difficulty affect household management?:

Things are not as they should be but noone has commented on this	1
It has been noticed that certain things don't get done	2
The house is completely disorganised and even the most essential things don't get done	3

			Other	4
			N/A	9
80	19	Relative feel able to control the problems that happen in household affairs?:		
			No control whatsoever	1
				2
				3
				4
				5
				6
			Can control all that happens	7
			D/K (Cannot say)	9
81	20	What influence does relative feel that S has over household management?:		
			S has no influence	1
				2
				3
				4
				5
				6
			All that happens depends on S	7
			D/K (Cannot say)	9
82	21	Other difficulties in household management?:		
			Difficulty in doing more physically demanding housework, such as washing floors and windows	1
			Conflicts in sharing housework/household duties	2
			Household problems due to other family member(s)	3
			Other	4
			N/A	9

Problem - Household Affairs CARD 5

VARI	CLMN	IDENT	CODE
83	1,2	Series no:	01-99
84	3,4	Card no:	05
85	5	Difficult problem/situation regarding household affairs over the past month?:	
		Yes	1
		No	2

Coping Questionnaire
How relative coped psychologically

VARI	CLMN	IDENT	CODE
86	6	Relative try to feel better by eating, drinking, smoking, taking drugs or medication, etc?:	
		Used a little	1
		Used quite a bit	2
		Used a great deal	3
		Other	4
		N/A	9
87	7	Think that S is not so important to him/her?:	
		Used a little	1
		Used quite a bit	2
		Used a great deal	3
		Other	4
		N/A	9
88	8	Know what has to be done and double efforts to make things work?:	
		Used a little	1
		Used quite a bit	2
		Used a great deal	3
		Other	4
		N/A	9
89	9	Accept sympathy or understanding from someone?:	
		Used a little	1
		Used quite a bit	2
		Used a great deal	3
		Other	4
		N/A	9

90	10	Look for the silver lining: try to look on the bright side of things?:		
			Used a little	1
			Used quite a bit	2
			Used a great deal	3
			Other	4
			N/A	9
91	11	Keeps feelings to him/herself?:		
			Used a little	1
			Used quite a bit	2
			Used a great deal	3
			Other	4
			N/A	9
92	12	Try to see things from the other person's point of view?:		
			Used a little	1
			Used quite a bit	2
			Used a great deal	3
			Other	4
			N/A	9
93	13	Criticise or lecture oneself?:		
			Used a little	1
			Used quite a bit	2
			Used a great deal	3
			Other	4
			N/A	9
94	14	Think that things could be worse. We are all in the same boat?:		
			Used a little	1
			Used quite a bit	2
			Used a great deal	3
			Other	4
			N/A	9
95	15	Draw on past experiences; has been in similar situation before?:		
			Used a little	1
			Used quite a bit	2
			Used a great deal	3
			Other	4
			N/A	9
96	16	These things happen in life; one has to take the good with the bad?:		

		Used a little	1
		Used quite a bit	2
		Used a great deal	3
		Other	4
		N/A	9
97	17	Try not to act too hastily or follow one's first hunch?:	
		Used a little	1
		Used quite a bit	2
		Used a great deal	3
		Other	4
		N/A	9
98	18	Wish that the situation would go away or somehow be over with?:	
		Used a little	1
		Used quite a bit	2
		Used a great deal	3
		Other	4
		N/A	9
99	19	Go over in my mind what I will say or do?:	
		Used a little	1
		Used quite a bit	2
		Used a great deal	3
		Other	4
		N/A	9
100	20	Talk to someone to find out more about the situation?:	
		Used a little	1
		Used quite a bit	2
		Used a great deal	3
		Other	4
		N/A	9
101	21	Go along with fate; sometimes one just has bad luck?:	
		Used a little	1
		Used quite a bit	2
		Used a great deal	3
		Other	4
		N/A	9
102	22	Come up with a different number of solutions to the problem?:	
		Used a little	1
		Used quite a bit	2

Used a great deal	3
Other	4
N/A	9

Leisure Activities CARD 6

VARI	CLMN	IDENT	CODE
103	1,2	Series no:	01-99
104	3,4	Card no:	06
105	5	Does relative have any free time?:	
		None	1
		Some days	2
		Everyday	3
		Other	4
		N/A	9
106	6	Relative take part in leisure/social activities? If so, how often?	
		Doesn't go out	1
		< Once a month	2
		Once a month	3
		2-3 times a month	4
		Once a week or more	5
		Everyday	6
		Other	7
		N/A	9
107	7	Relative feel OK about leaving S at home on his/her own?:	
		No problem	1
		A bit reluctant, leaves S at home alone	2
		Rarely leaves S alone	3
		Doesn't go out when S is unwell	4
		Other	5
		N/A	9
108	8	S take part in leisure/social activities? If so, how often?:	
		Doesn't go out	1
		< Once a month	2
		Once a month	3
		2-3 times a month	4
		Once a week or more	5
		Everyday	6
		Other	7
		N/A	9
109	9	S and relative go out together?	

		If so, how often?:		
			Do not go out together	1
			< Once a month	2
			Once a month	3
			2-3 times a month	4
			Once a week or more	5
			Other	6
			N/A	9
110	10	Reduction in number of times relative goes out since S became ill?:		
			No change	1
			Slight reduction	2
			Considerable reduction	3
			Since S becoming ill relative rarely goes out	4
			Doesn't go out only when S is unwell	5
			Other	6
			N/A	9
111	11	Relative doesn't feel like going out given concern/difficulty relating to problems linked to S?:		
			Occasionally	1
			Always	2
			Other	3
			N/A	9
112	12	Looking after S takes up so much time, no space for seeing other people?:		
			Occasionally	1
			Always	2
			Other	3
			N/A	9
113	13	S's condition is such that friends rarely or don't call round any more?:		
			Fewer friends call	1
			Evident drop in number of friends who call round or don't visit anymore	2
			Other	3
			N/A (No change)	9
114	14	Close friends/relatives that relative had contact with in		

		past week?:		
			1-2	1
			2-5	2
			> 5	3
			Other	4
			N/A (None)	9
115	15	More contact with friends before S became ill?:		
			More contact	1
			Less contact	2
			Other	3
			N/A (No change)	9
116	16	Does relative have friend/relative to confide in, in times of difficulty?:		
			Certain number of people	1
			1-2 people	2
			No one to confide in	3
			Has someone but prefers not to and does it alone	4
			Other	5
			N/A	9
117	17	Relative ever feel isolated like s/he the only one in this situation or do they have contact with/know of someone in a similar situation?:		
			Knows/has contact with someone in same situation	1
			Knows of someone in similar situation	2
			Knows no one else, but doesn't feel isolated	3
			Knows no one in such a situation, hence feels isolated	4
			Other	5
			N/A	9

Relationship Between S and Relative CARD 7

VARI	CLMN	IDENT	CODE
118	1,2	Series no:	01-99
119	3,4	Card no:	07
120	5	How does S and relative spend time together when at home?:	
		Do nothing together	1
		S and relative do somethings together	2
		S and relative, for the most part, share most activities	3
		Other	4
		N/A	9
121	6	How are things between S and relative at the moment?:	
		Quite good	1
		Very good	2
		Some problems in getting on	3
		Very difficult at the moment	4
		Other	5
		N/A	9
122	7	What was this situation like before S became ill?:	
		No change	1
		Relationship become more tense	2
		Much worse since S became ill	3
		Other	4
		N/A	9
123	8	If 2 chosen: Arguments/disagreements increased? How often do they occur?:	
		< Once a month	1
		Once a month	2
		Once every 2 weeks	3
		Once a week or more	4
		Every day	5
		Other	6
		N/A (Don't argue)	9

124	9	Overall, relative finding things with S stressful?:	
		A bit, but copes	1
		Very difficult to get on with S	2
		So difficult relative not sure if can continue for much longer	3
		Other	4
		N/A (No)	9
125	10	In relation ship with S how much influence does relative have over what happens?	
		No control over relationship	1
			2
			3
			4
			5
			6
		Relative can control all that happens	7
		D/K (Cannot say)	9
126	11	To what extent does relative think that S controls relationship?:	
		S has no influence over relationship	1
			2
			3
			4
			5
			6
		Whatever happens depends on S	7
		D/K (Cannot say)	9

Effects on Physical and Psychological Health of Relative
CARD 8

VARI	CLMN	IDENT	CODE
127	1,2	Series no:	01-99
128	3,4	Card no:	08
129	5	Physical health: any problems over the past month?:	
		Some problems, but nothing serious	1
		Significant problems	2
		Other	3
		N/A (None)	9
130	6	If 1-3 chosen: Has relative seen a doctor, received or undergoing treatment?:	
		Been to a doctor, but nothing prescribed	1
		Been to a doctor and prescribed medicine which is still being taken	2
		Other	3
		N/A	9
131	7	How long has relative had these physical health problems?:	
		< a week	1
		> a week but < 3	2
		> 3 months but < a year	3
		> a year	4
		Almost always	5
		Other	6
		N/A	9
132	8	Is this related in some way to S's condition?:	
		Not related to S	1
		Probably related to S's condition	2
		Definitely related to S's condition	3
		Other	4
		N/A	9
133	9	Has relative had psychological/ emotional difficulties over the	

		past month?:	
		Some problems, but nothing serious	1
		Significant problems	2
		Other	3
		N/A (None)	9
134	10	If 1-3 chosen: Has relative seen a doctor or another professional about these problems?:	
		Some problems, but not done/taken anything	1
		Sufficient problems: received treatment/ therapy or still in progress	2
		Other	3
		N/A (Not a problem)	9
135	11	If 1-3 chosen: How long has relative had these psychological/ emotional problems?:	
		< a week	1
		> a week but < 3	2
		> 3 months but < a year	3
		> a year	4
		Almost always	5
		Other	6
		N/A	9
136	12	Are these psychological problems in anyway related to S?:	
		No related to S	1
		Probably	2
		Definitely	3
		Other	4
		N/A	9

Difficult Behaviour 1
CARD 9

VARI	CLMN	IDENT	CODE
137	1,2	Series no:	01-99
138	3,4	Card no:	09
139	5	Has S been **miserable** in the past month? How has relative reacted to it?:	
		Relative accepts is and doesn't worry	1
		Relative sometimes worries, sometimes doesn't	2
		Quite a problem and relative always finds it difficult to confront	3
		Very difficult to tolerate and often relative not able to confront it	4
		Other	5
		N/A (S hasn't done so or doesn't behave like this)	9
140	6	If 1-5 chosen: How often is S miserable?:	
		< once a month	1
		Once a month	2
		Once a week	3
		Every day	4
		Other	5
		N/A (Never)	9
141	7	How serious is S's miserableness?	
		Not serious	1
		Moderate	2
		Quite serious	3
		Very serious	4
		Other	5
		N/A	9
142	8	To what extent is miserableness a part of S's condition?:	
		Behaviour is part of S's condition	1
		Behaviour is partly due to condition but S is able to control it	2

		Nothing to do with condition, S has always been like that	3
		Behaviour is due to medication S takes	4
		Behaviour is due to medication and condition	5
		Other	6
		D/K (Relative cannot say whether behaviour is due to condition)	9
143	9	**Withdrawn?** How has relative reacted to this?:	
		Relative accepts is and doesn't worry	1
		Relative sometimes worries, sometimes doesn't	2
		Quite a problem and relative always finds it difficult to confront	3
		Very difficult to tolerate and often relative not able to confront it	4
		Other	5
		N/A (S hasn't done so or doesn't behave like this)	9
144	10	If 1-5 chosen: How often is S withdrawn?:	
		< once a month	1
		Once a month	2
		Once a week	3
		Every day	4
		Other	5
		N/A (Never)	9
145	11	How serious is S's withdrawal?	
		Not serious	1
		Moderate	2
		Quite serious	3
		Very serious	4
		Other	5
		N/A	9
146	12	To what extent is withdrawal a part of S's condition?:	
		Behaviour is part of S's condition	1
		Behaviour is partly due to condition but S	

			is able to control it	2
			Nothing to do with condition, S has always been like that	3
			Behaviour is due to medication S takes	4
			Behaviour is due to medication and condition	5
			Other	6
			D/K (Relative cannot say whether behaviour is due to condition)	9
147	13	**Slow?** How has relative reacted to this?:		
			Relative accepts is and doesn't worry	1
			Relative sometimes worries, sometimes doesn't	2
			Quite a problem and relative always finds it difficult to confront	3
			Very difficult to tolerate and often relative not able to confront it	4
			Other	5
			N/A (S hasn't done so or doesn't behave like this)	9
148	14	If 1-5 chosen: How often is S withdrawn?:		
			< once a month	1
			Once a month	2
			Once a week	3
			Every day	4
			Other	5
			N/A (Never)	9
149	15	How serious is S's slowness?		
			Not serious	1
			Moderate	2
			Quite serious	3
			Very serious	4
			Other	5
			N/A	9
150	16	To what extent is slowness a part of S's condition?:		
			Behaviour is part of S's condition	1
			Behaviour is partly	

		due to condition but S is able to control it	2
		Nothing to do with condition, S has always been like that	3
		Behaviour is due to medication S takes	4
		Behaviour is due to medication and condition	5
		Other	6
		D/K (Relative cannot say whether behaviour is due to condition)	9
151	17	**Forgetful?** How has relative reacted to this?:	
		Relative accepts is and doesn't worry	1
		Relative sometimes worries, sometimes doesn't	2
		Quite a problem and relative always finds it difficult to confront	3
		Very difficult to tolerate and often relative not able to confront it	4
		Other	5
		N/A (S hasn't done so or doesn't behave like this)	9
152	18	If 1-5 chosen: How often is S forgetful?:	
		< once a month	1
		Once a month	2
		Once a week	3
		Every day	4
		Other	5
		N/A (Never)	9
153	19	How serious is S's forgetfulness?	
		Not serious	1
		Moderate	2
		Quite serious	3
		Very serious	4
		Other	5
		N/A	9
154	20	To what extent is forgetfulness a part of S's condition?:	
		Behaviour is part of S's condition	1

		Behaviour is partly due to condition but S is able to control it	2
		Nothing to do with condition, S has always been like that	3
		Behaviour is due to medication S takes	4
		Behaviour is due to medication and condition	5
		Other	6
		D/K (Relative cannot say whether behaviour is due to condition)	9
155	21	**Underactive?** How has relative reacted to this?:	
		Relative accepts is and doesn't worry	1
		Relative sometimes worries, sometimes doesn't	2
		Quite a problem and relative always finds it difficult to confront	3
		Very difficult to tolerate and often relative not able to confront it	4
		Other	5
		N/A (S hasn't done so or doesn't behave like this)	9
156	22	If 1-5 chosen: How often is S underactive?:	
		< once a month	1
		Once a month	2
		Once a week	3
		Every day	4
		Other	5
		N/A (Never)	9
157	23	How serious is S's underactivity?	
		Not serious	1
		Moderate	2
		Quite serious	3
		Very serious	4
		Other	5
		N/A	9
158	24	To what extent is underactivity a part of S's condition?:	
		Behaviour is part of S's	

			condition	1
			Behaviour is partly due to condition but S is able to control it	2
			Nothing to do with condition, S has always been like that	3
			Behaviour is due to medication S takes	4
			Behaviour is due to medication and condition	5
			Other	6
			D/K (Relative cannot say whether behaviour is due to condition)	9
159	25	**Sleep excessively?** How has relative reacted to this?:		
			Relative accepts is and doesn't worry	1
			Relative sometimes worries, sometimes doesn't	2
			Quite a problem and relative always finds it difficult to confront	3
			Very difficult to tolerate and often relative not able to confront it	4
			Other	5
			N/A (S hasn't done so or doesn't behave like this)	9
160	26	If 1-5 chosen: How often does S sleep excessively?:		
			< once a month	1
			Once a month	2
			Once a week	3
			Every day	4
			Other	5
			N/A (Never)	9
161	27	How serious is S's oversleeping?		
			Not serious	1
			Moderate	2
			Quite serious	3
			Very serious	4
			Other	5
			N/A	9
162	28	To what extent is excessive sleep a part of S's condition?:		

