

CHRONIC MENTAL ILLNESS
AND IT'S EFFECTS ON
THE PORTUGUESE FAMILY.

by

DEBORAH WENHAM.

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School of Community Health
Faculty of Health Sciences
The University of Sydney

Adviser's Signature.....

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I certify that it has not been submitted, in part or whole, for a higher degree in any other university and/or institution.

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ABSTRACT.

Australian studies have indicated that NESB mentally ill live with and are cared for by their families to a much greater degree than the ESB host community.

The possibilities for interaction between migration stressors and the stressors associated with caring for a mentally ill person, have health and quality of life implications for NESB carers and mentally ill. So far the experiences of NESB carers have received little research.

This study is a qualitative evaluation of the experiences of four Portuguese families caring for a person with a chronic psychotic illness. In depth interviews of both carers and Health workers working with Portuguese carers and clients were used to reveal aspects of carer experience such as Migration, Leisure, and Knowledge of Mental illness.

The study concluded that the Portuguese carers and mentally ill have been successful migrants who have achieved what they came here to do. The Portuguese women were found to be the major providers of care to the mentally ill and their experiences appear to parallel those of other NESB and ESB carers of the mentally ill or other chronically ill or disabled persons.

For two carers however the personal cost of caring was very high. The negativity of their experience can be directly attributed to the cultural factors of male alcoholism and domestic violence which appear to be endemic in Portuguese communities.

The client directed orientation of mental health servicing whereby the expertise and/ or the difficulties of carers and their children are not assessed or incorporated in care planning was also found to contribute directly to carer burden.

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CHAPETER ONE

INTRODUCTION AND LITERATURE REVIEW

Cultural and linguistic diversity is a major challenge for Australia's Community mental health services. Minas (1990) describes Australia's mental health systems as mono lingual and monocultural, with a " dearth of assessment and treatment programs designed to meet the needs of N.E.S.B. groups." (Minas, 1990, cited in Reid and Trompf, 1990 p250.)

Most Australian research concerning the mental health of Australia's migrants emphasize the special mental health needs of NESB people and lack of appropriate research done on these needs. (Minas, 1991, 1990; Mcdonald, 1991).

Although there is a considerable body of published work concerned with the migrant experience in Australia, the majority of papers focus on migrant history, physical health, social welfare, labour issues, and biography.(Reid, et.al. 1990, Liffman, 1987; Kalisperis, 1986; Morrissey, 1980, 1984).

Australian Studies researching incidence, prevalence , treatment and service provision for mentally ill migrants with major psychoses not numerous. The majority of reports and papers concerning the mental health of Australia's

Migrants focus on Victorian Ethnic Communities. These papers appear to be primarily concerned with issues of health policy, service planning and delivery for Psychiatrically ill

Work relating to mental illness issues in specific communities, (Chiu, et al., 1988), and utilization rates. (Krupinski, et al., 1965;1973; 1986).

Reports and papers from studies conducted in the NSW Mental Health System are mainly concerned with NESB utilization rates of psychiatric inpatient units. (Mcdonald,1991; Kraus,1969, a,b); (Yusuf,F, et al., 1984).

Torture and trauma of refugees, (Reid et al., 1987; 1988) or small studies of specific ethnic groups or geographical areas within the state.(Sanzone, 1991; Senuik et al., 1987). There are a few papers from other states. e.g. (Burvill et al., 1982).

Economically major mental illnesses like Schizophrenia, are extremely expensive diseases in that their onset in Western countries usually occurs in early adulthood. The majority of cases are diagnosed between the ages of 15 and 45 with a median age of 30 years. (Andrews, 1984, p19). Individuals with chronic major mental illness tend to become episodically or continually dependent on society, or family members, when they would usually be self supporting and active financial and social contributors to their families and communities. (Torrey, 1983, p3).

Prevalence rates for schizophrenia alone in industrialised nations average 2 - 4 per 1000 persons. (Torrey(1983) pp197-206). In Australia Schizophrenia is estimated to effect 1 in 200 Australians. (Andrews, 1984, p.1).

Cross cultural epidemiological studies have shown Prevalence rates for major mental illness to be similar, between different cultures, but illness outcomes differed. On average 26% of suffers of major mental illness recover well and return to normal life. 56% need life long medication and support to cope in their communities, and 12% were continually too ill to cope.

(Ming Lin, et al.,1988).

Fadden, et al., in their review of family studies noted that 50% of psychiatric patients remain in contact with relatives life long. (1987, p285.). More significantly they and other authors of similar reviews, e.g. Macarthy et al.,(1989) and Smith, et al., (1990) have acknowledged the lack of recognition and support for the contribution made by families, and the degree of burden they carry.

The studies also showed that 50% to 70 % of Families reported extensive stress. e.g." The divorce rate for couples if one had mental illness was four times greater than the general population". Social isolation, curtailment of leisure activities, and financial disturbance, were also shown to be common place experiences for these carers.

The following observations were commonly found or referred to in most of the Australian research. The two primary observations were that NESB mentally ill under utilized mental health services, and that the family played a greater role in the care of the mentally ill.

McDonald (1991) profiled NESB clients in a NSW Psychiatric hospital and found that NESB patients were more likely to be married and be living with their family. Less likely to be employed or on benefits, and more likely to have been aggressive or violent towards a family member prior to admission, conveyed to hospital by the police and to be made an involuntary patient more often.

Resistance to help seeking due to the stigma and shame associated with mental illness, as well as use of traditional health practices and practitioners are also mentioned as commonplace factors influencing help seeking behaviour of NESB persons. All of the above, have potentially negative implications for the quality of life of NESB carers, and the mentally ill they care for.

Studies concerning the experience of these carers are few. "Who Cares?: The Health and Well Being of women who are carers." (1993), a report for the NSW Women's Advisory Council concluded that there was little research in the area of ethnic carers. What papers there were indicated that NESB carers had health problems and had inadequate support services.

Alcorso and Schofield, (unpublished.) in their study of disability and NESB women clearly identify these women as disadvantaged in their role of carers for disabled spouses, relatives, and children. Several Authors describe Service provision for NESB Carers as usually inaccessible, culturally inappropriate, and unavailable. NESB psychiatric clients and carers utilize Mental Health Services much less than the host community. (Morrissey, 1984; Liffman, 1981; McDonald, 1991; Kalisperis, et al.,)

Schofield,(1990) in her paper on The N.E.S.B carers of disabled persons, named pain, both physical and mental, poverty, and isolation from both their own community and the greater community as the predominant experience of such persons. NESB women were shown to be particularly affected due to the traditional care giving role ascribed to women. (Schofield, in Reid et al., 1990 p 288-309.)

The possibilities for interaction between migration stressors and the stressors associated with caring for a mentally ill person, have health and quality of life implications for both NESB carers and mentally ill.

The greater degree of NESB family care of the mentally ill. The often reported diminution of the quality of life for NESB carers, and the reported inadequacy of support servicing and paucity of research into their experiences, have motivated this investigation. The Project is titled 'Chronic Mental Illness and it's Effects on the Portuguese Family' and it seeks to address in a small way the lack of research in the

area of Chronic mental illness and its effects on NESB families. The project involved a survey of Portuguese carers, living with a person suffering from major psychoses, and health workers whose professional roles required involvement and contact with Portuguese mentally ill persons and their families.

CHAPTER TWO: AIMS AND METHODS

AIMS OF THE RESEARCH

In order to document the experiences of the Portuguese Carers, the study had as it's primary aim:

a. To evaluate the experience of Portuguese persons, caring for a family member or members with chronic mental illness.

Hopefully the results of this survey will provide an information base useful for persons either researching or providing mental health services to Portuguese and other NESB groups.

METHODS

Study Design

This study was not intended to make comparisons or propose hypotheses. A more personal view of carers experiences was sought.

A qualitative approach was selected on the following grounds: The aims of the project required the evaluation of an individual's experience of a particular phenomenon. The Project's area of interest had been subject to little previous research, and the sample size was extremely small.