		Behaviour is part of S's condition	1	
		Behaviour is partly due to condition but S is able to control it	2	
		Nothing to do with condition, S has always been like that	3	
		Behaviour is due to medication S takes	4	
		Behaviour is due to medication and condition	5	
		Other	6	
		D/K (Relative cannot say whether behaviour is due to condition)	9	
163	29	**Overdependent?** How has relative reacted to this?:		
		Relative accepts is and doesn't worry	1	
		Relative sometimes worries, sometimes doesn't	2	
		Quite a problem and relative always finds it difficult to confront	3	
		Very difficult to tolerate and often relative not able to confront it	4	
		Other	5	
		N/A (S hasn't done so or doesn't behave like this)	9	
164	30	If 1-5 chosen: How often is S overdependent?:		
		< once a month	1	
		Once a month	2	
		Once a week	3	
		Every day	4	
		Other	5	
		N/A (Never)	9	
165	31	How serious is S's overdependency?		
		Not serious	1	
		Moderate	2	
		Quite serious	3	
		Very serious	4	
		Other	5	
		N/A	9	
166	32	To what extent is overdependency part of S's condition?:		a

			Behaviour is part of S's condition	1
			Behaviour is partly due to condition but S is able to control it	2
			Nothing to do with condition, S has always been like that	3
			Behaviour is due to medication S takes	4
			Behaviour is due to medication and condition	5
			Other	5
			D/K (Relative cannot say whether behaviour is due to condition)	9
167	33	**Worrying?** How has relative reacted to this?:		
			Relative accepts is and doesn't worry	1
			Relative sometimes worries, sometimes doesn't	2
			Quite a problem and relative always finds it difficult to confront	3
			Very difficult to tolerate and often relative not able to confront it	4
			Other	5
			N/A (S hasn't done so or doesn't behave like this)	9
168	34	If 1-5 chosen: How often does S worry?:		
			< once a month	1
			Once a month	2
			Once a week	3
			Every day	4
			Other	5
			N/A (Never)	9
169	35	How serious is S's worrying?		
			Not serious	1
			Moderate	2
			Quite serious	3
			Very serious	4
			Other	5
			N/A	9
170	36	To what extent is worrying a part of S's condition?:		

		Behaviour is part of S's condition	1
		Behaviour is partly due to condition but S is able to control it	2
		Nothing to do with condition, S has always been like that	3
		Behaviour is due to medication S takes	4
		Behaviour is due to medication and condition	5
		Other	6
		D/K (Relative cannot say whether behaviour is due to condition)	9
171	37	**Fearful/anxious?** How has relative reacted to this?:	
		Relative accepts is and doesn't worry	1
		Relative sometimes worries, sometimes doesn't	2
		Quite a problem and relative always finds it difficult to confront	3
		Very difficult to tolerate and often relative not able to confront it	4
		Other	5
		N/A (S hasn't done so or doesn't behave like this)	9
172	38	If 2-5 chosen: How often is S fearful/anxious?:	
		< once a month	1
		Once a month	2
		Once a week	3
		Every day	4
		Other	5
		N/A (Never)	9
173	39	How serious is S's fear/anxiety?	
		Not serious	1
		Moderate	2
		Quite serious	3
		Very serious	4
		Other	5
		N/A	9
174	40	To what extent is fear/anxiety a part of S's condition?:	

		Behaviour is part of S's condition	1	
		Behaviour is partly due to condition but S is able to control it	2	
		Nothing to do with condition, S has always been like that	3	
		Behaviour is due to medication S takes	4	
		Behaviour is due to medication and condition	5	
		Other	6	
		D/K (Relative cannot say whether behaviour is due to condition)	9	
175	41	**Obsessive?** How has relative reacted to this?:		
		Relative accepts is and doesn't worry	1	
		Relative sometimes worries, sometimes doesn't	2	
		Quite a problem and relative always finds it difficult to confront	3	
		Very difficult to tolerate and often relative not able to confront it	4	
		Other	5	
		N/A (S hasn't done so or doesn't behave like this)	9	
176	42	If 2-5 chosen: How often is S obsessional?:		
		< once a month	1	
		Once a month	2	
		Once a week	3	
		Every day	4	
		Other	5	
		N/A (Never)	9	
177	43	How serious is S's obsessiveness?		
		Not serious	1	
		Moderate	2	
		Quite serious	3	
		Very serious	4	
		Other	5	
		N/A	9	
178	44	To what extent is obsessionality part of S's condition?:		a

			Behaviour is part of S's condition	1
			Behaviour is partly due to condition but S is able to control it	2
			Nothing to do with condition, S has always been like that	3
			Behaviour is due to medication S takes	4
			Behaviour is due to medication and condition	5
			Other	6
			D/K (Relative cannot say whether behaviour is due to condition)	9
179	45	**Indecisive?** How has relative reacted to this?:		
			Relative accepts is and doesn't worry	1
			Relative sometimes worries, sometimes doesn't	2
			Quite a problem and relative always finds it difficult to confront	3
			Very difficult to tolerate and often relative not able to confront it	4
			Other	5
			N/A (S hasn't done so or doesn't behave like this)	9
180	46	If 2-5 chosen: How often is S indecisive?:		
			< once a month	1
			Once a month	2
			Once a week	3
			Every day	4
			Other	5
			N/A (Never)	9
181	47	How serious is S's indecisiveness?		
			Not serious	1
			Moderate	2
			Quite serious	3
			Very serious	4
			Other	5
			N/A	9
182	48	To what extent is indecisiveness a part of S's condition?:		

		Behaviour is part of S's condition	1
		Behaviour is partly due to condition but S is able to control it	2
		Nothing to do with condition, S has always been like that	3
		Behaviour is due to medication S takes	4
		Behaviour is due to medication and condition	5
		Other	6
		D/K (Relative cannot say whether behaviour is due to condition)	9
183	49	**Strange ideas?** How has relative reacted to this?:	
		Relative accepts is and doesn't worry	1
		Relative sometimes worries, sometimes doesn't	2
		Quite a problem and relative always finds it difficult to confront	3
		Very difficult to tolerate and often relative not able to confront it	4
		Other	5
		N/A (S hasn't done so or doesn't behave like this)	9
184	50	If 1-5 chosen: How often does S have strange ideas?:	
		< once a month	1
		Once a month	2
		Once a week	3
		Every day	4
		Other	5
		N/A (Never)	9
185	51	How serious are S's strange ideas?	
		Not serious	1
		Moderate	2
		Quite serious	3
		Very serious	4
		Other	5
		N/A	9
186	52	To what extent are strange ideas a part of S's condition?:	

			Behaviour is part of S's condition	1
			Behaviour is partly due to condition but S is able to control it	2
			Nothing to do with condition, S has always been like that	3
			Behaviour is due to medication S takes	4
			Behaviour is due to medication and condition	5
			Other	6
			D/K (Relative cannot say whether behaviour is due to condition)	9
187	53	**Overactive?** How has relative reacted to this?:		
			Relative accepts is and doesn't worry	1
			Relative sometimes worries, sometimes doesn't	2
			Quite a problem and relative always finds it difficult to confront	3
			Very difficult to tolerate and often relative not able to confront it	4
			Other	5
			N/A (S hasn't done so or doesn't behave like this)	9
188	54	If 1-5 chosen: How often is S overactive?:		
			< once a month	1
			Once a month	2
			Once a week	3
			Every day	4
			Other	5
			N/A (Never)	9
189	55	How serious is S's overactivity?		
			Not serious	1
			Moderate	2
			Quite serious	3
			Very serious	4
			Other	5
			N/A	9
190	56	To what extent is overactivity a part of S's condition?:		

		Behaviour is part of S's condition	1
		Behaviour is partly due to condition but S is able to control it	2
		Nothing to do with condition, S has always been like that	3
		Behaviour is due to medication S takes	4
		Behaviour is due to medication and condition	5
		Other	6
		D/K (Relative cannot say whether behaviour is due to condition)	9
191	57	**Elated mood?** How has relative reacted to this?:	
		Relative accepts is and doesn't worry	1
		Relative sometimes worries, sometimes doesn't	2
		Quite a problem and relative always finds it difficult to confront	3
		Very difficult to tolerate and often relative not able to confront it	4
		Other	5
		N/A (S hasn't done so or doesn't behave like this)	9
192	58	If 1-5 chosen: How often is S elated?:	
		< once a month	1
		Once a month	2
		Once a week	3
		Every day	4
		Other	5
		N/A (Never)	9
193	59	How serious is S's elated mood?	
		Not serious	1
		Moderate	2
		Quite serious	3
		Very serious	4
		Other	5
		N/A	9
194	60	To what extent is elated mood a part of S's condition?:	

Behaviour is part of S's condition	1
Behaviour is partly due to condition but S is able to control it	2
Nothing to do with condition, S has always been like that	3
Behaviour is due to medication S takes	4
Behaviour is due to medication and condition	5
Other	6
D/K (Relative cannot say whether behaviour is due to condition)	9

Difficult Behaviour 2
CARD 10

VARI	CLMN	IDENT	CODE
195	1,2	Series no:	01-99
196	3,4	Card no:	10
197	5	**Unpredictable?** How has relative reacted to this?:	
		Relative accepts is and doesn't worry	1
		Relative sometimes worries, sometimes doesn't	2
		Quite a problem and relative always finds it difficult to confront	3
		Very difficult to tolerate and often relative not able to confront it	4
		Other	5
		N/A (S hasn't done so or doesn't behave like this)	9
198	6	If 1-5 chosen: How often is S unpredictable?:	
		< once a month	1
		Once a month	2
		Once a week	3
		Every day	4
		Other	5
		N/A (Never)	9
199	7	How serious is S's unpredictability?	
		Not serious	1
		Moderate	2
		Quite serious	3
		Very serious	4
		Other	5
		N/A	9
200	8	To what extent is unpredictability a part of S's condition?:	
		Behaviour is part of S's condition	1
		Behaviour is partly due to condition but S is able to control it	2

		Nothing to do with condition, S has always been like that	3
		Behaviour is due to medication S takes	4
		Behaviour is due to medication and condition	5
		Other	6
		D/K (Relative cannot say whether behaviour is due to condition)	9
201	9	**Irritable?** How has relative reacted to this?:	
		Relative accepts is and doesn't worry	1
		Relative sometimes worries, sometimes doesn't	2
		Quite a problem and relative always finds it difficult to confront	3
		Very difficult to tolerate and often relative not able to confront it	4
		Other	5
		N/A (S hasn't done so or doesn't behave like this)	9
202	10	If 1-5 chosen: How often is S irritable?:	
		< once a month	1
		Once a month	2
		Once a week	3
		Every day	4
		Other	5
		N/A (Never)	9
203	11	How serious is S's irritability?	
		Not serious	1
		Moderate	2
		Quite serious	3
		Very serious	4
		Other	5
		N/A	9
204	12	To what extent is irritability a part of S's condition?:	
		Behaviour is part of S's condition	1
		Behaviour is partly	

		due to condition but S is able to control it	2
		Nothing to do with condition, S has always been like that	3
		Behaviour is due to medication S takes	4
		Behaviour is due to medication and condition	5
		Other	6
		D/K (Relative cannot say whether behaviour is due to condition)	9
205	13	**Nagging/grumbling?** How has relative reacted to this?:	
		Relative accepts is and doesn't worry	1
		Relative sometimes worries, sometimes doesn't	2
		Quite a problem and relative always finds it difficult to confront	3
		Very difficult to tolerate and often relative not able to confront it	4
		Other	5
		N/A (S hasn't done so or doesn't behave like this)	9
206	14	If 1-5 chosen: How often does S nag/grumble?:	
		< once a onth	1
		Once a month	2
		Once a week	3
		Every day	4
		Other	5
		N/A (Never)	9
207	15	How serious is S's nagging/grumbling?	
		Not serious	1
		Moderate	2
		Quite serious	3
		Very serious	4
		Other	5
		N/A	9
208	16	To what extent is nagging/grumbling a part of S's condition?:	

		Behaviour is part of S's condition	1
		Behaviour is partly due to condition but S is able to control it	2
		Nothing to do with condition, S has always been like that	3
		Behaviour is due to medication S takes	4
		Behaviour is due to medication and condition	5
		Other	6
		D/K (Relative cannot say whether behaviour is due to condition)	9
209	17	**Rude?** How has relative reacted to this?:	
		Relative accepts is and doesn't worry	1
		Relative sometimes worries, sometimes doesn't	2
		Quite a problem and relative always finds it difficult to confront	3
		Very difficult to tolerate and often relative not able to confront it	4
		Other	5
		N/A (S hasn't done so or doesn't behave like this)	9
210	18	If 1-5 chosen: How often is S rude?:	
		< once a month	1
		Once a month	2
		Once a week	3
		Every day	4
		Other	5
		N/A (Never)	9
211	19	How serious is S's rudeness?	
		Not serious	1
		Moderate	2
		Quite serious	3
		Very serious	4
		Other	5
		N/A	9
212	20	To what extent is rudeness a part of S's condition?:	

		Behaviour is part of S's condition	1
		Behaviour is partly due to condition but S is able to control it	2
		Nothing to do with condition, S has always been like that	3
		Behaviour is due to medication S takes	4
		Behaviour is due to medication and condition	5
		Other	6
		D/K (Relative cannot say whether behaviour is due to condition)	9
213	21	**Violent?** How has relative reacted to this?:	
		Relative accepts is and doesn't worry	1
		Relative sometimes worries, sometimes doesn't	2
		Quite a problem and relative always finds it difficult to confront	3
		Very difficult to tolerate and often relative not able to confront it	4
		Other	5
		N/A (S hasn't done so or doesn't behave like this)	9
214	22	If 1-5 chosen: How often is S violent?:	
		< once a month	1
		Once a month	2
		Once a week	3
		Every day	4
		Other	5
		N/A (Never)	9
215	23	How serious is S's violence?	
		Not serious	1
		Moderate	2
		Quite serious	3
		Very serious	4
		Other	5
		N/A	9
216	24	To what extent is violence a part of S's condition?:	

			Behaviour is part of S's condition	1
			Behaviour is partly due to condition but S is able to control it	2
			Nothing to do with condition, S has always been like that	3
			Behaviour is due to medication S takes	4
			Behaviour is due to medication and condition	5
			Other	6
			D/K (Relative cannot say whether behaviour is due to condition)	9
217	25	**Destructive?** How has relative reacted to this?:		
			Relative accepts is and doesn't worry	1
			Relative sometimes worries, sometimes doesn't	2
			Quite a problem and relative always finds it difficult to confront	3
			Very difficult to tolerate and often relative not able to confront it	4
			Other	5
			N/A (S hasn't done so or doesn't behave like this)	9
218	26	If 1-5 chosen: How often is S destructive?:		
			< once a month	1
			Once a month	2
			Once a week	3
			Every day	4
			Other	5
			N/A (Never)	9
219	27	How serious is S's destructiveness?		
			Not serious	1
			Moderate	2
			Quite serious	3
			Very serious	4
			Other	5
			N/A	9
220	28	To what extent is destructive-		

		ness a part of S's condition?:	
		Behaviour is part of S's condition	1
		Behaviour is partly due to condition but S is able to control it	2
		Nothing to do with condition, S has always been like that	3
		Behaviour is due to medication S takes	4
		Behaviour is due to medication and condition	5
		Other	6
		D/K (Relative cannot say whether behaviour is due to condition)	9
221	29	**Threatened or attempted suicide?** How has relative reacted to this?:	
		Relative accepts is and doesn't worry	1
		Relative sometimes worries, sometimes doesn't	2
		Quite a problem and relative always finds it difficult to confront	3
		Very difficult to tolerate and often relative not able to confront it	4
		Other	5
		N/A (S hasn't done so or doesn't behave like this)	9
222	30	If 1-5 chosen: How often does S threaten or attempt suicide?:	
		< once a month	1
		Once a month	2
		Once a week	3
		Every day	4
		Other	5
		N/A (Never)	9
223	31	How serious are S's suicide threats or attempts?:	
		Not serious	1
		Moderate	2
		Quite serious	3
		Very serious	4
		Other	5
		N/A	9

224	32	To what extent are threats or suicide attempts a part of S's condition?:	
		Behaviour is part of S's condition	1
		Behaviour is partly due to condition but S is able to control it	2
		Nothing to do with condition, S has always been like that	3
		Behaviour is due to medication S takes	4
		Behaviour is due to medication and condition	5
		Other	6
		D/K (Relative cannot say whether behaviour is due to condition)	9
	225	33 **Offensive?** How has relative reacted to this?:	
		Relative accepts is and doesn't worry	1
		Relative sometimes worries, sometimes doesn't	2
		Quite a problem and relative always finds it difficult to confront	3
		Very difficult to tolerate and often relative not able to confront it	4
		Other	5
		N/A (S hasn't done so or doesn't behave like this)	9
226	34	If 1-5 chosen: How often is S offensive?:	
		< once a month	1
		Once a month	2
		Once a week	3
		Every day	4
		Other	5
		N/A (Never)	9
227	35	How serious is S's offensiveness?	
		Not serious	1
		Moderate	2
		Quite serious	3
		Very serious	4
		Other	5
		N/A	9

228	36	To what extent offensiveness a part of S's condition?:		
			Behaviour is part of S's condition	1
			Behaviour is partly due to condition but S is able to control it	2
			Nothing to do with condition, S has always been like that	3
			Behaviour is due to medication S takes	4
			Behaviour is due to medication and condition	5
			Other	6
			D/K (Relative cannot say whether behaviour is due to condition)	9
229	37	**Drink heavily?** How has relative reacted to this?:		
			Relative accepts is and doesn't worry	1
			Relative sometimes worries, sometimes doesn't	2
			Quite a problem and relative always finds it difficult to confront	3
			Very difficult to tolerate and often relative not able to confront it	4
			Other	5
			N/A (S hasn't done so or doesn't behave like this)	9
230	38	If 1-5 chosen: How often does S drink heavily?:		
			< once a month	1
			Once a month	2
			Once a week	3
			Every day	4
			Other	5
			N/A (Never)	9
231	39	How serious is S's drinking?		
			Not serious	1
			Moderate	2
			Quite serious	3
			Very serious	4
			Other	5
			N/A	9

232	40	To what extent drinking a part of S's condition?:	
		Behaviour is part of S's condition	1
		Behaviour is partly due to condition but S is able to control it	2
		Nothing to do with condition, S has always been like that	3
		Behaviour is due to medication S takes	4
		Behaviour is due to medication and condition	5
		Other	6
		D/K (Relative cannot say whether behaviour is due to condition)	9
233	41	**Gamble?** How has relative reacted to this?:	
		Relative accepts is and doesn't worry	1
		Relative sometimes worries, sometimes doesn't	2
		Quite a problem and relative always finds it difficult to confront	3
		Very difficult to tolerate and often relative not able to confront it	4
		Other	5
		N/A (S hasn't done so or doesn't behave like this)	9
234	42	If 1-5 chosen: How often does S gamble?:	
		< once a month	1
		Once a month	2
		Once a week	3
		Every day	4
		Other	5
		N/A (Never)	9
235	43	How serious is S's gambling?	
		Not serious	1
		Moderate	2
		Quite serious	3
		Very serious	4
		Other	5
		N/A	9

236	44	To what extent gambling a part of S's condition?:		
			Behaviour is part of S's condition	1
			Behaviour is partly due to condition but S is able to control it	2
			Nothing to do with condition, S has always been like that	3
			Behaviour is due to medication S takes	4
			Behaviour is due to medication and condition	5
			Other	6
			D/K (Relative cannot say whether behaviour is due to condition)	9
237	45	**Neglects him/herself?** How has relative reacted to this?:		
			Relative accepts is and doesn't worry	1
			Relative sometimes worries, sometimes doesn't	2
			Quite a problem and relative always finds it difficult to confront	3
			Very difficult to tolerate and often relative not able to confront it	4
			Other	5
			N/A (S hasn't done so or doesn't behave like this)	9
238	46	If 1-5 chosen: How often does S neglect him/herself?:		
			< once a month	1
			Once a month	2
			Once a week	3
			Every day	4
			Other	5
			N/A (Never)	9
239	47	How serious is S's self neglect?		
			Not serious	1
			Moderate	2
			Quite serious	3
			Very serious	4
			Other	5
			N/A	9

240	48	To what extent self neglect a part of S's condition?:	
		Behaviour is part of S's condition	1
		Behaviour is partly due to condition but S is able to control it	2
		Nothing to do with condition, S has always been like that	3
		Behaviour is due to medication S takes	4
		Behaviour is due to medication and condition	5
		Other	5
		D/K (Relative cannot say whether behaviour is due to condition)	9
241	49	**Overeats?** How has relative reacted to this?:	
		Relative accepts is and doesn't worry	1
		Relative sometimes worries, sometimes doesn't	2
		Quite a problem and relative always finds it difficult to confront	3
		Very difficult to tolerate and often relative not able to confront it	4
		Other	5
		N/A (S hasn't done so or doesn't behave like this)	9
242	50	If 1-5 chosen: How often does S overeat?:	
		< once a month	1
		Once a month	2
		Once a week	3
		Every day	4
		Other	5
		N/A (Never)	9
243	51	How serious is S's overeating?	
		Not serious	1
		Moderate	2
		Quite serious	3
		Very serious	4
		Other	5
		N/A	9

244	52	To what extent is overeating a part of S's condition?:	
		Behaviour is part of S's condition	1
		Behaviour is partly due to condition but S is able to control it	2
		Nothing to do with condition, S has always been like that	3
		Behaviour is due to medication S takes	4
		Behaviour is due to medication and condition	5
		Other	6
		D/K (Relative cannot say whether behaviour is due to condition)	9
245	53	**Complain about bodily aches and pains?** How has relative reacted to this?:	
		Relative accepts is and doesn't worry	1
		Relative sometimes worries, sometimes doesn't	2
		Quite a problem and relative always finds it difficult to confront	3
		Very difficult to tolerate and often relative not able to confront it	4
		Other	5
		N/A (S hasn't done so or doesn't behave like this)	9
246	54	If 1-5 chosen: How often does S complain about bodily aches and pains?:	
		< once a month	1
		Once a month	2
		Once a week	3
		Every day	4
		Other	5
		N/A (Never)	9
247	55	How serious are S's complaints?	
		Not serious	1
		Moderate	2
		Quite serious	3
		Very serious	4

		Other	5
		N/A	9
248	56	To what extent are these complaints a part of S's condition?:	
		Behaviour is part of S's condition	1
		Behaviour is partly due to condition but S is able to control it	2
		Nothing to do with condition, S has always been like that	3
		Behaviour is due to medication S takes	4
		Behaviour is due to medication and condition	5
		Other	6
		D/K (Relative cannot say whether behaviour is due to condition)	9
249	57	**Behave oddly?** How has relative reacted to this?:	
		Relative accepts is and doesn't worry	1
		Relative sometimes worries, sometimes doesn't	2
		Quite a problem and relative always finds it difficult to confront	3
		Very difficult to tolerate and often relative not able to confront it	4
		Other	5
		N/A (S hasn't done so or doesn't behave like this)	9
250	58	If 1-5 chosen: How often does S behave oddly?:	
		< once a month	1
		Once a month	2
		Once a week	3
		Every day	4
		Other	5
		N/A (Never)	9
251	59	How serious is S's odd behaviour?	
		Not serious	1
		Moderate	2
		Quite serious	3

		Very serious	4
		Other	5
		N/A	9
252	60	To what extent is odd behaviour a part of S's condition?:	
		Behaviour is part of S's condition	1
		Behaviour is partly due to condition but S is able to control it	2
		Nothing to do with condition, S has always been like that	3
		Behaviour is due to medication S takes	4
		Behaviour is due to medication and condition	5
		Other	6
		D/K (Relative cannot say whether behaviour is due to condition)	9
253	61	**Hallucinate?** How has relative reacted to this?:	
		Relative accepts is and doesn't worry	1
		Relative sometimes worries, sometimes doesn't	2
		Quite a problem and relative always finds it difficult to confront	3
		Very difficult to tolerate and often relative not able to confront it	4
		Other	5
		N/A (S hasn't done so or doesn't behave like this)	9
254	62	If 1-5 chosen: How often does S hallucinate?:	
		< once a month	1
		Once a month	2
		Once a week	3
		Every day	4
		Other	5
		N/A (Never)	9
255	63	How serious are S's hallucinations?	
		Not serious	1

			Moderate	2
			Quite serious	3
			Very serious	4
			Other	5
			N/A	9
256	64	To what extent are hallucinations a part of S's condition?:		
			Behaviour is part of S's condition	1
			Behaviour is partly due to condition but S is able to control it	2
			Nothing to do with condition, S has always been like that	3
			Behaviour is due to medication S takes	4
			Behaviour is due to medication and condition	5
			Other	6
			D/K (Relative cannot say whether behaviour is due to condition)	9
257	65	**Attention seeking?** How has relative reacted to this?:		
			Relative accepts is and doesn't worry	1
			Relative sometimes worries, sometimes doesn't	2
			Quite a problem and relative always finds it difficult to confront	3
			Very difficult to tolerate and often relative not able to confront it	4
			Other	5
			N/A (S hasn't done so or doesn't behave like this)	9
258	66	If 1-5 chosen: How often does S attention seek?:		
			< once a month	1
			Once a month	2
			Once a week	3
			Every day	4
			Other	5
			N/A (Never)	9
259	67	How serious is S's attention seeking?		

		Not serious	1
		Moderate	2
		Quite serious	3
		Very serious	4
		Other	5
		N/A	9
260	68	To what extent is attention seeking a part of S's condition?:	
		Behaviour is part of S's condition	1
		Behaviour is partly due to condition but S is able to control it	2
		Nothing to do with condition, S has always been like that	3
		Behaviour is due to medication S takes	4
		Behaviour is due to medication and condition	5
		Other	6
		D/K (Relative cannot say whether behaviour is due to condition)	9

Problem - Difficult Behaviour CARD 11

VARI	CLMN	IDENT	CODE
261	1,2	Series no:	01-99
262	3,4	Card no:	11
263	5	Difficult problem/situation regarding household affairs over the past month?:	
		Yes	1
		No	2
		Coping Questionnaire How relative coped psychologically	
264	6	Relative try to feel better by eating, drinking, smoking, taking drugs or medication, etc?:	
		Used a little	1
		Used quite a bit	2
		Used a great deal	3
		Other	4
		N/A	9
265	7	Think that S is not so important to him/her?:	
		Used a little	1
		Used quite a bit	2
		Used a great deal	3
		Other	4
		N/A	9
266	8	Know what has to be done and double efforts to make things work?:	
		Used a little	1
		Used quite a bit	2
		Used a great deal	3
		Other	4
		N/A	9
267	9	Accept sympathy or understanding from someone?:	
		Used a little	1
		Used quite a bit	2
		Used a great deal	3
		Other	4
		N/A	9

268	10	Look for the silver lining: try to look on the bright side of things?:		
			Used a little	1
			Used quite a bit	2
			Used a great deal	3
			Other	4
			N/A	9
269	11	Keeps feelings to him/herself?:		
			Used a little	1
			Used quite a bit	2
			Used a great deal	3
			Other	4
			N/A	9
270	12	Try to see things from the other person's point of view?:		
			Used a little	1
			Used quite a bit	2
			Used a great deal	3
			Other	4
			N/A	9
271	13	Criticise or lecture oneself?:		
			Used a little	1
			Used quite a bit	2
			Used a great deal	3
			Other	4
			N/A	9
272	14	Think that things could be worse. We are all in the same boat?:		
			Used a little	1
			Used quite a bit	2
			Used a great deal	3
			Other	4
			N/A	9
273	15	Draw on past experiences; has been in similar situation before?:		
			Used a little	1
			Used quite a bit	2
			Used a great deal	3
			Other	4
			N/A	9
274	16	These things happen in life; one has to take the good with the bad?:		

		Used a little	1
		Used quite a bit	2
		Used a great deal	3
		Other	4
		N/A	9
275	17	Try not to act too hastily or follow one's first hunch?:	
		Used a little	1
		Used quite a bit	2
		Used a great deal	3
		Other	4
		N/A	9
276	18	Wish that the situation would go away or somehow be over with?:	
		Used a little	1
		Used quite a bit	2
		Used a great deal	3
		Other	4
		N/A	9
277	19	Go over in my mind what I will say or do?:	
		Used a little	1
		Used quite a bit	2
		Used a great deal	3
		Other	4
		N/A	9
278	20	Talk to someone to find out more about the situation?:	
		Used a little	1
		Used quite a bit	2
		Used a great deal	3
		Other	4
		N/A	9
279	21	Go along with fate; sometimes one just has bad luck?:	
		Used a little	1
		Used quite a bit	2
		Used a great deal	3
		Other	4
		N/A	9
280	22	Come up with a different number of solutions to the problem?:	
		Used a little	1
		Used quite a bit	2