The survey was done as a series of in-depth interviews with the carers of four Portuguese clients registered with a Community Mental Health Service in Central Sydney. The persons cared for were diagnosed as having a chronic psychotic illness. An interpreter as well as the interviewer was also present during the carer interviews. The interviews took place over five weeks in August and September 1993.

To add depth and further insights into the carer's experiences, four health workers whose work role required contact with Portuguese clients requiring adult mental health services were interviewed. The four files of the carers, relatives and an additional four files of Portuguese with similar diagnoses were also examined. Data from the Australian Bureau of Statistics and Central Sydney Community Health Information Systems was also used to provide information about the Portuguese community and Portuguese using community mental health services.

THE SUBJECTS

The Carers asked to participate in the study had to be eighteen years of age or over and their mentally ill relative had to be mentally well at the time of interview. Carer's known to the interviewer were excluded, and where possible, clients and carers well known to the interpreter.

A total number of six carers agreed to be interviewed. They were two wives and one husband. The other three belonged in a dual family group sharing one large residence. They were the sister, brother in law and niece of the client. All except one woman were interviewed in their homes. The Carer's median age was 49 years, with a range of 21 to 52 years. The niece was the only unmarried carer interviewed.

Two carers had no formal education. Three carers had 3 - 5 years of primary education and one had a NSW Leaving Certificate.

Three carers needed interpreting when being interviewed. The others did not have any difficulty expressing themselves and the interpreter or the Australian born carer only had to clarify or restate a question occasionally.

The Regions of Portugal the carers came from were the Madeira Islands (2), Southern Portugal (1), Central Portugal (2), and Australia (1).

The carers had had no criminal charges made against them nor had they made any compensation claims.

ADDITIONAL INFORMANTS AND FILE INFORMATION

The Health Workers

The health workers were contacted and interviewed by the investigator only. The Health workers were selected from willing participants from Adult Mental Health and Crisis team staff, and the Health Care Interpreter Service. They were asked questions directly relating to their experience as professional carers in addition to answering the same questions presented to the carers.

The four workers were women. Three were bi-lingual and one spoke english only. They had 4, 7, 14, and 15 years of experience working with the Portuguese Community.

Two workers were social workers. One was bilingual and worked in Adult Mental Health. The other spoke english only and worked with a Crisis Team. The other two were Portuguese Interpreters with the Health Care Interpreter Service.

The Interpreter's case load was 100% Portuguese. The bi-lingual social worker's case load was 98% Portuguese and the English speaker believed 1% of the clients she saw were Portuguese.

The bi-lingual Social Worker saw most of her clients in her office, while the Crisis Team worker and the Interpreters worked in private dwellings, Offices, Hospitals, and Health centres. The crisis worker visited sites outside of the public health arena the most.

The Social Worker in the Crisis Team usually saw clients for two weeks . The bi- lingual Social Worker supported clients on a case by case basis and her involvement varied from months to years. The clients from the files had mostly community ESB Mental Health Nurses as Case Managers.

Collectively the workers provided the following services Assessment, Community treatment, Support, Counseling, Practical assistance, Education, Referral, Interpreting, Translation, Facilitation of women's and pensioner health and recreation groups, Intake services, Staff education, and Radio programs.

The Files

The client files selected for the study had the following inclusion criteria namely: Current registration, a diagnosis of psychotic illness, a primary case manager either with the crisis or adult mental health team, and their current medication being reviewed and/or prescribed by the centre's Psychiatrist or Registrar.

SURVEY FORMAT

Because of the small number of carers and health workers to be interviewed the amount of information was maximised by the construction of a long questionnaire covering several areas

of carer experience. The questionnaire had an initial section where basic demographic information e.g. Age, sex, and occupation, was requested. The remainder of the questions were divided into the following sections.

Employment and Finances: Migration: Family composition: History of Caring: Carer's Leisure: Services Performed by Carers: Coping: Carer's Health: Help Seeking: Interpreting: Treatment Experience: Treatment Preferences: Mental Illness Beliefs: Knowledge of Mental Illness: Informing Carers: Comprehension of Information: Problem Behaviours: Medication: Carer's Long Term Concerns: Services Used: Suggestions From Carers. Health workers were asked additional questions which referred directly to their experience as health service providers.

Other factors governing the construction of the questionnaire, were the use of simple words and short questions, to promote ease of interpretation from English to Portuguese. A draft of the questionnaire was shown to two Portuguese speaking health workers who checked it for ease of translation, and cultural insensitivity. The workers advice was also sought in regard to administering the questionnaire. The final form of the questionnaire is contained in Appendix 8 p 81.

The carers were contacted with the assistance of the Portuguese speaking Bi - Lingual counsellor working at the health centre. The clients were initially contacted in Portuguese by telephone and the purpose and means of the study and the participants rights to withdraw, and to

confidentiality were explained to them. Carers agreeing to be interviewed could chose the place and time for their interview. The same counsellor later assisted the investigator by acting as an interpreter and observer during the carer interviews. At the commencement of each interview, the Information Letter and a Consent form were translated for the Carers. An example of the Information Letter can be found in Appendix F page 80.

The respondents answers were recorded in writing by the interviewer. Any overtly identifying information was not written on response forms or collected from files.

CHAPTER THREE:

RESULTS FROM CENSUS AND COMMUNITY MENTAL HEALTH SERVICES

The Carer's Community

The Portuguese community selected for the study resides in the Marrickville Local Government Area. According to the Australian bureau of statistics 1991 Census data, 46.5%, (11918) of persons from a Portuguese speaking birthplace in Australia were living in Sydney. 32% (3813) were residents of the Marrickville LGA. The Community increased by only 200 between 1986 and 1991 and is the third largest NESB group and the second largest Southern European NESB group in the LGA. According to 1986 Census figures an additional 14% of NSW Portuguese speakers lived in the adjoining suburbs of bordering LGA's. (Luckey et al., 1990, p3).

Where Carers Lived

The Marrickville Local Government Area is an Inner Western Municipality of Sydney. The LGA is high density mixture of Industrial and residential sites crossed by major roads and rail lines, with half the suburbs affected by the flight paths of Sydney Airport. Closeness to the Central Business District and the age and architectural charm of residences have led to the increasing gentrification of some suburbs. However, the LGA is still one of Australia's poorest. The

municipality has above average proportions of low income families, (\leq \$15000); Pension and benefit recipients; and the unemployed. (ABS census 1986).

44.5 % (33359) of Marrickville residents were from a NESB Birthplace. Only three groups had population numbers \geq to 10% of the LGA's NESB residents. These were the Greeks 13.8%, Vietnamese 11.5% and Portuguese 11.4%. 128 different NESB birthplaces have been recorded by Marrickville residents.(ABS census 1991).

Portuguese using Community Mental Health Services

The data source for this summary was the Central Sydney Community Health Services Information Systems.

Between 1/7/92 and the 30/6/93 there were 52 Ethnic Portuguese registered with Adult Mental Health services of the Central Sydney Community Health Service. 92% or 48 of these people used services based in Marrickville.

98% of these people were born in Portugal not former Portuguese colonies. 86 % had Portuguese for their first and only language. While 90% spoke the language at home, only 14% had english as a second language. 42% of clients required an interpreter, even though a bi - lingual counsellor worked full time.

61% of the clients were Women, and 36.5% were between 19 and 40 with 46.2% between 40 and 60 years of age. Their ages ranged from 19 to 93 years.

23% were employed with one third working part time. 32% did unpaid work at home. Only 12% were unemployed and 28% relied on Social Security payments. 48% of workers were in semi or unskilled occupations.

73% of clients lived with their partners and/or dependents, and only 17% lived alone. 63.5 % were either married or defacto. 80.7% lived in the Marrickville LGA while 19.3% lived in adjoining LGAs.

63% of clients were newly registered within the previous 12 months, with 36.5% of clients being registered since 1978. Referrals were mainly from public hospitals 27%, or self or family referrals at 40.4%.

Marital conflict and domestic violence was the most often reported discrete presenting problem; (8.9%). Depression and Anxiety states were next with 31.2% of presenting problems. Only 14.5% (13) of the clients had a Psychosis of some form as a presenting problem. i.e. Schizophrenia (5.6%), Psychosis (5.6%) and Manic Depression (3.3%). Psycho- social problems were the major reason for referral. Alcohol related problems were only 5.6%.

The Portuguese born were the third largest NESB group registered with the Adult Mental Health and Crisis Teams. With the Crisis team they were third behind the Greeks (6%) and Vietnamese (4%) with 3 % of registrations. The Adult Mental Health Team registrations were 11% Vietnamese born, 7% Greek born, and 6% Portuguese born.

THE CLIENTS

Client based information was derived from eight files. Four of the files were the carer's relatives. Combined they made 61.5% or 8/13 of clients fitting the selection criteria. Five out of the eight were women. The mean age of the clients was 51 years with ages ranging from 45 - 57 years.

Three clients had no formal education, and the other five had 3 - 5 years of primary education. Five clients needed an interpreter. No clients had had criminal charges laid against them or had ever made compensation claims of any kind.

All the female clients were mothers, three were married, and one was separated. Two male clients were husbands and fathers. The third male was divorced and childless. Divorced or separated clients lived with either their sister's or daughter's families. Married couples mostly lived as single family units. However, two related couples in the study shared the same house. Five clients lived in their own home, one had a mortgage, and two lived in homes owned by the relative they lived with. They all spoke Portuguese at home.

Three female clients worked full or part time. Two were now unable to work but helped with house work and child minding. Both however worked until they became too ill to continue. Only one male worked full time, one had been recently retrenched and one was unable to work, but previously worked

full time. The clients either worked or had previously worked as cleaners, factory hands, or laboring.

Clients were supported at home by female relatives. e.g. their daughter, sister, wife, mother, or mother in law.

Seven of the clients had been originally referred to the centre by a Psychiatric hospital or unit and one via a General practitioner.

Six clients had a primary diagnosis of Schizophrenia, and two had a chronic serious Depression. They had been ill on average 12.5 years. (median = 12.5; range 2 - 23 years.)

As a group they were being prescribed the following drugs.

Antipsychotics. Fluphenazine decanoate / (Modicate(inj)); Haloperidol decanoate / (Haldol (inj)); Pimozide/ (Orap, oral); Thioridazine /(Melleril (oral)); Trifluoperizine / (Stelazine (oral)); Chlorpromazine /(Largactil,(oral)).

Anti- Parkinsonians;(i.e. for side effects). Benztropine /(Cogentin,(oral); Orphenadrine /(Disipal,(oral)).

Anti-depressants; Doxepin HCL / Sinequan or Deptran,(oral): Imipramine /(Tofranil,(oral)).

Other illnesses the client group had were Varicose veins; Cancer; Arthritis; Hypertension; Obesity; Spinal injury.

All clients had nominated a General Practitioner they saw.

CHAPTER FOUR:

RESULTS OF THE INTERVIEWS

Questions directed to Health Workers only

The bi-lingual workers believed they were advantaged in their work by having the language, and the ability to discern culturally inappropriate or incongruent speech, emotion and body language. Assessment was therefore quicker and more accurate.

The Disadvantages workers mentioned were, that their different social and educational background could make clients more concerned than usual about the impression they made. Client's perception of confidentiality was another. The clearest insight into the latter problem was given by the interpreter.

"Clients are not concerned about confidentiality, but feel embarrassed that a compatriot knows the family and the person has problems."

All the workers believed that projecting a professional image was important when assessing and engaging Portuguese clients.

"Professionals are regarded as 'people with studies' and are therefore expected to be knowledgeable in all things, mature, and a keeper of their secrets."

Workers were divided as to need to maintain a conservative appearance, but the ability to be firm, offer reassurance, and show respect through politeness was important.

"The Portuguese are usually very polite, almost business like and always offer drinks. They have a strong need to impress. Being offered home made food and drink means acceptance and expresses appreciation. A refusal can be felt as an insult to the house initially, or concern that they may have caused offense."

The Portuguese are polite but not austere.

"Portuguese do not like people with 'closed faces', such a person is respected out of politeness but they won't accept a thing they say."

Quick and effective practical assistance was definitely preferable to " talking about thoughts and emotions."

Workers were divided over the importance of staff being aware of regional differences. The bi-lingual social worker and an interpreter believed, Azoran or Madeira islanders and coastal Portuguese were more fatalistic and superstitious. Sudden and frequent death being a fact of life in fishing and seafaring communities. Urban people were more progressive and contemporary in outlook. Regions also had varying ambience and colloquial expressions. e.g. To be 'al Mareado', an expression used often by Algarvians, meaning , sea sick, or dizzy.

The workers believed there were gender differences in regard to manner and forthrightness. The Portuguese man is seen as more assertive, arrogant, and inclined to mask the truth. The women are more open, but very reticent and the family are more inclined to speak for her. Males were more comfortable with other males. Men could be difficult clients for female workers. The workers thought Portuguese males responded positively to male workers because asking for help for himself, and admitting difficulty to a woman was a 'sign of weakness'. The women were more accepting of male workers as long as physical contact was not involved. Gynecological issues especially are not a male domain.

EMPLOYMENT AND FINANCES

The male carers had full time work, and one wife worked part time. The niece was retrenched just prior to being interviewed. The other two women were fully occupied with unpaid work at home, but 1 made extra money by occasionally child minding in her home. The carers who worked, did cleaning, retail service, and plumbing.

The health workers thought that male and female carers would continue working in some capacity, in addition to caring. Only clients with severe disabilities became reliant on benefits. Neither health workers or carers thought caring for a mentally ill person caused financial difficulty for the families. Only one carer had been unable to work due to a

mentally ill family member, but she would like to, and still occasionally baby sat. Her husband was inordinately suspicious of her being away from the home, and she also had a young child.

MIGRATION

Most Carers and clients had family members in Sydney when they came. Two male carers preceded their families and two female carers came with their husband and/or child to no resident family. Most of the health workers believed carers and clients were sponsored by relatives.

All the clients and carers migrated for economic reasons. Other reasons given were, a better life for the children, better life style, building a home, and family reunion.

The health workers believed most immigrant Portuguese were of peasant background with little or no education. They immigrated for economic reasons to create opportunity for themselves and especially their children. Their priority on arrival is to work and buy a home. Their homes in Sydney imitate the more wealthy homes in Portugal.

The home reflects the success and social mobility of the family, and is the outward symbol of the Portuguese reverence for their culture and family life. The house represents the man's ability to provide, and the woman's prowess at home making. Portuguese homes are usually, very clean, extensively

renovated, with lots of tiles, polished floorboards and archways and usually a formal sitting room.

Embroidery (Madeiran particularly), Religious artifacts, especially our Lady of Fatima, Ornaments, Bottles of alcohol, and house plants decorated the rooms. Gardens are usually well tended with fruit trees, vegetables, herbs both culinary and medicinal, and flowers favored in Portugal. e.g. the Carnation.

Six of the eight clients became mentally ill after arriving in Australia. Two of the carer's relatives had their illness before they came. The majority of clients who became ill after arrival were well for at least 10 years. However the range of 2 to 20 years was extremely broad. The health workers believed most Portuguese migrants became ill after arrival and gave estimates varying from six months to ten years as the initial wellness period. They thought newcomers and women became ill earlier, and stated migration shock, isolation and work crises as precipitants.

The Portuguese health workers thought awareness of the class differences existing in Portugal when local residents migrated, was important for understanding them. However the Portugal that newcomers now leave has undergone considerable social change in the last 30 years. They believed newly arriving Portuguese were more educated, and sophisticated, and faced different challenges and problems e.g. Having professional qualifications not recognised, or experiencing a drop in their living standards.