Used a great deal	3
Other	4
N/A	9

Service/Professional Contact by Relative with Regards to S CARD 12

VARI	CLMN	IDENT	CODE	
281	1,2	Series no:	01-99	
282	3,4	Card no:		12
283	5	Relative seen GP? If so, when was GP last seen?:		
		2 times in the past		1
		< a year, but > 3 months ago		2
		< 3 months, but > a month ago		3
		< a month ago		4
		Other		5
		N/A		9
284	6	If 1-5 chosen: place where GP was seen?:		
		Home visit		1
		Surgery		2
		Other		3
		N/A		9
285	7	Relative seen psychiatrist? If so, when was s/he last seen?:		
		2 times in the past		1
		< a year, but > 3 months ago		2
		< 3 months, but > a month ago		3
		< a month ago		4
		Other		5
		N/A		9
286	8	If 1-5 chosen: place where psychiatrist was last seen?:		
		Home visit		1
		Consulting room		2
		Psychiatric ward		3
		CMHC		4
		Other		5
		N/A		9
287	9	Relative seen nurse? If so, when was nurse last seen?:		
		2 times in the past		1

		< a year, but > 3 months ago	2
		< 3 months, but > a month ago	3
		< a month ago	4
		Other	5
		N/A	9
288	10	If 1-5 chosen: place where nurse was seen?:	
		Home visit	1
		Psychiatric ward	2
		CMHC	3
		Other	4
		N/A	9
289	11	Relative seen psychologist? If so, when was psychologist last seen?:	
		2 times in the past	1
		< a year, but > 3 months ago	2
		< 3 months, but > a month ago	3
		< a month ago	4
		Other	5
		N/A	9
290	12	If 1-5 chosen: place where psychologist seen?:	
		Home visit	1
		Consulting room	2
		Psychiatric ward	3
		CMHC	4
		Other	5
		N/A	9
291	13	Relative seen social worker? If so, when was SW last seen?:	
		2 times in the past	1
		< a year, but > 3 months ago	2
		< 3 months, but > a month ago	3
		< a month ago	4
		Other	5
		N/A	9
292	14	If 1-5 chosen: place where SW seen?:	
		Home visit	1

			Psychiatric ward	2
			CMHC	3
			Other	4
			N/A	9
293	15	Relative informed about S's diagnosis?:		
			Yes	1
			No	2
294	16	Relative need to know more about S's diagnosis?:		
			No need	1
			Slight need	2
			Moderate need	3
			Considerable need	4
			Urgent need	5
			Other	6
			N/A	9
295	17	Relative informed about nature of condition and S's future prospects?:		
			No information	1
			Little information, but still knows little about S's condition/prospects	2
			Sufficient information, but not as much as relative would have liked	3
			Relative feels s/he understands fully S's condition/prospects	4
			Other	5
			N/A	9
296	18	Relative need to know more about nature of S's condition/future prospects?:		
			No need	1
			Slight need	2
			Moderate need	3
			Considerable need	4
			Urgent need	5
			Other	6
			N/A	9
297	19	Relative been informed about drugs S takes/taken and about side effects?:		
			No need	1

			Little information, but still knows little about S's medication	2
			Sufficient information, but not as much as relative would have liked	3
			Relative feels s/he understands fully S's medication	4
			Other	5
			N/A	9
298	20	Relative need to know more about drugs S's takes and possible side effects?:		
			No need	1
			Slight need	2
			Moderate need	3
			Considerable need	4
			Urgent need	5
			Other	6
			N/A	9
299	21	Relative been invited to discuss any psychological problems they might have in relation to S?:		
			Yes	1
			No	2
300	22	Relative need to discuss their own psychological problems with a professional?:		
			No need	1
			Slight need	2
			Moderate need	3
			Considerable need	4
			Urgent need	5
			Other	6
			N/A	9
301	23	Received any home visits?:		
			None	1
			< once a month	2
			Once a month	3
			Once a week	4
			Every day	5
			Other	6
			N/A	9
302	24	Relative need more home visits?:		
			No need	1

		Slight need	2
		Moderate need	3
		Considerable need	4
		Urgent need	5
		Other	6
		N/A	9
303	25	Has relative ever been offered respite or alternative accommodation for S?:	
		Yes	1
		No	2
304	26	Does relative feel the need for respite or alternative accommodation for S?:	
		No need	1
		Slight need	2
		Moderate need	3
		Considerable need	4
		Urgent need	5
		Other	6
		N/A	9
305	27	In times of crisis with S relative receive help easily from services?:	
		Not available easily	1
		No doubt about service availability and received help immediately	2
		Other	3
		N/A	9
306	28	How quickly have services responded to a crisis with S?:	
		No help within 24 hours	1
		Help within 24 hours in form of an appointment	2
		Help within 24 hours in form of home visit	3
		S taken to casualty	4
		Other	5
		N/A	9
307	29	Can crisis services be improved in any way according to relative?:	
		Reduce medical treatment following a crisis	1
		Relative is satisfied, hence no need for change	2

		More immediate intervention rather than an appointment at a later date	3
		Relative unsatisfied though not sure how can be improved	4
		Home visit rather than appointment	5
		Other	6
		N/A	9
308	30	Does relative feel s/he can contact CMHC/hospital if worried about S? Has relative ever done this?:	
		Relative never done this and doesn't think it is possible	1
		Relative thinks you can do it, but has never done so	2
		Relative thinks help can be obtained and has done so in the past	3
		Other	4
		N/A	9
309	31	Relative been invited to discuss what services are appropriate for S? Has relative attended?:	
		Never invited	1
		Invited but did not go	2
		Invited and attended	3
		Other	4
		N/A	9

What should services be offering relative in their situation?:

			Yes	No
310	32	Satisfied with services as they are overall	1	2
311	33	Unsatisfied, though relative is not sure how services can be improved	1	2
312	34	More support for relative - further advice/reassurance	1	2
313	35	Staff to be more cooperative/receptive	1	2
314	36	Improvements in making appointments for clients by relatives	1	2

315	37	Help in seeking financial support	1	2	
		Other			3
		N/A			9

Service/Contact with Professionals by Patient Member
CARD 13

VARI	CLMN	IDENT	CODE
316	1,2	Series no:	01-99
317	3,4	Card no:	13
318	5,6	First contact with Borgo Roma services: MONTH:	01-98+ N/A 99
319	7,8	First contact with BR services: YEAR	01-98+ N/A 99
320	9,10	Last contact with BR services (up until Oct '89, see Reg): MONTH	01-98+ N/A 99
321	11,12	Last contact with BR services: YEAR	01-98+ N/A 99+
322	13,14,15	How many contacts, as listed on Register (1979-Oct88)	01-998+ N/A 999
323	16,17	Most typical place of contact:	

Clinica psi.ricov.vol	1	Altra sede (es.tel.)	11
Clinical psi. TSO	2	O.P. Verona	12
Ambul.individuale	3	Altri O.P.	13
Terapia familiare	4	Divi. neurol. Verona	14
Consulenza policlinico	5	" " Zevio (rico)	15
Pronto soccorso	6	Altre instit.pubbl. "	16
Visita domiciliare	7	Clinica S.Giuliana "	17
Day hospital CSM	8	Clinica S. Chiara "	18
Gruppo CSM	9	Other	19
Colloquio CSM	10	N/A	99

324	18,19	How many admissions, according to Register:	01-98+ N/A 99
325	20,21	Longest period of admission: How many days (according to Register list):	01-98+ N/A 99
326	22	Who client has seen most often: (1979-88 list):	

			Psychiatrist/Doctor	1
			Psychologist	2
			Nurse	3
			Social Worker	4
			Student	5
			Equipe con medico	6
			Equipe senza medico	7
			Other	8
			N/A	9
327	23	Who client has been most often referred by:		
			Self	1
			Relative	2
			Neighbour	3
			Staff member	4
			Police	5
			GP	6
			Psychiatrist	7
			Other specialist	8
			N/A	9
328	24	Last time client saw psychiatrist:		
			2 times in the past	1
			< a year, but > 3 months ago	2
			< 3 months, but > a month ago	3
			< a month ago	4
			Other	5
			N/A	9
329	25	If 1-5 chosen: place where psychiatrist was last seen?:		
			Home visit	1
			Consulting room	2
			Psychiatric ward	3
			CMHC	4
			Other	5
			N/A	9
330	26	Client seen nurse? If so, when was nurse last seen?:		
			2 times in the past	1
			< a year, but > 3 months ago	2
			< 3 months, but > a month ago	3
			< a month ago	4
			Other	5
			N/A	9

331	27	If 1-5 chosen: place where nurse was seen?:		
			Home visit	1
			Psychiatric ward	2
			CMHC	3
			Other	4
			N/A	9
332	28	Client seen psychologist? If so, when was psychologist last seen?:		
			2 times in the past	1
			< a year, but > 3 months ago	2
			< 3 months, but > a month ago	3
			< a month ago	4
			Other	5
			N/A	9
333	29	If 1-5 chosen: place where psychologist seen?:		
			Home visit	1
			Consulting room	2
			Psychiatric ward	3
			CMHC	4
			Other	5
			N/A	9
334	30	Client seen social worker? If so, when was SW last seen?:		
			2 times in the past	1
			< a year, but > 3 months ago	2
			< 3 months, but > a month ago	3
			< a month ago	4
			Other	5
			N/A	9
335	31	If 1-5 chosen: place where SW seen?:		
			Home visit	1
			Psychiatric ward	2
			CMHC	3
			Other	4
			N/A	9
336	32	Client ever been offered sheltered work in Day Centre? If so, has client ever		

		attended?:		
		Never been offered	1	
		Been offered, but did not attend	2	
		Been offered and attended	3	
		Other	4	
		N/A	9	
337	33	Relative think that S needs more of this type of work to occupy their time?:		
		Slight need	1	
		Moderate need	2	
		Considerable need	3	
		Urgent need	4	
		Other	5	
		N/A (No need)	9	
338	34	S been offered to take part in any outings or social activities organised by the service?:		
		Never been offered	1	
		Been offered, but did not attend	2	
		Been offered and attended	3	
		Other	4	
		N/A	9	
339	35	Relative feel S needs to be offered more of these social activities?:		
		No need	1	
		Slight need	2	
		Moderate need	3	
		Considerable need	4	
		Urgent need	5	
		Other	6	
		N/A	9	
		Relative think that service could offer more help to S? If so, in what way?:		
			Yes	No
340	36	Staff to be more available to listen to client	1	2
341	37	Reduction in use of medications	1	2

342	38	Increase in the use of medications 1 2	
343	39	More suitable environment for client during admissions to psychiatric ward or when attending CMHC 1 2	
344	40	Satisfied with what client is receiving(ed) in general 1 2	
345	41	Dissatisfied, but unsure about what/how improvements should be made 1 2	
346	42	Inventions on a more regular basis for client, including suitable follow-up 1 2	
347	43	Assistance in seeking employment, social/leisure activities or financial support 1 2	
		Other 3	
		N/A	9
348	44	If client no longer in contact with BR services, what are the reasons?:	
		Client transferred to another service due to dissatisfaction with BR	1
		Client transferred to other service due to BR not having required facilities, ie.inpatient beds	2
		Client moved house outside catchment area	3
		Client sought private facilities as dissatisfied4	
		Client ceased contact with psychiatric services altogether	5
		Client ceased contact for time beine	6
		Other	6
		N/A	9
349	45	Client ever attended the Day hospital CSM or Gruppo CSM?:	
		Regularly in the past	1
		On occasion in the past	2
		Once a month	3
		2-3 times a month	4
		Once a week	5
		2-3 times a week	6
		Every day	7
		Other	8
		N/A (Never attended)	9

350	46,47	Received family therapy? If so, how many times?: 01-98+ N/A 99

Housing Situation CARD 14

VARI	CLMN	IDENT	CODE	
351	1,2	Series no:	01-99	
352	3,4	Card no:		14
		Owns own house?	Yes No	
353	5	Own house	1 2	
354	6	Rented privately	1 2	
355	7	Rented from council	1 2	
356	8	Furnished flat (rented)	1 2	
357	9	Unfurnished flat (rented)	1 2	
		Other	3	
		N/A		9
358	10	Type of accommodation?:		
		House		1
		Flat		2
		Room(s) in a house		3
		Other		4
		N/A		9
359	11	Number of rooms:		
		One		1
		2-3		2
		3-4		3
		5-6		4
		7-9		5
		> 9		6
		Other		7
		N/A		9
360	12	Number of bedrooms:		
		One		1
		Two		2
		Three		3
		Four		4
		Five		5
		Six or more		6
		Other		7
		N/A		9
361	13	Problems with present accommodation?:		
		Some problems, but made no attempt to move		1
		Serious problems and relative made attempts to move		2

		Other	3
		N/A	9
362	14	Number of years family lived in current accommodation:	
		Temporary accommodation	1
		Not more than 6 months	2
		Between 6 months to 1 year	3
		Between 1-5 years	4
		Between 5-10 years	5
		More than 10 years	6
		Always	7
		Other	8
		N/A	9

Data Variables
Item List

Demographic Details

ID	1-2	Series number a
CARD	3-4	Card number a
CSEX	5	Client sex
CAGE	6-7	Client age
CMARI	8	Client marital status
RESID	9	Residence
DIAG	10	Diagnosis
RSEX	11	Relative sex
RAGE	12-13	Relative age
RMARI	14	Relative marital status
RETOCLI	15	Relation to client
FAMSIZE	16	Family size (S included)
OTFAMMEM	17	Other family member (eldest)
OFMAGE	18-19	Other family member age
MCHILD	20	Male children
FCHILD	21	Female children
CHILDAGE	22-23	Eldest child's age
OFAMOCC	24	Occupation of eldest family member
FRSTCONM	25-26	First psychiatric contact, month
FRSTCONY	27-28	First psychiatric contact, year
HIST1	29	Onset
HIST2	30	Crisis(ses)
HIST3	31	Deterioration
HIST4	32	Behaviour more difficult
HIST5	33	Medication problems
HIST6	34	Tense family relations
HIST7	35	Improvement in condition
SDIFFSLP	36	Client difficulty in sleeping

Employment Activities

ID	1-2	Series number b
CARD	3-4	Card number b
RELOCC	5	Relative's occupational status
RELJOB	6	Relative's occupation
RELWCHG	7	Relative made changes to work
WHYWCHG	8	Reasons for any such changes
OTHFWK	9	Any other member sought work
WHYMON	10	If so, for financial reasons
WHYSOC	11	If so, for social reasons
RELHOL	12	Relative or other had to take time off
RELFNDWK	13	How is relative finding work
WKDIFF	14	What difficulties at work for relative
WKDECL	15	Decline in standard of work
OTHWDIFF	16	Any other difficulty at work
COCC	17	Client occupational status
CJOB	18	Client's current or past job
CNOWKCON	19	If client not working due to condition

Financial Activities

ID	1-2	Series number c
CARD	3-4	Card number c
CINCOME	5	Client have an income
CADMONEY	6	Client administer own money
NOADCOND	7	If not, due to condition
CHGFAINC	8	Change in family income
INCDROPH	9	If drop in income, by how much
INCDROPW	10	If drop in income, why
FAMREDSP	11	Family reduced spending
ARRBILLS	12	Fallen behind with bills/payments
ARRSHL	13	How long difficulties with payments
ARRSCOND	14	Arrears related to condition
MAFAMFIN	15	Main person responsible for finances
MASAME	16	Same person responsible before onset
FAMDISA	17	Family disagreements over money
RELWRMON	18	Relative worry about money problems
CONTRMON	19	Relative control over money problems
CSAYMON	20	Client have a say over money