FAMILY COMPOSITION

The Portuguese mentally ill usually live with their spouse and children. If not, they live with relatives, usually female kin. The average number in a household is five. Either an elderly parent or young children are the only other persons in the house needing care. Parents appear to produce only two or three well spaced children. An adolescent and a younger child living at home was common for all carers interviewed.

The health workers believed unanimously that the family had a powerful influence over the lives of mentally ill members, and that they suffered acute embarrassment, and subsequently hid problems. They usually tried Portuguese speaking G.p.s or traditional avenues e.g. prayers, witchcraft, natural healing, and home remedies before calling mental health specialists.

Because of the strength of the family bond the family will speak for the client, and discuss their condition as a unit, with older children included. The families co-operation is usually influential for treatment regimes to be accepted. Portuguese families tend to be very knowledgeable about the behaviour of their individual members.

Both health workers and carers said that the male head of household be they a carer or client had the right of veto in family decision making. This power had negative consequences for some families.

A female carer and client both complained of having to buy christmas presents, and extras for themselves and children from part time work or surreptitiously manipulating the house keeping money. One spouse was hyper vigilant, and penurious, the other refused to pay for domestic needs. Both men were alcoholic.

Final decisions about treatment were left to the ill person and their health carers unless the family thought the person was too unwell. If male, his spouse or eldest male relative would approve any treatment decisions.

The health workers differed as to who made the final decisions concerning the clients care. One believed the health team did, others believed the spouse, eldest child or the relative most directly involved with the clients care.

The Portuguese workers believed clients spoke for themselves if they were able to. If the family believed the client was too sick, they would speak for them, and there was a tendency to make a person seem worse than they are. The english speaker believed the Portuguese family did not volunteer much at all, and tended to tell the health worker what they wanted the worker to hear.

"The family does the person in but won't speak for them."

HISTORY OF CARING

Carers had been living with and looking after their mentally ill relatives for 2, 8, 11, and 20 years. For three carers, their duty as a wife or husband, was the reason they became carers. The other three carers from the extended family saw caring as a family duty.

The Health workers believed it was shameful for the Portuguese not to care for ill family members. It was the customary duty of the spouse, or the female kin of the ill person to care for them, if a spouse couldn't. Men would cook, provide transport or supervise the children. Daughters or female relatives ran the house, if the wife was ill.

The women carers in the study received little help when the person they cared for was ill. The two wives who migrated with their husband only had no help and felt very alone, their life just became harder.

The male carer received help from his mother, and mother in law. The sister in the extended family worked twice as hard because she now looked after both families. Caring was strictly a family matter, and not be expected of friends.

CARER'S LEISURE

The Male carers and one female carer went out regularly on weekdays or weekends. They went to Portuguese clubs, and

visited family and friends. One of them liked fishing and had a boat. The remaining female carers did not have time for leisure and rarely left home for pleasure at all. One wife baked cakes on a Sunday. These women rarely, if ever went to church.

The two wives of mentally ill husbands rarely went out. One of the wives could not go to church even though she dearly wished to. Her husband due to his delusional beliefs had created scenes in the church, and he now refused to go, or allow her to. These women looked forward to their husband going to work. One husband had been recently retrenched.

Through tears a carer talked of the 'misery' of her life now her husband was always home.

"My life ended the day I married him, I have to do every thing, everything. He follows me about the house all day, even to the toilet. I feel I am going crazy."

Health workers believed that Portuguese women, especially from rural backgrounds, were usually home bound. It was only really legitimate for men to go out and openly socialize. A mentally ill male would often go out alone, whereas a woman would go with the family.

Church going, especially for the women was primarily a social occasion where they met with other women and displayed themselves, not a statement of fervor. Four carers went weekly to church except for the two wives with mentally ill husbands.

Only two of the six carers had annual holidays out side of Sydney, and they took the person they care for with them.

The two carers who had been back to Portugal on holidays, went with the mentally ill person, and they had only returned home once. Similarly five of the mentally ill had returned home, with family and only once.

SERVICES PERFORMED BY CARERS

The female Carers performed all the tasks associated with the emotional and physical care of their families and were responsible for the smooth running of the family and the home. The women did not drive and two had spouses who would not take them shopping. Some were also doing paid work.

The women performed the following services for clients.

Cooking, shopping, housework, laundry, baby sitting, outings, medication, escorting, interpreting, personal care, and companionship. A mentally ill woman received help when she was sick and was usually expected to resume her workload when well.

COPING

The carers all had periods when they felt they could not cope with the ill persons behaviour. This usually occurred when their loved one was very ill. The two carers whose spouses had chronic periods of mental ill health felt they barely coped with the person even when they were well. One said she felt

like dying when the person was very ill. All of the carers had either a close relative , or the extended family to share problems with, and be comforted, except for one extremely distressed spouse who had no family she could turn to. All carers expressed their difficulty to family members only. The health workers believed carers expressed their inability to cope, but usually too late. Carers had a tendency to hide difficulties until the ill person's behaviour had reached crisis proportions. Carers also understated the degree of difficulty they were experiencing. The cultural expectations of families to cope privately with problems, and that women sacrifice their needs for the good of the family underpinned these tendencies. Carers said they dealt with stress by 'blowing up', going for a drive or walk, discussing problems with the family, or keeping themselves as busy as possible.

CARER'S HEALTH

Only one wife reported any physical illness and she had Diabetes and Hypertension. The male carers reported no illnesses at all. However Insomnia and frequent headaches were reported by three female carers. The health workers believed most carers were well, and expected carers to report back injury or arthritis.

Carers either rarely went, or did not go to doctors on their own behalf. One male believed going to doctors would make him sick. Most did not have the time to look after their own needs. If ill they treated themselves at home, usually with home remedies or non prescribed medications.

e.g. Malvas, to the uninitiated is nothing more than a common weed growing on footpaths and waste ground around Marrickville. The leaves are steeped in boiling water. The cold solution is used as an antiseptic wash for the vagina, skin and throat. When imbibed it supposedly cleared the system and quickened recovery. A carer eased muscular spasms in her son's back by laying a thick towel over the affected area and ironing it.

Only three female carers self medicated. They said they took a lot of Panadol. Two of these women were also using benzodiazepines. (Mogadon and Valium). Carers commonly used herbal teas like Camomile, for sleeping, depression or nerves. One woman said she was too afraid to sleep deeply, she always felt tired. She never slept when her spouse was ill due to fear of her husbands behaviour.

The health workers believed use of home remedies as well as analgesics and tranquilizers was commonplace. Importation of medicine from Portugal and self prescription on the recommendation of family and friends happened frequently. One worker believed that tranquilizer and analgesic abuse was a hidden problem in the community.

HELP SEEKING

Four of the carers only supervised or gave medication when the person was ill. Consequently most of the ill persons in this study took their own oral medication. The same pattern

occurred with escorting their loved one to psychiatrists or other health worker appointments.

Carers at risk of abuse were fearful and ambivalent in regard to escorting or reporting their perceptions of their loved one's illness behaviour.

Carers took loved ones to different Doctors during the initial stages of their relatives illness. File data revealed that the eight mentally ill averaged two admissions within the initial three years of illness. They then tend to remain stable long term clients of the Community Health Centre. Medication non compliance was the common reason for relapse.

The health workers had varied opinions. Some thought carers and clients tried different professionals seeking cures, especially for physical illness. One worker believed the Portuguese to be very respectful of Doctors and very loyal to the one practitioner even if they were ineffective. Another thought that Portuguese sought different professionals for physical problems but avoided psychiatrists out of suspicion or unfamiliarity with the profession.

Carers admitted using prayer, increased church going, clairvoyants, and spiritual and/or natural healers, to help themselves or relatives, especially when their relatives illness began. Two carers would have consulted folk practitioners if they had known how to make contact.

INTERPRETING

Carers who had good or adequate English, interpreted for their relatives. One young carer said

"I was bothered by having to do this when I was young, I felt embarrassed, and wanted to do other things, it's different now I'm older".