Domestic Activities

ID	1-2	Series number d
CARD	3-4	Card number d
SHOUSW	5	S help with housework
NOSHOUSW	6	Condition that S does not help in house
SSHOP	7	S able to do shopping
NOSSHOP	8	Due to condition that S does not shop
SCOOK	9	S able to cook
NOSCOOK	10	Due to condition that S does not cook
RELHOUS	11	How much housework does relative do
HDUECOND	12	Condition that relative does housework
RELORESP	13	Relative's other household respon.
SHOUAFF	14	S involved in household affairs
RELHOINC	15	Relative's household respon increase
HOUPROMG	16	Household management problems
GENHDIFF	17	General household difficulties
HDIFFHOW	18	How is household management affected
RELCNTHA	19	Relative control problems in household
SINFLHA	20	Influence S has over household affairs
OTDIFFHM	21	Other difficulties in house management

Problem - Household Affairs

ID	1-2	Series number e
CARD	3-4	Card number e
DIFFPRHA	5	Difficult problem in household affairs
RELBETT	6	Relative try to feel better, eating etc
SNOIMP	7	S is not so important
RELKNOW	8	Relative knows what has to be done
RELACC	9	Relative accept sympathy
RELSILV	10	Relative look for siver lining
RELKPFEE	11	Relative keep feelings to self
RELSEE	12	Relative see from other view point
RELCRIT	13	Relative critise or lecture self
RELWORS	14	Relatvie think things could be worse
RELDRAW	15	Relatvie draw on past experience
RELHAPPE	16	Happens in life, take good with the bad
RELHAST	17	Relative try not to act hastily
RELWISH	18	Relative wish situation would go away
RELGOVER	19	Relative go over what to say or do
RELTALK	20	Relative talk to find out more
RELFATE	21	Relative go along with fate
RELSOLU	22	Relative seek number of solutions

Social and Leisure Activites

ID	1-2	Series number f
CARD	3-4	Card number f
RFREETM	5	Relative have free time
RLEISOC	6	Relative do leisure/social activities
ROKLEVS	7	Relative OK about leaving S at home
SLEISOC	8	S do leisure/social activities
SRGOUT	9	S and relative go out together
REDGOUT	10	Reduction in relative going out
RNOFEEL	11	Relative doesn't feel like going out
LOOKSTM	12	Looking after S takes up much time
CONDNOVS	13	Condition such that friends don't visit
RFRRECON	14	Friends/relatives contact with relative
RMORECON	15	Relative more contact with friends prev
RFRCONFI	16	Relative have friend to confide in
RISOLAT	17	Relative feel isolated or know someone

Interpersonal Relationship

ID	1-2	Series number g
CARD	3-4	Card number g
SRTMTO	5	S and relative time together at home
SRGETON	6	Things between S and relative
STBEFORE	7	What was situation like before onset
INCRARG	8	Arguments/disagreements increased
RSTRESS	9	Relative find things with S stressful
INFRHAS	10	In relationship relative have influence
SCNTRS	11	Extent S has control in relationship

Physical and Psychological Health

ID	1-2	Series number h
CARD	3-4	Card number h
RPHYSHLT	5	Relative physical health problems (mth)
RSEEDOC	6	Relative seen doctor for phys. health
HOWLGHP	7	How long relative had health problems
HPDCOND	8	Health problems due to condition
RPSYPRO	9	Relative psychological problems (mth)
RSEEPROF	10	Relative seen prof. for psych.problems
HOWLGGPP	11	How long relative had psycho.problems
PPDCOND	12	Psychological problems due to condition

Patient Behaviour 1

ID	1-2	Series number i
CARD	3-4	Card number i
SMISRREA	5	Relative's reaction to S' miserableness
MISOFTEN	6	How often is S miserable
MISSERIO	7	Severity of miserableness
MISCOND	8	Miserableness part of condition
SWTDRREA	9	Relative's reaction to withdrawal
WTDOFTEN	10	How often withdrawn
WTDSERIO	11	Severity of withdrawal
WTDCOND	12	Withdrawal part of condition
SSLWRREA	13	Relative's reaction to slowness
SLWOFTEN	14	How often slow
SLWSERIO	15	Severtiy of slowness
SLWCOND	16	Slowness part of condition
SFGFRREA	17	Relative's reaction to forgetfulness
FGFOFTEN	18	How often forgetful
FGFSERIO	19	Severity of forgetfulness
FGFCOND	20	Forgetfulness part of condition
SUDARREA	21	Relative's reaction to underactivity
UDAOFTEN	22	How often underactive
UDASERIO	23	Severity of underactivity
UDACOND	24	Underactivity part of condition
SSLPRREA	25	Relative's reaction to excess sleeping
SLPOFTEN	26	How often sleep excessively
SLPSERIO	27	Severity of excessive sleeping
SLPCOND	28	Excessive sleeping part of condition
SOVDRREA	29	Relative's reaction to overdependency
OVDOFTEN	30	How often overdependent
OVDSERIO	31	Severity of overdependency
OVDCOND	32	Overdependency part of condition
SWRYRREA	33	Relative's reaction to worry
WRYOFTEN	34	How often worries
WRYSERIO	35	Severity of worrying
WRYCOND	36	Worrying part of condition
SFFARREA	37	Relative's reaction to fear/anxiety
FFAOFTEN	38	How often fearful/anxious
FFASERIO	39	Severity of fear/anxiety
FFACOND	40	Fear/anxiety part of condition
SOBSRREA	41	Relative's reaction to obsessionality
OBSOFTEN	42	How often obsessive
OBSSERIO	43	Severity of obsessiveness
OBSCOND	44	Obsessiveness part of condition
SINDRREA	45	Relative's reaction to indecision
INDOFTEN	46	How often indecisive
INDSERIO	47	Severity of indecision
INDCOND	48	Indecision part of condition
SSTGRREA	49	Relative's reactions to strange ideas
STGOFTEN	50	How often have strange ideas
STGSERIO	51	Severity of strange ideas
STGCOND	52	Strange ideas part of condition
SOVARREA	53	Relative's reaction to overactivity
OVAOFTEN	54	How often overactive
OVASERIO	55	Severity of overactivity

OVACOND	56	Overactivity part of condition
SELMRREA	57	Relative's reaction to elated mood
ELMOFTEN	58	How often elated
ELMSERIO	59	Severity of elation
ELMCOND	60	Elation part of condition

Patient Behaviour 2

ID	1-2	Series number j
CARD	3-4	Card number j
SUPRRREA	5	Relative's reaction of unpredictability
UPROFTEN	6	How often unpredictable
UPRSERIO	7	Severity of unpredictability
UPRCOND	8	Unpredictability part of condition
SIRTRREA	9	Relative's reaction to irritability
IRTOFTEN	10	How often irritable
IRTSERIO	11	Severity of irritability
IRTCOND	12	Irritability part of condition
SNAGRREA	13	Relative's reaction to nagging
NAGOFTEN	14	How often nag
NAGSERIO	15	Severity of nagging
NAGCOND	16	Nagging part of condition
SRDERREA	17	Relative's reaction to rudeness
RDEOFTEN	18	How often rude
RDESERIO	19	Severity of rudeness
RDECOND	20	Rudeness part of condition
SVIORREA	21	Relative's reaction to violence
VIOOFTEN	22	How often rude
VIOSERIO	23	Severity of rudeness
VIOCOND	24	Violence part of condition
SDSTRREA	25	Relative's reaction to destructiveness
DSTOFTEN	26	How often destructive
DSTSERIO	27	Severity of destructiveness
DSTCOND	28	Destructiveness part of condition
STASRREA	29	Relative's reaction to suicide
TASOFTEN	30	How often suicide
TASERIO	31	Severity of suicide
TASCOND	32	Suicide part of condition
SOFSRREA	33	Relative's reaction to offensiveness
OFSOFTEN	34	How often offensive
OFSSERIO	35	Severity of offensiveness
OFSCOND	36	Offensiveness part of condition
SDRKRREA	37	Relaitve's reaction to drinking
DRKOFTEN	38	How often drinks
DRKSERIO	39	Severity of drinking
DRKCOND	40	Drinking part of condition
SGABRREA	41	Relaitve's reaction to gambling
GMBOFTEN	42	How often gambles
GMBSERIO	43	Severity of gambling
GMBCOND	44	Gambling part of condition
SNGLRREA	45	Relative's reaction to self neglect
NGLOFTEN	46	How often neglects self
NGLSERIO	47	Severity of self neglect
NGLCOND	48	Self neglect part of condition
SOVERREA	49	Relative's reaction to overeating
OVEOFTEN	50	How often overeats
OVESERIO	51	Severity of overeating
OVECOND	52	Overeating part of condition
SBAPRREA	53	Relative's reaction to aches and pains
BAPOFTEN	54	How often have aches and pains
BAPSERIO	55	Severity of aches and pains

BAPCOND	56	Aches and pains part of condition
SBODRREA	57	Relative's reaction to odd behaviour
BODOFTEN	58	How often behave oddly
BODSERIO	59	Severity of odd behaviour
BODCOND	60	Odd behaviour part of condition
SHALRREA	61	Relative's reaction to hallucinations
HALOFTEN	62	How often hallucinates
HALSERIO	63	Severity of hallucinations
HALCOND	64	Hallucinations part of condition
SATSRREA	65	Relative's reaction to attention seeking
ATSOFTEN	66	How often seek attention
ATSSERIO	67	Severity of attention seeking
ATSCOND	68	Attention seeking part of condition

Problem - Patient Behaviour

ID	1-2	Series number k
CARD	3-4	Card number k
DIFFPRBE	5	Difficult problem in behaviour
RELBETT2	6	Relative try to feel better, eating etc
SNOIMP2	7	S is not so important
RELKNOW2	8	Relative knows what has to be done
RELACC2	9	Relative accept sympathy
RELSILV2	10	Relative look for siver lining
RELKPFE2	11	Relative keep feelings to self
RELSEE2	12	Relative see from other viewpoint
RELCRIT2	13	Relative critise or lecture self
RELWORS2	14	Relative think things could be worse
RELDRAW2	15	Relative draw on past experience
RELHAPP2	16	Happens in life, take good with the bad
RELHAST2	17	Relative try not to act hastily
RELWISH2	18	Relative wish situation would go away
RELGOVE2	19	Relative go over what to say or do
RELTALK2	20	Relative talk to find out more
RELFATE2	21	Relative go along with fate
RELSOLU2	22	Relative seek number of solutions

Service/Professional Contact - Relative

ID	1-2	Series number l
CARD	3-4	Card number l
RSEEGP	5	When relative saw GP
RGPPLC	6	Place where relative saw GP
RSEEPSYI	7	When relative saw psychiatrist
RPSYIPLC	8	Place where relative saw psychiatrist
RSEENRS	9	When relative saw nurse
RNRSEPLC	10	Place where relative saw nurse
RSEEPSYO	11	When relative saw psychologist
RPSYOPLC	12	Place where relative saw psychologist
RSEESW	13	When relative saw social worker
RSWPLC	14	Place where relative saw social worker
RINFDGN	15	Relative informed about diagnosis
RMREDGN	16	Relative need more about diagnosis
RINFNCF	17	Relative told about nature of condition
RMRENCF	18	Relative need more info on nat.of cond.
RINFDRG	19	Relative informed about drugs
RMREDRG	20	Relative need more info on drugs
RINVPP	21	Relative invited to discuss psy prob.s
RMREPP	22	Relative need more discu on psy prob.s
RDHMVTS	23	How many home visits received
NDMREHM	24	Need more home visits
ROFRSAA	25	Relative offered respite/alt.accomm.
RMRERSAA	26	Need more respite/alt.accommo
CRSHLP	27	In crisis help received easily
HQCRSHLP	28	How quickly help in crisis received
CRSIMPR	29	Crisis service be improved
RCNTCHOS	30	Relative feel can contact hospital/CMHC
RINUSER	31	Relative invited to discuss services
RSERSAT	32	Relative satisfied with services
RSERUSA	33	Relative unsatisfied with services
RMRESUPP	34	Relative need more support/reassurance
RSTFCOOP	35	Staff more cooperative towards relative
IMPAPP	36	Improvements in making appointments
HLPFINC	37	Help in seking financial support

Service/Professional Contact - Patient Member

ID	1-2	Series number m
CARD	3-4	Card number m
FRCONBRM	5-6	First contact with BR, month
FRCONBRY	7-8	First contact with BR, year
LSCONBRM	9-10	Last contact with BR, month
LSCONBRY	11-12	Last contact with BR, year
NUMBCONS	13-15	Number of contacts listed on register
TYPPLCON	16-17	Typical place of contact
NUMADMS	18-19	Number of admissions
LGPRDADM	20-21	Longest period of admission
WHOSSEEN	22	Who S has seen most
SREFFBY	23	S been most often referred by
SLTVPSYI	24	S's last visit to psychiatrist
PSLTPSYI	25	Place S last saw psychiatrist

SLVNRSE	26	S's last visit to nurse
PSLTNRSE	27	Place S last saw nurse
SLTVPSYO	28	S's last visit to psychologist
PSLTPSYO	29	Place S last saw psychologist
SLTOVSW	30	S's last visit to social worker
PSLTSW	31	Place S last saw social worker
SOFDCWK	32	S offer day centre work
SMREDCWK	33	S need more day centre work
SOFSOAT	34	S offered social activities
SMRESOAT	35	S need more social activities
SFMREAVS	36	Staf to be more avaliable to S
REDMEDI	37	Reduction in medication
INCRMEDI	38	Increase in medication
SUITADM	39	Suitable environment during admissions
SATSSER	40	Satisfied with services for S
DISATUNS	41	Dissatisfied unsure of improvements
INTVREG	42	Interventions on more regular basis
ASSEMSOC	43	Assistance seeking empl/social activ.s
WHYNOCON	44	Why no longer in contact with BR
SDHCSM	45	S attended day hospital or group at CSM
FAMTHER	46-47	Received family therapy

Housing Circumstances

ID	1-2	Series number n
CARD	3-4	Series number n
OWNHOUS	5	Own own house
RTPRIV	6	Rent privately
RTCOUNC	7	Rented from council
FURFLAT	8	Furnished flat (rented)
UNFUFLAT	9	Unfurnished flat (rented)
TYPEACC	10	Type of accommodation
NUMRMS	11	Number of rooms
NUMBEDRM	12	Number of bedrooms
PROPRACC	13	Problems with present accommodation
NUMYLIV	14	Years living in present accomm.