Health workers said it was usually older children or young adults who acted as interpreters. Interpreters were not used due to unavailability, unawareness, or embarrassment about having to use outside help. They believed young persons resented interpreting, due to difficulties expressing themselves, and having to participate in a process usually perceived by the ill person and carer as an invasion of privacy.

The only worker who used interpreters, used the Telephone Interpreter Service much more than arranged appointments.

Crisis team work required after hours, and frequent contact with clients over a short time span. Because they performed a lot of initial client assessments, access to interpreters for face to face work, especially after hours, was a perennial problem.

The worker said she has had to use carers as interpreters, in crisis situations, when a client was unable or unwilling to co-operate with a telephone interpreter. The interpreters believed that casemanagers in Adult Mental Health teams were also frequently unable to obtain interpreters when needed so most case managers relied on the family to interpret and report significant behaviour change with their Portuguese clients. Although interpreter need is noted on files, frequency of usage outside of routine psychiatric reviews is rarely if ever noted, by english speaking staff. Usage levels for routine case work by english speaking staff is indeterminable.

TREATMENT EXPERIENCES

Only two of the five mentally ill who had holidayed in Portugal used medication they took with them or obtained when away. The others had a hospital admission or returned to Australia and subsequently relapsed. The persons who relapsed in Portugal were taken to hospital by relatives. Carers believed their loved one's condition improved in Portugal, through having a holiday and reuniting with the family. One carer believed her husband was worse because of the abundance of cheap wine.

Only two Health Workers thought both the mentally ill and carers believed going home may promote a cure. They expected clients to switch to Portuguese drugs, if they didn't cease medication.

Duplicating medicines prescribed in Portugal can be problematic for some on their return to Australia.

A worker described an instance where a patient and a psychiatrist differed over the efficacy of a drug, which was obtainable in both countries, but made by different companies. The patient accepted the drug was the same but insisted one brand worked better for him. The doctor wouldn't accept this, and believed the client to be delusional, and insisted the client take the drug as prescribed. The client now imports and self administers the drug and avoids having necessary medication reviews.

Three workers thought Carers and the mentally ill would prefer treatment in Portugal due to ease of communication and a commonly held local belief that the Australian climate made them sick. Some Portuguese also uncritically believed all things Portuguese were superior. However, the four carers who had experienced the mental health services of both countries preferred treatment in Australia.

TREATMENT PREFERENCES

Five of the six carers preferred their relative to be in hospital when ill. Reasons given by carers were they and the children had a break, rested and slept well. Being without fear of the ill persons behaviour was equally important. One male carer preferred home based treatment for his wife. He believed being with the family, and in the home was better

because the family could provide the love and familiarity not present in hospitals.

The health workers believed attitudes towards home and hospital care would vary from family to family. Carers who preferred hospital treatment would do so due to a perception of hospitals as officially sanctioned healing places, and better access to doctors. Those that preferred home care would do so out of tradition, and the belief that only the family can give the person the level of care they need. Looking after a sick person at home also showed the family's love for the ill person.

The health workers believed families delayed and avoided hospitalization, out of a need to hide their problems from the community. There was a strong fear of mental institutions, in the Marrickville community. Residents often respond to aberrant or errant behaviour by telling the offender they'll be 'sent to Parramatta.' The workers could not explain this but said it was a common saying. Community Mental Health Centres were accepted by the mentally ill and carers because they were not overtly connected with hospitals.

The perception of hospitals as unfriendly environments for loved ones and relatives also needed exploring. One worker also mentioned non segregated ward environments as a major concern for carers. Male and female family members were afraid for the sexual safety and propriety of ill relatives (especially female) when hospitalized.

Half the carers had health insurance. They liked health insurance for physical health, but preferred to use the public sector for mental health. Half the Health workers thought Portuguese liked health insurance because in Portugal, the cost of a practitioners services was an indicator of their expertise. The other two workers believed Portuguese preferred not to pay.

MENTAL ILLNESS BELIEFS

Carers thought that mental illness was a serious 'illness of the nerves' or 'nervous illness' in which people lost control of their lives.

The health workers thought Portuguese believed nervous illnesses resulted from agencies external to the person not from within the person. The dysfunction of the brain would be God's retribution for aberrant personal or family behaviour. Tragedy within the family is another cause. Being in Australia, or Australia's climate, stupidity (meaning mental retardation), or the behaviour of carers, particularly wives can be considered causal.

The infidelity of spouses, particularly wives was a common delusion held by mentally ill males. One man stalked his wife at home and outside. Another believed his wife had a lover in the cupboard. One woman always accused her exhusband's new wife of using spells to lure him away. The Mentally ill males who drank were particularly suspicious of their wives.

A female client became psychotically depressed after the spirit of a recently dead cousin, had accused her of causing his death. In reality she had not been speaking with this cousin for some time before they died, and a relative had criticized her for this after the death. Both a depressed and a schizophrenic female client prayed obsessively for hours when unwell. Seeing ghosts, vampires, and black witches were common hallucinations experienced by clients.

Old folk beliefs such as showering when in labour, or when menstruating causing excess blood flow to the head. The mixture of Menstrual fluids with iron to seduce or change the behaviour of men. Mental disturbance due to lack of sexual discharge in men or the opposite in women. The work of the devil, or the 'evil eye' are also believed to be possible causal agents in the creation of mental disturbance and illness.

All the carers said they had changed what they thought about mental illness. This change resulted from personal experience. Initially they did not take the illness seriously, but now believed mental illness to be a very serious illness, and they felt compassion for others in similar situations.

Half the health workers believed carers and ill clients gradually changed beliefs about mental illness.

This change depended on the client and/or the family believing the treatment was working. Two health workers believed clients or carers would not change their beliefs at all.

Even if carers and clients beliefs about illness causation was relatively congruent with Australian ideology, both clients and carers were very superstitious.

One Carer happily explained three amulets he was wearing to keep bad luck and/or malevolent influences at bay.

The small gold charms consisted of a clenched fist with upturned thumb (Horns), an eye shaped medallion with a six pointed star, and a crescent moon. Women often pinned them inside their bodice.

The English speaking health worker did not know any cases where spiritual healers or mediums were used. The Portuguese workers believed witches, clairvoyants and natural healers were often consulted by community members.

A Witch or Bruxa was consulted to remove or place curses, as well as provide advice for their customers. The making of amulets or potions for protection from malevolent intent, luck or entities was an essential part of their practice. Madeiran healers had a particular form of massage for anxiety. Anxiety is believed to be caused by changed or reversed positioning of the stomach. The torso is then massaged to coax the stomach back to its proper place thereby curing the patient.

A client who suffered from delusions of persecution, plus vivid auditory and visual hallucinations performed rituals to repulse malevolent spirits. She also believed certain persons were cursing her and took steps to reverse the spells.

"Maria X asked me to her home and insisted I bring some charcoal. We went to a laundry at the back of the house. My role was to fill a basin on the floor with charcoal and burn it. Maria X then criss crossed branches of rosemary and Arruda and began jumping over the smoking herbs while chanting prayers of protection to various saints. She changed direction at the start of each chant cycle. The ritual lasted about 30 minutes. Maria X later took the smoking branches and purified the house.

Rosemary (Alecrim) in combination with Arruda, another rather innocuous local weed, supposedly have power against malevolent entities. Smoke from Rosemary is also used to disinfect and freshen the air in the home. Maria X also put salt on the door steps."

Carers reported they used or heard the following words and phrases referring to mental illness.

Nervosa, Louco, Maluco, Tonto, nerves, crazy, Macacos No Sotao, (loose screws) and Saude Mental (extreme sadness or homesickness). This latter state was said to be uniquely Portuguese by the bi -lingual workers.

These words appear to reflect the educational background of carers. Other terms describing mind disturbances in the language are demente, doidice for madness or being mad. Depresssao and desanimador/a for depression or depressed person. Esquizofrenia, or esquizofrenico for schizophrenia or schizophrenic. Mania and maniac were words to describe mania or a mad person.

CARER'S AND THEIR COMMUNITY

All carers interviewed said having a mentally ill family member affected their treatment by the community. The male carer reported people to be more supportive than usual when his wife became ill.

Female carers reported the opposite. They felt many did not realize just how sick the person was, particularly if the ill person was male. The women felt the community was divided as to who was to blame, and that they and their family were subject to gossip. The community usually blamed the wife for being disloyal or wingeing if the degree of the person's illness was not realized.

If their illness was recognised, but the ill person's behaviour not accepted, then community members distanced themselves from the family increasing their social isolation, especially if they had no family support.

The health workers thought the community reaction to the mentally ill and their families was either condescension or avoidance. However they expected the family to be subjected to gossip.

Female carers and clients were more subject to critical gossip and rejection than males. If a woman could not cope with the demands of running her household she could be openly criticised and /or ostracized.

KNOWLEDGE OF MENTAL ILLNESS

The carers used the word 'nerves' when referring to a loved one's illness. Five of the six carers did not know the ill persons diagnosis. The carer of the depressed client both knew and accepted the persons diagnosis.

The health workers unanimously believed neither the mentally ill or the carers would know or accept diagnoses given to the ill person. The workers believed the majority of the local community would not have the educational background for the concepts and vocabulary necessary to comprehend Australian Psychiatric terminology. The workers thought that diagnoses given to Portuguese clients were correct. Only one worker had an instance where she disagreed with a diagnosis. They all believed that improved cultural awareness in mental health staff and use of bi-lingual staff had improved diagnosis.

INFORMING CARERS

Four of the six carers said they had not had their loved one's medication, possible side effects, causes, or symptoms either explained or discussed with them.

Only two carers talked with the ill person about their illness. Two female carers did not talk to the ill person due to fear and the persons denial of their illness.

One wife said there was no point discussing things with her husband because he only accepted his illness when sober. Because he drank all the time, her husband was not worth talking to.

The two health workers who case managed clients and carers said they educated and informed, as well as discussed illness experiences with clients and carers. The interpreters remembered being present when medication and illness issues were discussed, but only with clients not carers.

COMPREHENSION OF INFORMATION

The health workers thought that acceptance of the material mental health workers explained to carers and clients varied from case to case. They believed clients or carers either accept what is said out of respect or rejected what was told them totally.

The workers believed that carers and clients had problems understanding due to poor education, and unfamiliarity with the concepts and vocabulary associated with psychiatry. Information should be conveyed in the simplest of terms and analogies. One interpreter said that clients and carers were told too much too quickly during initial contacts with health workers, and suggested a graduated education process to promote absorption of information.

PROBLEM BEHAVIORS

Both carers and health workers believed the mentally ill varied in their ability to recognize signs of relapse. Women clients had less problems with denial, or loss of insight. Carers were confident of their ability to detect illness behaviour, and the workers believed this to be true. Carers were usually accurate assessors of their loved one's mental state.

The health workers thought that behaviours that bothered clients and carers varied from case to case.

Delusions could be problematic for clients. They believed the family was turning against them, because they didn't accept their viewpoint any more. In some cases this has lead to violence against carers, particularly wives.

Amotivation was regarded as laziness for female clients but dismissed as illness with male clients. Female clients suffered more criticism, hostility, and intolerance from their families especially if schizophrenic.

Both Carers and health workers reported the following behaviours as the most disturbing for families. Violence, suspicion, Verbal abuse and threats. Lack of respite and privacy from the ill person. Having to continually justify actions, loud or repetitive speech. Excessive drinking. Social withdrawal and the expectation or insistence that carers do likewise.

Delusions of infidelity by spouses was particularly trying for Carers. This was particularly bad for female carers when clients espoused such beliefs to outsiders. Lack of sleep, and continual fear and tension at home were extremely problematic for two female carers.

What health workers did not mention but carers mentioned extensively was continual worry about protecting their children from the behaviour of the ill person, particularly ill husbands. Harassment of the eldest son by mentally ill and alcoholic fathers was a problem for two wives.

All carers were concerned about their children's education being negatively effected, and found it very difficult to protect and foster their children's interests especially if the ill parent had irrational and socially inappropriate beliefs. The other problem was trying to maintain their children's respect for their ill parent especially as they got older, " My son is beginning to think his father is odd." Some children were living in very tense and fearful situations at home.

SMOKING AND ALCOHOL

Two of the three mentally ill Males studied had alcohol problems, the women did not. However four of the five mentally ill women had a spouse or ex spouse with an alcohol problem. Five female carers had a spouse or other immediate male family member abusing alcohol. Women rarely abused alcohol, their problem was coping with alcoholic men.

Health workers believed alcohol abuse common place for men. Home brewing of wines often occurred, and Alcohol was thought of as a tonic and an integral aspect of Portuguese dining and socializing.

Only two men in the study smoked. The women did not. They thought smoking was very bad for women and they did not like the smell. They believed it was better to keep your health.

VIOLENCE

Violence was part of the experience of all carers. Three carer families had experienced violent outbursts from acutely ill relatives just prior to their admission.

Two carers were subject to episodic violence particularly if ill person was drinking heavily. One carer described her life as 'walking on eggs, and having to make herself 'as invisible as possible.' The carers reported no violent incidents from other members in their families.

The file search revealed mentally ill females usually experiencing violence either from spouses or other male family members especially drinkers. Female carers were subject to violence from mentally ill spouses, or spouses who drank heavily.

The health workers believed violence against women was common place in the community and usually alcohol related.

MEDICATION

Both carers and health workers thought injections were the preferred and most accepted form of medication for mentally ill Portuguese. Tablets were poorly accepted because Portuguese hold strong beliefs linking health and peace of mind with the absence or presence of digestive upset, appetite changes, and constipation. The enjoyment of food and drink, pride in preparation and adherence to Portuguese cuisine, were extremely important to the Portuguese way of life.

Medication side effects that inhibit or change women's menstruation patterns or male sexual performance; Tremor or lethargy inhibiting the ability to work, and concurrent alcohol usage by male clients taking medication are important considerations when medicating Portuguese clients.

Although the health workers believed carers expected medication to work immediately most did not and said experience has taught them the medicines work gradually.

The wishes of carers in relation to their involvement or non involvement in supervising a relatives medication can be a delicate issue.

A carer interviewed in the study was very fearful of her spouses illness behaviour, and subsequently had a strong need to supervise her spouse's medication. She had become extremely angry and had deliberately isolated herself from service providers when her spouse was encouraged to be responsible for medicating himself.

Her intense need for safety and her distrust of her spouse's intention to take medication were not being considered as far as she was concerned, and she now believed her spouses health carers were stupid.

She had consequently become increasingly stressed, distrustful and fearful. The carer feared that the service providers, whom she now believed distrusted her opinion, would not believe her if she said her spouse was getting ill. This particular carer was extremely isolated socially, except for work, and she had no extended family to support her.

CARER'S LONG TERM CONCERNS

Five out of six carers were happy to remain in Australia. One carer would like to return but her family wanted to stay. Most carers were staying because of their children's education and preference for Australia. Some were satisfied with there life here, and now had very few or no relatives left in Portugal.

What worried carers most about the future, was their fear of their relatives mental condition worsening. One wife despaired that her husband would ever get better. The ill person or the carer becoming unemployed or unemployable was also a major worry.

The health workers were concerned about Male clients drinking themselves into oblivion, and the associated violence towards carers.

The side effects and inadequacy of available medication and the unlikely hood of improved treatments, plus decreasing opportunities for clients to be hospitalized either for their own or the families sake concerned most of the health workers.

The loss of family, especially their children by the mentally ill, and the unavailability of accommodation options for mentally ill Portuguese without family support were seen as major problems. Culturally appropriate community respite facilities for clients and families did not exist.

SERVICES USED BY CARERS

Services used by carers were; The Crisis team, Adult Mental Health staff, and the bi-lingual counsellor. Portuguese, Spanish and Italian speaking G.p.s. Specialists in private practice and Public Hospital psychiatric units were also used. Respite care or Rehabilitation services were not mentioned, either by carers, health workers, or in the files.