Recode List for T-Test Analyses

```
RECODE DIAG (1,2=1).
RECODE RETOCLI (3,5 THRU 9=0).
RECODE RELOCC (3,4=2)(1,2,5=1)(6=3)(9=0).
RECODE WHYWCHG (1=5)(2=4)(4=2)(5=1)(8,9=0).
RECODE OTHFWK (1=4)(4=1)(6,9=0).
RECODE WHYMON TO WHYSOC (1=2)(2=1)(3,9=0).
RECODE RELHOL (5,9=0).
RECODE RELFNDWK (3=4)(4=3)(9=0).
RECODE WKDIFF (3=4)(4=3)(5,9=0).
RECODE WKDECL (5,9=0).
RECODE OTHWDIFF (4,9=0).
RECODE COCC (1,2,4=2)(3,5=1)(6,9=0).
RECODE CNOWKCON (1=2)(2=1)(9=0).
RECODE CADMONEY (1=3)(3=1)(4,9=0).
RECODE NOADCOND (1=2)(2=3)(3,9=0).
RECODE CHGFAINC (1,2=1)(3=2)(4=3)(5,9=0).
RECODE INCDROPH (5,9=0).
RECODE INCDROPW (1=2)(2=1)(4,9=0).
RECODE FAMREDSP (1=2)(2=1).
RECODE ARRBILLS (1=2)(2=1).
RECODE ARRSHL (6,9=0).
RECODE ARRSCOND (2=3)(3=2)(4,9=0).
RECODE MASAME (2=3)(3=2)(4,9=0).
RECODE FAMDISA (5,9=0).
RECODE RELWRMON (4,9=0).
RECODE SHOUSW (1=4)(2=3)(3=2)(4=1)(5,9=0).
RECODE NOSHOUSW (4,9=0).
RECODE SSHOP (1=4)(2=3)(3=2)(4=1)(5,9=0).
RECODE NOSSHOP (4,9=0).
RECODE SCOOK (1=4)(2=3)(3=2)(4=1)(5,9=0).
RECODE NOSCOOK (4,9=0).
RECODE RELHOUS (5,9=0).
RECODE HDUECOND (3,9=0).
RECODE RELORESP (5,9=0).
RECODE SHOUAFF (1=2)(2=3)(3=4)(4=5)(5=1)(6,9=0).
RECODE RELHOINC (2=3)(3=4)(4=2)(5,9=0).
RECODE HOUPROMG (3=4)(4=3)(5,9=0).
RECODE GENHDIFF (5,9=0).
RECODE HDIFFHOW (4,9=0).
RECODE OTDIFFHM (4,9=0).
RECODE DIFFPRHA (1=2)(2=1).
RECODE RFREETM (1=3)(3=1)(4,9=0).
RECODE RLEISOC (1=6)(2=5)(3=4)(4=3)(5=2)(6=1)(7,9=0).
RECODE ROKLEVS (3=4)(4=3)(5,9=0).
RECODE SLEISOC (1=6)(2=5)(3=4)(4=3)(5=2)(6=1)(7,9=0).
RECODE REDGOUT (3=4)(4=5)(5=3)(6,9=0).
RECODE RNOFEEL (3,9=0).
RECODE LOOKSTM (3,9=0).
RECODE CONDNOVS (1=2)(2=3)(3,9=0).
RECODE RFRRECON (1=3)(3=1)(4,9=0).
RECODE RMORECON (1=2)(2=1)(3,9=0).
RECODE RFRCONFI (5,9=0).
RECODE RISOLAT (5,9=0).
RECODE SRGETON (1,2=1)(3=2)(4=3)(5,9=0).
```

```
RECODE STBEFORE (4,9=0).
RECODE INCRARG (6,9=0).
RECODE RSTRESS (4,9=0).
RECODE RPHYSHLT (3,9=0).
RECODE RSEEDOC (3,9=0).
RECODE HOWLGHP (6,9=0).
RECODE HPDCOND (4,9=0).
RECODE RPSYPRO (3,9=0).
RECODE RSEEPROF (3,9=0).
RECODE HOWLGGPP (6,9=0).
RECODE PPDCOND (4,9=0).
RECODE SMISRREA TO MISSERIO (5,9=0).
RECODE MISCOND (1=4)(3=1)(4=3)(6,9=0).
RECODE SWTDRREA TO WTDSERIO (5,9=0).
RECODE WTDCOND (1=4)(3=1)(4=3)(6,9=0).
RECODE SSLWRREA TO SLWSERIO (5,9=0).
RECODE SLWCOND (1=4)(3=1)(4=3)(6,9=0).
RECODE SFGFRREA TO FGFSERIO (5,9=0).
RECODE FGFCOND (1=4)(3=1)(4=3)(6,9=0).
RECODE SUDARREA TO UDASERIO (5,9=0).
RECODE UDACOND (1=4)(3=1)(4=3)(6,9=0).
RECODE SSLPRREA TO SLPSERIO (5,9=0).
RECODE SLPCOND (1=4)(3=1)(4=3)(6,9=0).
RECODE SOVDRREA TO OVDSERIO (5,9=0).
RECODE OVDCOND (1=4)(3=1)(4=3)(6,9=0).
RECODE SWRYRREA TO WRYSERIO (5,9=0).
RECODE WRYCOND (1=4)(3=1)(4=3)(6,9=0).
RECODE SFFARREA TO FFASERIO (5,9=0).
RECODE FFACOND (1=4)(3=1)(4=3)(6,9=0).
RECODE SOBSRREA TO OBSSERIO (5,9=0).
RECODE OBSCOND (1=4)(3=1)(4=3)(6,9=0).
RECODE SINDRREA TO INDSERIO (5,9=0).
RECODE INDCOND (1=4)(3=1)(4=3)(6,9=0).
RECODE SSTGRREA TO STGSERIO (5,9=0).
RECODE STGCOND (1=4)(3=1)(4=3)(6,9=0).
RECODE SOVARREA TO OVASERIO (5,9=0).
RECODE OVACOND (1=4)(3=1)(4=3)(6,9=0).
RECODE SELMRREA TO ELMSERIO (5,9=0).
RECODE ELMCOND (1=4)(3=1)(4=3)(6,9=0).
RECODE SUPRRREA TO UPRSERIO (5,9=0).
RECODE UPRCOND (1=4)(3=1)(4=3)(6,9=0).
RECODE SIRTRREA TO IRTSERIO (5,9=0).
RECODE IRTCOND (1=4)(3=1)(4=3)(6,9=0).
RECODE SNAGRREA TO NAGSERIO (5,9=0).
RECODE NAGCOND (1=4)(3=1)(4=3)(6,9=0).
RECODE SRDERREA TO RDESERIO (5,9=0).
RECODE RDECOND (1=4)(3=1)(4=3)(6,9=0).
RECODE SVIORREA TO VIOSERIO (5,9=0).
RECODE VIOCOND (1=4)(3=1)(4=3)(6,9=0).
RECODE SDSTRREA TO DSTSERIO (5,9=0).
RECODE DSTCOND (1=4)(3=1)(4=3)(6,9=0).
RECODE STASRREA TO TASERIO (5,9=0).
RECODE TASCOND (1=4)(3=1)(4=3)(6,9=0).
RECODE SOFSRREA TO OFSSERIO (5,9=0).
RECODE OFSCOND (1=4)(3=1)(4=3)(6,9=0).
RECODE SDRKRREA TO DRKSERIO (5,9=0).
```

```
RECODE DRKCOND (1=4)(3=1)(4=3)(6,9=0).
RECODE SGABRREA TO GMBSERIO (5,9=0).
RECODE GMBCOND (1=4)(3=1)(4=3)(6,9=0).
RECODE SNGLRREA TO NGLSERIO (5,9=0).
RECODE NGLCOND (1=4)(3=1)(4=3)(6,9=0).
RECODE SOVERREA TO OVESERIO (5,9=0).
RECODE OVECOND (1=4)(3=1)(4=3)(6,9=0).
RECODE SBAPRREA TO BAPSERIO (5,9=0).
RECODE BAPCOND (1=4)(3=1)(4=3)(6,9=0).
RECODE SBODRREA TO BODSERIO (5,9=0).
RECODE BODCOND (1=4)(3=1)(4=3)(6,9=0).
RECODE SHALRREA TO HALSERIO (5,9=0).
RECODE HALCOND (1=4)(3=1)(4=3)(6,9=0).
RECODE SATSRREA TO ATSSERIO (5,9=0).
RECODE ATSCOND (1=4)(3=1)(4=3)(6,9=0).
RECODE RMREDGN (6,9=0).
RECODE RINFNCF (1=4)(2=3)(3=2)(4=1)(5,9=0).
RECODE RMRENCF (6,9=0).
RECODE RINFDRG (1=4)(2=3)(3=2)(4=1)(5,9=0).
RECODE RMREDRG (6,9=0).
RECODE RMREPP (6,9=0).
RECODE RDHMVTS (1=5)(2=4)(4=2)(5=1)(6,9=0).
RECODE NDMREHM (6,9=0).
RECODE RMRERSAA (6,9=0).
RECODE CRSHLP (1=2)(2=1)(3,9=0).
RECODE HQCRSHLP (1=4)(3=1)(4=3)(5,9=0).
RECODE RCNTCHOS (1=3)(3=1)(4,9=0).
RECODE RSERSAT (3,9=0).
RECODE RSERUSA TO HLPFINC (1=2)(2=1)(3,9=0).
RECODE SOFDCWK (1=3)(3=1)(4,9=0).
RECODE SMREDCWK (1=2)(2=3)(3=4)(4=5)(5,9=0).
RECODE SOFSOAT (1=3)(3=1)(4,9=0).
RECODE SMRESOAT (6,9=0).
RECODE SFMREAVS TO SUITADM (1=2)(2=1)(3,9=0).
RECODE SATSSER (3,9=0).
RECODE DISATUNS TO ASSEMSOC (1=2)(2=1)(3,9=0).
RECODE WHYNOCON (1=6)(2=4)(3=1)(4=5)(5=2)(6=3)(7,9=0).
RECODE SDHCSM (1=7)(2=6)(3=5)(5=3)(6=2)(7=1)(8,9=0).
RECODE RAGE (15 THRU 35=1)(36 THRU 55=2)(56 THRU 75=3)
 (76 THRU 85=4).
RECODE CAGE (15 THRU 35=1)(36 THRU 55=2)(56 THRU 75=3)
 (76 THRU 85=4).
RECODE NUMBCONS (1 THRU 25=1)(26 THRU 50=2)(51 THRU 100=3)
 (101 THRU 260=4).
RECODE NUMADMS (1 THRU 5=1)(6 THRU 15=2)(16 THRU 40=3).
COMPUTE BEHAVSOC = MISOFTEN+MISSERIO+UDAOFTEN+UDASERIO+
 WRYOFTEN+WRYSERIO+FFAOFTEN+FFASERIO+IRTOFTEN+IRTSERIO+
 WTDOFTEN+WTDSERIO+SLWOFTEN+SLWSERIO+OVDOFTEN+OVDSERIO+
 NGLOFTEN+NGLSERIO+INDOFTEN+INDSERIO+FGFOFTEN+FGFSERIO+
 ATSOFTEN+ATSSERIO+NAGOFTEN+NAGSERIO.
COMPUTE BEHAVSOM = SLPOFTEN+SLPSERIO+UPROFTEN+UPRSERIO+
 BAPOFTEN+BAPSERIO+STGOFTEN+STGSERIO+OVEOFTEN+OVESERIO+
 RDEOFTEN+RDESERIO+OFSOFTEN+OFSSERIO+TASOFTEN+TASSERIO+
 OVAOFTEN+OVASERIO+BODOFTEN+BODSERIO+OBSOFTEN+OBSSERIO+
 ELMOFTEN+ELMSERIO+DSTOFTEN+DSTSERIO+HALOFTEN+HALSERIO+
 VIOOFTEN+VIOSERIO+DRKOFTEN+DRKSERIO+GMBOFTEN+GMBSERIO.
```

```
COMPUTE COPREAC = SMISRREA+SUDARREA+SWRYRREA+SFFARREA+
 SIRTRREA+SWTDRREA+SSLWRREA+SOVDRREA+SNGLRREA+SINDRREA+
 SFGFRREA+SATSRREA+SNAGRREA.
COMPUTE COPREAM = SSLPRREA+SUPRRREA+SBAPRREA+SSTGRREA+
 SOVERREA+SRDERREA+SOFSRREA+STASRREA+SOVARREA+SBODRREA+
 SOBSRREA+SELMRREA+SDSTRREA+SHALRREA+SVIORREA+SDRKRREA+
 SGMBRREA.
```

Bibliography

Abrams P. (1977) Community care: some research problems and priorities. *Policy and Politics*, **6**, 125-151.

Alloway R, Bebbington P. (1987) The buffer theory of social support - a review of the literature. *Psychological Medicine*, **17**, 91-108.

Anderson CM, Reiss DN, Hogarty GE. (1986) Schizophrenia and the Family: A Practitioner's Guide to Psychoeducation and Management. New York: Guildford Press.

Appleton WS. (1974) Mistreatment of patients' families by psychiatrists. *American Journal of Psychiatry*, **131**, 655-657.

Arber S, Gilbert N. (1989) Men: the forgotten carers. *Sociology*, **23**, 111-118.

Ascoli U. (1987) Le iniziative di solidarieta e di volontariate nei moderni sistemi di Welfare. In, Azione Volontaria e Welfare State. Ascoli U (Ed). Il Mulino: Bologna.

Baines CT, Evans PM, Neysmith SM. (1991) Caring: Its impact on the lives of women. In, Women's Caring: Feminist Perspectives on Social Welfare. Baines C, Evans P, Neysmith S (Eds), pp.10-35. McClelland and Stewart: Toronto.

Balbo L. (1978) La doppia presenza. [The double presence]. *Inchiesta*, **32**, 7-11.

Balestrieri M, Micciolo R, Tansella M. (1987) Long-stay and long-term psychiatric patients in an area with a community-based system of care. A register follow-up study. *International Journal of Social Psychiatry*, **33**, 251-262.

Barratt M, McIntosh M. (1982) The Anti-Social Family. Verso: London.

Barusch AS, Spaid WM. (1989) Gender differences in caregiving: why do wives report greater burden? *The Gerontologist*, **29**, 667-676.

Barzini L. (1964) The Italians. Hamish Hamilton: London.

Basaglia F (Ed). (1967) L'Istituzione Negata: Rapporto da un Ospedale Psichiatrico. Einaudi: Turin.

Bateson G. (1972) Steps to an Ecology of Mind. Ballantine: New York.

Bateson G, Ruesch J. (1951) Communication: The Social Matrix of Psychiatry. Norton: New York.

Becker T. (1985) Psychiatric reform in Italy - How does it work in Piedmont? *British Journal of Psychiatry*, **147**, 254-260.

Beechey V. (1985) Familial Ideology. In, Subjectivity and Social Relations. V Beechey, J Donald (Eds), pp.98-120. Open University Press: Milton Keynes.

Berkowitz SG. (1984) Familism, kinship and sex roles in Southern Italy: contradictory ideals and real contradictions. *Anthropological Quarterly*, **57**, 83-91.

Bernheim KF. (1987) Family consumerism: coping with the winds of change. In, Family of the Mentally Ill. Coping and Adaptation, AR Hartfield, HP Lefley (Eds). Guilford Press: New York.

Billings AG, Moos RH. (1981) The role of coping responses and social resources in attenuating the stress of life events. *Journal of Behavioral Medicine*, **4**, 139-157.

Bollini P, Relch M, Muscettola G. (1988) Revision of the Italian psychiatric reform: North/South differences and future strategies. *Social Science and Medicine*, **27**, 1327-1335.