SUGGESTIONS FOR IMPROVING TREATMENT AND SERVICES

The carers believed caring would be easier, if they could get more sleep and peace of mind, and women wanted to go out more or look for work. One woman could not offer a suggestion. She never thought of herself or her own needs. All the female carers would like more assistance from family members, especially with house work and increased protection when their loved one was acutely ill.

The carers suggested the following ways to improve their loved ones treatment. Carers were emphatic in their support of injectable medication. For some, supervising and/or administering tablets was a fearful experience. These carers were primarily female spouses. They feared the resentment and abuse when they reminded, or insisted the person take medication. Unfortunately they were equally fearful of the person's illness behaviour.

Injections administered and supervised by an external authority has a quality of life benefit especially for women carers. More information and consultation with carers was also requested.

All the carers were willing to come to a carers support group as long as the time suited their needs. Only one health worker recognised this as a carer need.

The health workers believed improved interpreting availability and more bi-lingual staff in professions associated with Psychiatry would improve the support of the mentally ill Portuguese, their carers and children.

Most workers expressed the need for flexibility of psychiatric services in regard to the involvement and consultation needs of families. The expertise of the family regarding it's members behaviour, was not being sufficiently acknowledged or utilised.

Carers also requested more information about 'helping the mind.' The carers wanted to be listened to more and have their wishes respected.

The workers indentified two primary service needs which had to be met if services were to improve. These were the employment of more Portuguese speaking health professionals at all levels of Psychiatric care, and the establishment of a Portuguese run hostel for mentally ill clients, providing accommodation and respite care.

CHAPTER FIVE:

CONCLUSIONS.

Quality of life is determined by a person's physical and mental health and the social factors that shape them. Portuguese families like other NESB groups have experienced the stressors of migration. The most comprehensive survey of the international research into mental health and migration was conducted by the Canadian Task Force on Mental Health Issues Affecting Immigrants and Refugees. (1988 a,b). The Task Force concluded that migration was not associated with a higher risk of mental illness, but rather a migrants personal characteristics, and the circumstances that they found themselves in, determined their mental health outcomes in the new host country. Seven factors were identified as potentially contributory to mental illness in Migrants, and the following section examines the experiences of the carers and clients in relation to these factors.

a. Traumatic experience or prolonged stress prior to migration. The carers and their relatives chose to migrate. They came for economic reasons and wanted a better life for themselves or their children. The Portuguese also have a very long history of migration, going back at least 400 years. Portugal except for a brief period of colonial expansion, has been a traditionally impoverished nation with a great gulf in living standards between the rich and poor. The Portuguese started migrating during Portugal's great seafaring and colonial period. This century they have migrated to non

colonial countries such as the U.S.A., Canada or Australia. Most Portuguese migrants are of peasant background. (Luckey, 1990, p2) (Nunes, 1986, p11 -19). It is also common for Portuguese men to be European guest workers, leaving their wives and family behind. Migration for the Portuguese is not such an unusual step to take, and is usually not a forced one.

b. Age at time of migration. The clients and carers came to Australia as young adults. Adolescent and elderly migrants were considered most at risk of mental illness.

c. Lack of a friendly reception by the surrounding host population. The Portuguese in the study came to Australia either during the mid sixties or early seventies. Therefore they were exposed to the same levels of social disadvantage that other southern European NESB groups experienced. However they found work on arrival either via their own compatriots or links with the Italian community. (Luckey, 1990). The Portuguese also have a habit of blending into their surroundings and drawing their resources either from the family or other Portuguese.

They therefore don't advocate politically on behalf of their community and consequently keep a very low profile in host countries. This trait protects the community to some extent but also causes their communities to be isolative, insular and overlooked politically. (Nunes, 1986). The Portuguese in this study had had no criminal charges made against them or claimed compensation.

d. Isolation from persons of similar cultural background.

The clients and carers migrated to an established community. Presently there is a small Portuguese business district in the suburb of Petersham and there are Solicitors, Doctors, a Welfare Centre, Sports Clubs amongst other varied activities.

e. Separation from family. The clients and carers came as couples or sponsored by family. A similar pattern was found in studies of American and Canadian Portuguese. (Moitoza,McGoldrick et al.).

f. Inability to speak the host language. The carers and clients spoke Portuguese at home, and used Interpreter services extensively. Reasons given for this were poor educational background and illiteracy in their own language. In Canadian and American studies similar levels of illiteracy and English usage have been found. The reasons given were the habit of working with other Portuguese, the isolative nature of the communities, (Nunes,1986).(Moitoza,McGoldrick et al.). and the isolated lives of the women.(Estellie Smith,1980).(Franks et al,1990). This last factor is the only risk factor which affects the mental health of the community members. Franks et al., (1990) found that Portuguese women had the highest Depression scores out of 4 NESB groups. Poor language skills for Portuguese women was a major indicator for depression, but not so for women in the other groups.

The primary goals on arrival for the Marrickville Portuguese, and similarly for overseas communities is the building or purchase of a home. (Luckey, 1990). The Portuguese families examined in this study were all home owners and had a clear intention of staying in Australia. Their children were already better educated than they were and for some most of their family were here. Two families could afford health insurance and most worked. Except for language the Portuguese in the study have been successful migrants and the mental illness of a family member does not appear to have hindered this success.

Australian Studies of Mentally ill NESB migrants have found access barriers to Mental Health services explain migrant under utilization of services more satisfactorily than lower prevalence of mental illness in their communities. (McDonald, 1991).

The use of alternative resources such as bi-lingual practitioners and traditional healers of various kinds has been identified as a NESB alternative to using State Mental Health services. The Marrickville Portuguese certainly make use of alternative services both orthodox and unorthodox but the types and extent of the mental health problems covered by alternate practitioners is beyond the scope of this study.

The carers and clients have used government and private health services and appear to choose the services that suit their purposes the best. The carer and clients explored

different services during the initial years of their loved ones illness, but later settled with the community health centre.

Another barrier to Mental Health services for NESB persons is the lack of, or misinformation about available services. Most Portuguese attending the health centre were self or family referred. Word of mouth and Ethnic media are the ways health workers think service information is conveyed in the community. The service has also Portuguese speaking workers plus access to interpreters.

For the Portuguese suffering from psychoses knowing where to get help from community based mental health services at the onset of their illness appears problematic. Contacting the Psychiatric hospital as the initial source for help when their loved one became ill appears usual for Portuguese carers both in Australia and Portugal. The clients in this study were mainly referred from Psychiatric units. McDonald's (1991) study of Hunter Region NESB psychiatric inpatients found the majority of patients were taken to hospital via the Police, were extremely psychotic on admission and stayed longer than ESB patients when admitted. Carer's also experienced violence from the ill person just prior to admission. Carers in this study had had similar experiences.

The lack of culturally appropriate mental health services is another often cited problem for NESB mental health clients. (Minas, I. (1991)

The Portuguese mentally ill in this study did have access to some culturally appropriate services albeit not enough. However carers were unaware of respite and rehabilitation facilities. According to the health workers they did not exist. Rehabilitation may not be an issue for Portuguese clients because most worked in some capacity, or had homes and families to care for. Respite however was a significant problem especially for carers and their children, when their sick relative was relapsing or acutely ill, and clients without family support had no place to go except nursing homes or hospital.

The Portuguese workers thought establishing a hostel was a major priority that both the mental health services and the Portuguese community should address.

The non recognition of client's and carer's previous experience of health services was also a problem for the Portuguese studied. These Portuguese have experienced both general and mental health services in both Portugal and Australia. The Portuguese appear to have a strong tradition of individual responsibility for health, and they choose from a wide range of both orthodox and unorthodox health practitioners. The healing traditions of the women have not as yet been lost to the community.