Braun P, Kochansky G, Shapiro R, Greenberg S, Goudeman JE, Johnson S, Shore MF. (1981) Overview: deinstitutionalization of psychiatric patients: a critical review of outcome studies. *American Journal of Psychiatry*, **13**, 736-749.

Bridges JM, Lynam MJ. (1993) Informal carers: a Marxist analysis of social, political, and economic forces underpinning the role. *Advanced Nursing Science*, **15**, 33-48.

Broadhead WE, Kaplan BH, James SA, Wagner EH, Schoenbeck VJ, Grimson R, Heiden S, Tiblin G, Gehlbeck SH. (1983) The epidemiological evidence for a relationship between social support and health. *American Journal of Epidemiology*, **5**, 521-537.

Brooker C, Butterworth C. (1991) Working with families caring for a relative with schizophrenia: the evolving role of the community psychiatric nurse. *International Journal of Nursing Studies*, **28**, 189-200.

Brown GW, Birley JLT, Wing JK (1972) The influence of family life on the course of schizophrenic disorders: a replication. *British Journal of Psychiatry*, **121**, 241-258.

Brown GW, Carstairs GM, Topping G. (1958) Post hospital adjustment of chronic mental patients. *Lancet*, **2**, 682-689.

Brown GW, Rutter M (1966) The measurement of family activities and relationships: a methodological study. *Human Relations*, **19**, 241-263.

Caldwell L. (1991) Italian Family Matters: Women, Politics and Legal Reform. Macmillan: London.

Calvaruso C, Frisanco R, Izzo S. (Eds) (1982) Indagine Censis-Ciseff sulla Attuazione della Riforma Psichiatrica e sul Destino dei Dimessi dagli O.P. Edizioni Paoline: Roma.

Caring for People: Community Care in the Next Decade and Beyond, Cm 849. HMSO: London (1989).

Casi A, Traballisi R, Guidi A. (1984) Indagine catamnestica sui ricoverati della Siena degli anni 1978-1983. *Rassegna di Studi Psichiatrici*, **73**, 595ff

Centenaro MA, D'André MG, Rizzoli A. (1981) Deospedalizazione e reinserimento sociale. *Rivista di Psichiatria*, **16**, 250ff.

Centro Studi Investimenti Sociali (CENSIS). (1985) L'attuazione della riforma psichiatrica nel quadro delle politiche regionali e dell'offerta quantitativa e qualitativa dei servizi: Liguria, Mimeo. CENSIS: Roma.

Centro Studi Investimenti Sociali (CENSIS). (1984) Le politiche psichiatriche regionali ne doporiforma e lo stato attuale dei servizi. CENSIS: Roma.

Clark M. (1984) Modern Italy, 1871-1982. Longman: London.

Cohen S, Wills TA. (1985) Stress, social support and the buffering hypothesis. *Psychological Bulletin*, **98**, 310-357.

Cornelisen A. (1976) Women of the Shadows. Little, Brown and Co: Boston.

Creer C, Sturt E, Wykes T. (1982) The role of relatives. In, Long-term community care experience in a London borough, JK Wing (Ed). Psychological Medicine, 12, Mongraph Supplement 2, pp.29-39.

Creer C. (1975) Living with schizophrenia. *Social Work Today*, **6**, 2-7.

Creer C, Wing J. (1974) Schizophrenia at Home. National Schizophrenia Fellowship: Surbiton.

Crepet P. (1988) The Italian mental health reform nine years on. *Acta Psychiatrica Scandinavica*, **77**, 515-523.

Crepet P. (1990) A transition period in psychiatric care in Italy ten years after the reform. *British Journal of Psychiatry*, **156**, 27-36.

Crepet P, Pirella A. (1985) The transformation of psychiatric care in Italy: methodological premises, current status, and future prospects. *International Journal Mental Health*, **14**, 155-173.

Crepet P, De Plato G. (1983) Psychiatry without asylums: origins and prospects in Italy. *International Journal of Health Services*, **13**, 119-129.

Crotty P, Kulys R. (1986) Are schizophrenics a burden to their families? Significant others' views. *Health and Social Work*, **11**, 173-188.

Dalley G. (1983) Ideologies of care: a feminist contribution to the debate. *Critical Social Policy*, **3**, 72-82.

Dalley G. (1988) Ideologies of Caring: Rethinking Community and Collectivism.

MacMillan: Basingstoke.

De Salvia D. (1984) Elementi di statistica ed epidemiologia sull'applicazione della 180. *Fogli di Informazione*, **106**, 1-22.

De Salvia D, Barbato A. (1993) Recent trends in mental health services in Italy: An analysis of national and local data. *Canadian Journal of Psychiatry*, **38**, 195-202.

DHSS (1975) Better Services for the Mentally Ill. Cmnd no.6233, HMSO: London.

DHSS (1983) Health Care and its Costs. HMSO: London.

Donati P. (1985) Social welfare and social services in Italy since 1950. In, Social Policy in Western Europe and USA: 1950-1980, R Girod, P de Laubier, A Gladstone (Eds), MacMillan: Basingstoke.

Donnelly M. (1992) The Politics of Mental Health. Routledge: New York.

Durante Mangoni E, Ferrari M. (1983) La Evoluzione della Legislazione Psichiatrica Italiana. Piccin: Padova.

Endean C. (1993) Italy retreats from community care for mentally ill. *British Medical Journal*, **306**, 605.

Ernst C, Angst J. (1992) The Zurich Study: XII. Sex differences in depression: Evidence from longitudinal epidemiological data. *European Archives of Psychiatry and Clinical Neuroscience*, **241**, 222-230.

Faccincani C, Burti L, Garzotto N, Mignolli G, Tansella M. (1985) Organizational aspects of community care. The South Verona mental health center. *New Trends in Experimental and Clinical Psychiatry*, **1**, 201-216.

Fadden G. (1984) The Relatives of Patients with Depressive Disorders: A Typology of Burden and Strategies for Coping. Unpublished MPhil dissertation, Institute of Psychiatry, University of London.

Fadden G, Bebbington P, Kuipers L. (1987a) The burden of care: the impact of functional psychiatric illness on the patient's family. *British Journal of Psychiatry*, **150**, 285-292.

Fadden G, Bebbington P, Kuipers L. (1987b) Caring and its burdens: a study of relatives of depressed patients. *British Journal of Psychiatry*, **150**, 660-667.

Falloon IRH, Graham-Hole V, Woodroffe R. (1993) Stress and health of informal carers of people with chronic mental disorders. *Journal of Mental Health*, **2**, 165-173.

Fasolo E, Frisanco R. (1991) Mental health care: recent developments in Italy. *Social Policy and Administration*, **25**, 218-226.

Ferris PA, Marshall CA. (1987) A model project for families of the chronically mental ill. *Social Work,* **32,** 110-114.

Finch J. (1984) Community care: developing non-sexist alternatives. *Critical Social Policy,* **9,** 6-18.

Finch J. (1989) Family Obligations and Social Change. Polity Press: Cambridge.

Finch J, Groves D. (1983) A Labour of Love: Women, Work and Caring. Routledge, Kegan and Paul: London.

Finch J, Groves D. (1980) Community care and the family: a case for equal opportunities? *Journal of Social Policy,* **9,** 487-511.

Folkman S, Lazarus RS. (1980) An analysis of coping in a middle-aged community sample. *Journal of Health and Social Behaviour,* **21,** 219-239.

Gallio G, Giannichedda MG. (1982) Note per la lettura del modulo organizzativo dei servizi psichiatrici a Trieste. In, Psichiatria Senza Manicomio. Epidemiologia Critica della Riforma, D De Salvia, P Crepet (Eds). Feltrinelli: Milano.

Giannichedda MG. (1989) "A normality for us without confinement for them": Notes on the associations of families of the mentally ill. *International Journal of Social Psychiatry,* **35,** 62-69.

Gibbons JS, Horn SM, Powell JM, Gibbons JL. (1984) Schizophrenic patients and their families: a survey in a psychiatric service based on a DGH unit. *British Journal of Psychiatry,* **144,** 70-77.

Giel R, de Arango MV, Hafeiz Babikir A, Bonifacio M et al (1983) The burden of mental illness on the family: results of observations in four developing countries. *Acta Psychiatrica Scandinavica,* **68,** 186-201.

Gilhooly MLM. (1984) The impact of care-giving on care-givers: factors associated with the psychological well-being of people supporting a dementing relative in the community. *British Journal of Medical Psychology,* **57,** 35-44.

Gilleard CJ. (1987) Influence of emotional distress among supporter on the outcome of psychogeriatric day care. *British Journal of Psychiatry,* **150,** 219-223.

Gillian C. (1982) In a Different Voice: Psychological Theory and Women's Development. Harvard University Press: Cambridge, Mass.

Glendinning C. (1989) The Financial Needs and Circumstances of Informal Carers: Final Report. Social Policy Research Unit, University of York.

Goffman E. (1961) Asylums: Essays on the Social Situation of Mental Patients and Other Inmates. Doubleday: New York.

Goldman HH. (1982) Mental illness and family burden: a public health perspective. *Hospital and Community Psychiatry*, **33**, 557-560.

Golini A. (1988) Profilo demografico della famiglia italiana. In, La Famiglia Italiana Dall'Ottocento a Oggi, P Melograni (in collaboration with L Scaraffia) (Ed), pp.328-381. Laterza: Bari.

Goodwin S. (1989) Community care for the mentally ill in England and Wales: myths, assumptions and reality. *Journal of Social Policy*, **18**, 27-52.

Goodwin S. (1993) Community Care and the Future of Mental Health Service Provision. Avebury: Hants.

Grad J, Sainsbury P. (1963) Mental illness and the family. *Lancet*, i, 544-547.

Grad J, Sainsbury P. (1968) The effects that patients have on their families in a community-care and a control psychiatric service: a two year follow-up. *British Journal of Psychiatry*, **114**, 265-278.

Graham H. (1983) Caring: A labour of love. In, A Labour of Love: Women, Work and Caring, J Finch, D Groves (Eds), pp.13-30. Routledge, Kegan and Paul: London.

Graham H. (1991) The informal sector of welfare: A crisis in caring? *Social Science and Medicine*, **32**, 507-515.

Green H. (1988) Informal Carers: General Household Survey 1985. HMSO: London.

Greenley JR. (1979) Family symptom tolerance and rehospitalization experiences of psychiatric patients. In, Research in Community Mental Health, Vol 1,. RG Simmons (Ed). JAI Press: Greenwich, Conn.

Ham C. (1992) Health Policy in Britain. (3rd edition) Macmillan: Bastingstoke.

Hanson JG, Rapp CA. (1992) Families' perceptions of community mental health programs for their relatives with a severe mental illness. *Community Mental Health Journal*, **28**, 181-197.

Harris O. (1985) Households as natural units. In, Subjectivity and Social Relations. V Beechey, J Donald (Eds), pp.121-133. Open University Press: Milton Keynes.

Higgins J. (1981) States of Welfare: Comparative Analysis in Social Policy. Basil Blackwell: Oxford.

Hoenig J (1968) The de-segregation of the psychiatric patient. *Proceedings of the Royal Society of Medicine*, **61**, 115-120.

Hoenig J, Hamilton MW. (1967) The burden on the household in an extramural psychiatric service. In, New Aspects of the Mental Health Services, H Freeman, J Farndale (Eds), pp.612-635. Pergamon: London.

Hogarthy GE, Anderson CM, Reiss DJ, Kornblith SJ et al. (1986) Family psychoeducation, social skills training, and maintenance chemotherapy in the aftercare treatment of schizophrenia. *Archives of General Psychiatry*, **43**, 633-642.

Hoult J. (1986) Community care of the acutely mentally ill. *British Journal of Psychiatry*, **149**, 137-144.

Hoult J, Reynolds I. (1984) Schizophrenia: a comparative trial of community oriented and hospital oriented psychiatric care. *Acta Psychiatrica Scandinavica*, **69**, 359-372.

Hudson B. (1991) A policy for care - or for chaos? *Health Service Journal*, **101**, 30-31.

Iacono WG, Beiser M. (1992) Are males more likely than females to develop schizophrenia? *American Journal of Psychiatry*, **149**, 1070-1074.

Istituto Centrale di Statistica (ISTAT). Annuario Statistico Italiano, (1964-1987). ISTAT: Roma.

Johnstone EC, Owens DGC, Gold A, Crow TJ, MacMillan JF. (1984) Schizophrenic patients discharged from hospital - a follow-up study. *British Journal of Psychiatry*, **145**, 586-590.

Jones K. (1988) Experience in Mental Health: Community Care and Social Policy. Sage: London.

Jones K, Poletti A. (1985) Understanding the Italian experience. *British Journal of Psychiatry*, **146**, 341-347.

Judge K. (1982) The growth and decline of social expenditure. In: Walker A (Ed) Public Expenditure and Social Policy. Heinemann: London.

Kanter JK, Lamb HR, Loeper C. (1987) Expressed emotion in families: a critical review. *Hospital and Community Psychiatry*, **38**, 374-380.

Kingsley S. (1993) Managing change in mental health services: lessons from implementation. *Journal of Mental Health*, **2**, 295-304.

Kreisman D, Joy V. (1974) Family response to the mental illness of a relative: a review of the literature. *Schizophrenia Bulletin*, **10**, 34-57.

Kuipers L. (1992) Expressed emotion research in Europe. *British Journal of Clinical Psychology*, **31**, 429-443.

LABOS. (1987) Inchiesta sui servizi psichiatrici Italiani a 31.12.1984: Varie tipologie dei servizi. Lettura al meeting 'Valuatazione dei servizi psichiatrici', Arezzo, 1-4 giugno.

Land H. (1978) Who cares for the family? *Journal of Social Policy*, **7**, 257-284.

Land J, Rose H. (1985) Compulsory altruism for some or an altruistic society for all? Conference Paper: Comparative Aspects of Gender Divisions and Community Care. April 15th-17th, University of Kent at Canterbury.

Lavender A, Holloway F (Eds)(1988) Community Care in Practice: Services for the Continuing Care Client. John Wiley and Sons: Chichester.

Leff JP, Vaughn CE. (1985) Expressed Emotion in Families: Its Significance for Mental Illness. Guildford Press: London.

Leff J, Kuipers, Berkowitz R, Eberlein-Vries R, Sturgeon D. (1982) A controlled trial of social intervention in the families of schizophenic patients. *British Journal of Psychiatry*, **141**, 121-134.

Leff J, Kuipers, Berkowitz R, Sturgeon D. (1985) A controlled trial of social intervention in the families of schizophenic patients: two year follow-up. *British Journal of Psychiatry*, **146**, 594-600.

Lefley HP. (1987) Aging parents as caregivers of mentally ill adult children: an emerging social problem. *Hospital and Community Psychiatry*, **38**, 1063-1070.

Lesage AD, Pollini D. (1989) A new schedule to assess relatives satisfaction with psychiatric services: preliminary results on a sample of relatives living with a mentally retarded young adult. *New Trends in Experimental and Clinical Psychiatry*, **V**, 151-159.

Lesage AD, Tansella M. (1993) Comprehensive community care without long stay beds in mental hospitals: trends from an Italian good practice area. *Canadian Journal of Psychiatry*, **38**, 187-194.

Levin E, Sinclair I, Gorbach P. (1983) The supporters of confused elderly persons at home. National Institute of Social Work.

Lewis J, Meredith D. (1988) Daughters Who Care: Daughters Caring for Mothers at Home. Routledge, Kegan and Paul: London.

Livi Bacci M. (1977) History of Italian Fertility During the Last Two Centuries. Princeton University Press: Princeton, New Jersey.

MacCarthy B. (1988) The role of relatives. In, Community Care in Practise, A Lavender, F Holloway (Eds), pp.207-227. John Wiley and Sons: London.

MacCarthy B, Kuipers L, Hurry J, Harper R, LeSage A. (1989a) Counselling the relatives of the long-term adult mentally ill: I. Evaluation of the impact on relatives and patients. *British Journal of Psychiatry*, **154**, 768-775.

MacCarthy B, LeSage A, Brewin CR, Brugha TS, Mangen S, Wing JK. (1989b) Needs for care among the relatives of long-term users of day care. *Psychological Medicine*, **19**, 725-736.

Maj M. (1985) Brief history of Italian psychiatric legislation from 1904 to the 1978 Reform Act. *Acta Psychiatrica Scandinavica*, **Suppl.316**, 15-25.

Mandlebrote B, Folkard S. (1961) Some factors related to outcome and soical adjustment in schizophrenia. *Acta Psychiatrica Scandinavica*, **37**, 223-235.

Mangen S. (1989) The politics of reform: origins and enactment of the Italian experience. *International Journal of Social Psychiatry*, **35**, 7-19.

Marcolin MA. (1991) The prognosis of schizophrenia across cultures. *Ethnic Disorders*, **1**, 99-104.

Martini P, Cecchini M, Corlito G, D'Arco A, Nascimbeni P. (1985) A model of a single comprehensive mental health service for a catchment area: a community alternative to hospitalization. *Acta Psychiatrica Scandinavica*, **Suppl.71**, 95-120.

Martino A. (1986) Italian lessons on the welfare state. *Economic Affairs*, Jun-July 18-25.

Maurin JT, Boyd CB. (1990) Burden of mental illness on the family: a critical review. *Archives of Psychiatric Nursing*, **IV**, 99-107.

McCarthy M. (1985) Psychiatric care in Italy: evidence and assertion. *Hospital and Health Services Review*, **Nov**, 278-280.

McCreadie RG, Phillips K, Harvey JA, Waldron G et al. (1991) The Nithsdale schizophrenic surveys. VIII: do relatives want family intervention - and does it help? *British Journal of Psychiatry*, **158**, 110-113.

McCreadie RG, Robertson LJ, Hall DJ, Berry I. (1993) The Nithsdale schizophrenia surveys. XI: Relatives' expressed emotion. Stability over five years and its relation to relapse. *British Journal of Psychiatry*, **162**, 393-397.

McCreadie RG, Wiles DH, Moore JW, Frant SM, et al. (1987) The Scottish first episode schizophrenia study: IV. Psychiatric and social impact on relatives. *British Journal of Psychiatry*, **150**, 340-344.

McIntosh M. (1979) The welfare state and the needs of the dependent family. In, Fit Work for Women, S Burman (Ed), pp.153-172. Croom Helm: London.

Mezzina R, Mazzuia P, Vidoni D, Impagnatiello M. (1992) Networking consumers' participation in a community mental health service: mutual support groups, 'citizenship' and coping strategies. *International Journal of Social Psychiatry*, **38**, 68-73.

Mignolli G, Fiorio R, Faccincani C, Tansella M. (1984) Lungodegenza e lungoassistenza a Verona-Sud quattro anni dopo la riforma psichiatrica. *Rivista di Psichiatria*, **19**, 97-114.

Moos RH, Billings AG. (1982) Conceptualizing and measuring coping resources and processes. In, Handbook of Stress: Theoretical and Clinical Aspectsm L Goldberger, S Brenizt (Eds), pp.212-230. New York: MacMillan.

Morris J. (1991/1992) 'Us' and 'them'? Feminist research, community care and disability. *Critical Social Policy*, **11**, 22-39.

Mosher LR. (1982) Italy's revolutionary mental health law: an assessment. *American Journal of Psychiatry*, **139**, 199-203.

Mosher LR, Burti L. (1989) Community Mental Health: Principles and Practice. Norton: New York.

Muijen M, Marks I, Connolly J, Audini B. (1992) Home based care and standard hospital care for patients with severe mental illness: a randomised controlled trial. *British Medical Journal*, **304**, 749-754.

Namyslowska I. (1986) Social and emotional adaptation of the families of schizophrenic patients. *Family Systems Medicine*, **4**, 398-407.

New RS, Benigni L. (1987) Italian fathers and infants: cultural constraints on paternal behavior. In, The Father's Role: Cross Cultural Perspectives, Lamb ME (Ed), pp.139-167. Lawrence Erlbaum: New Jersey.

Noh S, Turner RJ. (1987) Living with psychiatric patients: implications for the mental health of family members. *Social Science and Medicine*, **25**, 263-271.

Noh S, Avison WR. (1988) Spouses of discharged patients: factors associated with their experience of burden. *Journal of Marriage and the Family*, **50**, 377-389.

Nolan MR, Grant G, Ellis NC. (1990) Stress is in the eye of the beholder: reconceptualizing the measurement of carer burden. *Journal of Advanced Nursing*, **15**, 544-555.

Ongaro-Basaglia F. (1989) The psychiatric reform in Italy: Summing up and looking ahead. *International Journal of Social Psychiatry*, **35**, 90-97.

Ongaro-Basaglia F. (1992) Politics and mental health II. *International Journal of Social Psychiatry*, **38**, 36-39.

Pai S, Kapur RL. (1981) The burden on the family of a psychiatric patient: development of an interview schedule. *British Journal of Psychiatry*, **138**, 332-335.

Parker G. (1989) A Study of Non-Elderly Spouse Carers: Final Report. Social Policy Research Unit, University of York.

Parker G. (1990) With Due Care and Attention: A Review of Research on Informal Care. Family Policy Studies Centre: London.

Parker R. (1981) Tending and social policy. In, A New Look at the Personal Social

Services, ME Goldberg, S Hatch (Eds), pp.17-34. Discussion Paper 4, Policy Studies Institute: London.

Paykel ES, Mangen S, Griffith JH, Burns TP. (1982) Community psychiatric nursing for neurotic patients: a controlled trial. British Journal of Psychiatry, **140**, 573-581.

Payne RL, Jones JG. (1987) Measurement and methodological issues in social support. In, Stress and Health: Issues in Research Methodology. SV Kasl, CL Cooper (Eds). Wiley: Chichester.

Pearlin LI, Schooler C. (1978) The structure of coping. *Journal of Health and Social Behaviour*, **19**, 2-21.

Perring C, Twigg J, Atkin K. (1990) Families Caring for People Diagnosed as Mentally Ill: The Literature Re-Examined. HMSO: London.

Pinker R. (1992) Making sense of the mixed economy of welfare. *Social Policy and Administration*, **26**, 273-284.

Pirella A. (1987) The implementation of the Italian psychiatric reform in a large conurbation. *International Journal of Social Psychiatry*, **33**, 119-131.

Platt S, Hirsch S. (1981) The effects of brief hospitalization upon the psychiatric patient's household. *Acta Psychiatrica Scandinavica*, **64**, 199-216.

Platt S, Hirsch S, Weyman A. (1983) Social Behaviour Assessment Schedule. Windsor: NFER-Nelson.

Platt S (1985) Measuring the burden of psychiatric illness on the family: an evaluation of some rating scales. *Psychological Medicine*, **15**, 383-393.

Ponzini G. (1993) Recent developments of welfare policies in Italy. Conference Paper: Comparative Research on Welfare States in Transition. 9th-12th September, Oxford.

Poster M. (1978) Critical Theory of the Family. Pluto Press: New York.

Ramon S. (1984) Reforming psychiatry lessons from Italy. *Medicine and Society*, **10**, 39-48.

Ramon S, Giannichedda MG (Eds) (1988) Psychiatry in Transition: The British and the Italian Experiences. Pluto Press: London.

Rogers A, Pilgrim D. (1987) Mental health reforms: some contrasts between Britain and Italy. *Free Associations*, **6**, 65-79.

Rogler L, Hollingshead A. (1965) Trapped: Families and Schizophrenia. Wiley: New York.

Rossetti M. (1987) La condizione delle famiglia italiano prima e dopo la legge 10. In, Psichiatria, tossicodipendenza, perizia. Ricerca su forme di tutela, diritti, modelli di servizia, MG Giannichedda, F Ongaro-Basaglia (Eds). P. Angeli: Milano.

Rutter M, Brown GW. (1966) The reliability and validity of measures of family life and relationships in families containing a psychiatric patient. *Social Psychiatry*, **1**, 38-53.

Samele C, Bologna C. (1991) Italian psychiatric care in the post 1978 reform era: difficulties, dilemmas and future directions. In, Mental Health Services in the Global Village, L Appleby and R Araya (Eds), pp.35-53. Gaskell: London.

Saraceno C. (1984) Shifts in public and private boundaries: women as mothers and service workers in Italian daycare. *Feminist Studies*, **10**, 7-29.

Scheper-Hughes N, Lovell A. (1986) Breaking the circuit of social control: lessons in public psychiatry from Italy and Franco Basaglia. *Social Science and Medicine*, **23**, 159-178.

Scheyett A. (1990) the oppression of caring: women caregivers of relatives with mental illness. *Affilia*, **5**, 32-48.

Shaw MC, Halliday PH. (1992) The family, crisis and chronic illness: an evolutionary model. *Journal of Advanced Nursing*, **17**, 537-543.

Soccorsi S. (1985) The impact of Law 180 on the family. *International Journal of Mental Health*, **14**, 149-154.

Sommer R, Osmond N. (1984) The schizophrenic no-society revisited. *Psychiatry*, **47**, 181-191.

Spiegel D (1983) Mothering, fathering and mental illness. In, Rethinking the Family, B Thorne, M Yalom (Eds), pp.95-110. Longman: New York.

St Leger F. (1992) Informal welfare: policy debate and sociological reality 1979-1991. In, Social Policy Review 4, N Manning, R Page (Eds), pp.48-69. Social Policy Association: London.

St Leger F, Gillespie N. (1991) Informal Welfare in Belfast: Caring Communities? Gower: Aldershot.

Tagliavini A. (1985) Aspects of the history of psychiatry in Italy in the second half of the nineteenth century. In, The Anatomy of Madness: Essays in the History of Psychiatry: Volume II, Institutions and Society, WF Bynum, R Porter and M Shepherd (Eds), pp.175-196. Tavistock: New York.

Tansella M, De Salvia D. (1987) Case registers in comprehensive community psychiatric service ares in Italy. In, Psychiatric Case Registers in Public Health. A

Worldwide Inventory 1960-1985, GHMM ten Horn, R Giel, Gulbinat (Eds). Elsevier: Amsterdam.

Tansella M, De Salvia D, Williams P. (1987) The Italian psychiatric reform: some quantitative evidence. *Social Psychiatry*, **22**, 37-48.

Tansella M, Williams P. (1987) The Italian experience and its implications. *Psychological Medicine*, **17**, 283-289.

Test MA, Stein LI. (1980) Alternative to mental hospital treatment: III, Social cost. *Archives of General Psychiatry*, **37**, 409-412.

Thompson EH, Doll W. (1982) The burden of families coping with the mentally ill: an invisible crisis. *Family Relations: Journal of Applied Family and Child Studies*, **35**, 379-388.

Thurer S. (1983) Deinstitutionalization and women: where the buck stops. *Hospital and Community Psychiatry*, **34**, 1162-1164.

Titterton M (1989) The Management of Personal Welfare. Unpublished MS: Department of Social Administration and Social Work, University of Glasgow.

Townsend P. (1962) The Last Refuge. Routledge, Kegan and Paul: London.

Twigg J. (1989) Models of carers: how do social care agencies conceptualise their relationship with informal carers? *Journal of Social Policy*, **18**, 53-66.

Twigg J, Atkin K, Perring C. (1990) Carers and Services: A Review of Research. HMSO: London.

Ungerson C. (1983) Women and caring: Skills, tasks and taboos. In, The Public and the Private, E Gamarnikow, D Morgan, J Purvis, D Taylorson (Eds), pp.62-77. Heinemann: London.

Ungerson C. (1985) Gender divisions and community care - A British perspective. Conference Paper: Comparative Aspects of Gender Divisions and Community Care. April 15th-17th University of Kent at Canterbury.

Ungerson C. (1987) Policy is Personal: Sex, Gender and Informal Care. Tavistock: London.

Ungerson C. (1990) The language of care: Crossing the boundaries. In, Gender and Caring: Work and Welfare in Britain and Scandinavia, C Ungerson (Ed), pp.8-33. Harvester: London.

Vaughn CE. (1977) Patterns of interactions in families of schizophrenics. In, Schizophrenia: The Other Side, H Katschnig (Ed). Urban and Schwarzenberg: Vienna.

Vaughn CE, Leff JP (1976) The influence of family and social factors on the course of psychiatric illness: a comparison of schizophrenic and depressed neurotic patients. *British Journal of Psychiatry*, **129**, 125-137.

Vicente B, Vielma M, Jenner FA, Mezzina R, Lliapas I. (1993) Users' satisfaction with mental health services. *International Journal of Social Psychiatry*, **39**, 121-130.

Walker A, Qureshi H. (1989) The Caring Relationship. MacMillan: Basingstoke.

Wallston BS, Alagna GW, DeVellis B, DeVellis RF. (1983) Social support and physical health. *Health Psychology*, **2**, 367-391.

Washburn S, Vannicelli M, Longabaugh R et al (1976) A controlled comparison of psychiatric day treatment and inpatient hospitalization. *Journal of Consulting and Clinical Psychology*, **44**, 665-675.

Wenger CG. (1985) Dependence, independence and reciprocity after eighty. Conference Paper: Comparative Aspects of Gender Divisions and Community Care. April 15th-17th University of Kent at Canterbury.

Wilkin D. (1979) Caring for the Mentally Handicapped Child. Croom Helm: London.

Wilson E. (1977) Women and the Welfare State. Tavistock: London.

World Health Organization. (1978) Mental disorders: Glossary and guide to their classification in accordance with the Ninth Revision of the International Classification of Diseases. World Health Organization: Geneva.

Wynne L, Ryckoff I, Day J, Hirsch S. (1968) Pseudo-mutuality in the family relations of schizophrenics. In, The Psychosocial Interior of the Family: A Sourcebook for the Study of Whole Families, G Handel (Ed), pp.443-468. Allen and Unwin: London.

Zimmerman-Tansella Ch, Donini S, Galvan U, Rizzetto A, Turrina C, Siciliani O, Wilkinson G. (1993) Social support, adversites and emotional distress in an Italian community sample. *Journal of Clinical Epidemiology*, **46**, 65-75.

Zimmerman-Tansella Ch, Burti L, Faccincani C, Garzotto N, Siciliani O, Tansella M. (1985) Bringing into action the psychiatric reform in South-Verona. A five year experience. *Acta Psychiatrica Scandinavia*, **Suppl.316**, 71-86.