Portuguese health services are market driven and much more deregulated than Australia. Most medicines are freely

available and not prescribed. The Portuguese continue the practise of self prescription and self medicating by importing medicines via relatives in Portugal. This has implications for clients and carers when mental health practitioners don't respect or aren't aware of the Portuguese experience of a much freer use and access to drugs and different treatments. The Portuguese studied have had difficulties having preferred drugs duplicated successfully, and preferred forms of medication respected.

The concurrent use of known and unknown medication, and the rejection by the Portuguese of tablets for long term use makes monitoring and prescription of clients medication difficult and medication compliance difficult to maintain for the chronically mentally ill. Beliefs linking digestion with well being, and the importance of eating to the Portuguese life style were stated by the Portuguese health workers as integral to the rejection of tablets. Cultural beliefs concerning wellness and the regularity of the digestive system, menstrual cycle and male sexual performance, plus the importance of working to the Portuguese implies a need in mental health workers to be very aware of the possible impact the side effects of most psychiatric medication may have for Portuguese clients.

Unfamiliarity with western mental health has also been reported as a factor influencing NESB utilisation of mental health services. The Portuguese studied have been exposed to similar mental health services for psychotic individuals.

Namely the Psychiatric hospital as a place for treatment in both countries. The carers have changed their attitudes about mental illness through experience and their beliefs reflect western ideas. The carers saw mental illness as a disease residing in the body (nerves) which manifests in behaviour change, which is potentially devastating and hard to bare. The carers views echo those of the relatives in studies in the family care of the severe or chronically mentally ill. (Fadden, G, et al.,1987). (Falloon, et al., 1984).

The Portuguese propensity for fatalism, their acceptance of the supernatural, or the belief in the power of saints to intercede on their behalf appears to manifest more in their expression of psychiatric symptoms. e.g. Delusions of persecution by spirits or curses and obsessive praying.

The problems of shame and stigma can profoundly affect the carers of NESB mentally ill. Such factors cause resistance to help seeking and can result in violence towards carers, prolonged stress and disturbance for the family, and extremely sick clients presenting to mental health services. The health workers believed this was a persistent problem for Portuguese carers and the carers themselves talked of community gossip, and blaming. Other cultural values influencing carers help seeking was the strong Portuguese tradition of keeping problems within the family and the family care of the ill.

The greater role of southern european NESB families in the care of their mentally ill has been recognised in most

Australian studies. The Portuguese families in the study appear to reflect what McDonald, (1989) in his paper on ethnic family structure terms a masculine conception of the family. In the masculine view, the family is a formal political entity, and male honour and prestige is judged by the performance of the family. The family according to Moitoza (McGoldrick et al), Nunes (1986) and Estelle - Smith, (1976, 1980), is the corner stone of Portuguese life. The maintenance of family tradition is revered both as a means of individual survival and as a major means of Portuguese cultural survival.

The Portuguese carers and clients lived in family groups. The male spouse had the final say in family decision making. There was strong shame attached to having a mentally ill member in the family. Strong traditions of family and spousal duty of care to ill relatives and keeping problems within the family are all southern european masculine family traditions. The most important aspect of the masculine tradition in relation to this study is the care giving role of Portuguese women.

The female carers, usually spouses were the primary carers of the mentally ill clients examined in this study. They carried out their traditional domestic work, did paid work, raised the children, and coped with the additional stress of the mentally ill persons behaviour. Some carers either had or were coping with alcoholic male relatives and domestic violence.

International studies into the experiences of carers looking after chronically ill relatives have found caring places large burdens on families, particularly the women.

(Sarantakos,s.) (Schultz, C. et al.,).

Caring also places burdens on carers which result in both Physical and mental health problems. (NSW Women's Advisory Council, 1993).

Carers health can be affected directly by exacerbating existing illness or indirectly by causing loss of income through job loss either by the carer and/or the ill person. Curtailment of Carers leisure activities and withdrawal from the outer community.

The buffer against psychological distress and stress related illnesses for carers was the degree of family and formal support they received. The carers perception of the carers role, absence or presence of financial difficulties, and the degree of impairment in the social functioning of the person they cared for and the relationship they had prior to the person becoming ill all play a part in whether a carer becomes stressed or not.

NESB carers also had to contend with Language difficulties, and problems stemming from family structure. The Portuguese women in the study were also affected by cultural attitudes towards mental illness, their acceptance of male dominance and the restriction of their social life to home and family.

The cultural expectation of Portuguese women to sacrifice their needs for the good of the family was noted by the health workers interviewed.

Both the health workers and the carers thought that carer's needs were not being met. Carer's complained of lack of consultation and support both from family and mental health services. The orientation of services appears to be client centred and neglects the integral role the family has for a Portuguese person. Carers believed they were not informed about the illness , symptoms, expected behaviours, and medication issues associated with the care of the mentally ill. Even though the health workers believed that did educate carers.

There appears to be a problem with not only consulting carers but how health knowledge they need to know is being conveyed to them. One worker believed they were being told too much too soon, and that carer education should be a graduated process.

Assessment of the needs of carers appears to be over looked. Two carers interviewed were already showing signs of stress related illness. These women were using a lot of analgesics and tranquilizers. Most carers in the study did not have difficulties in regard to finding work or housing, and they did not find caring for their mentally ill a financial problem. Some carers also had opportunities for leisure. These carers were either male or had the support of extended family and female kin.

There were however 2 carers who were particularly at risk of physical and mental ill health . They had several common factors. Their spouse was not only mentally ill but alcoholic. Both were without family support, and had little time for themselves. The each saw themselves as the bearer of sole responsibility for the care of their family and their spouse when he was ill.

Both had endured violence from their spouse, and were highly ambivalent about supervising their spouses medication. Their spouses symptoms e.g. excessive suspicion or delusional jealousy made their daily life a 'Misery'. One client never went out because of her husband's suspicion and the other lived for her work to get away.

These women were also very worried about their children and were concerned for their school performance, and upset that they had to endure tension within the family. The loss of respect for the ill parent by the children as they got older, and how to explain their ill parents odd behaviour was also problematic for these carers. All the carers complained of lack of rest and sleep when the person the cared for was ill.

The carers also indicated a strong interest in coming to a carer support group at a time that suited their needs. The establishment of this group should be looked at as a service priority. A carer assessment protocol based on factors affecting carers health could be used to identify at risk carers like the two women described above.

Care plans incorporating the needs of carers as well as the client could then be formulated. A English as a second language course for Portuguese women carers should also be given some thought. Language mastery having been found to be a factor for depression in Portuguese Migrant women.

Alcohol abuse by Portuguese men appears to be a problem endured by many families in the community not just the those with mentally ill relatives. (Luckey, 1990).

Alcohol abuse by Portuguese men both in Australia and Portugal is endemic to their communities. The acceptance of alcohol as a food stuff, tonic or source of strength. The association of Male pride with drinking, and drinking a lot, and social resistance to re-evaluate drinking as a source of social problems for their community are identified as factors perpetuating endemic alcoholism in Portuguese men. (Morrissey, M. et al., 1993).

Domestic violence was also a problem which Portuguese carers shared in common with other women in the community.

The acceptance of abuse by women of rural background, male dominance, and alcoholism all combine to make domestic violence a common problem in the Marrickville community. (Luckey, 1990). Moitoza (McGoldrick et al.) quotes a common Portuguese song in relation to Domestic violence.

Even the sea is married
Even the sea has a wife,
He is married to the seashore,
He beats it whenever he likes. (anonymous)

A Portuguese woman is expected to cover up for her drunken spouses violence or violent male behaviour in general. An alcoholic, or violent husband was considered Bad luck, which had to be accepted. Women don't leave difficult husbands due to fear of community ostracism. The two carers who were the most stressed and had the triple problem of a mentally ill, alcoholic and violent spouse, would not consider leaving there husbands. One carer whose only support was her married sister, found her sister's insistence that she leave her husband an added stress.

Portuguese carers and clients are also the parents of children and adolescents. Some of these children are living in extremely tension filled homes. The need of the children for breaks and respite from the mentally ill persons behaviour was a major concern of carers.

Children's peace of mind, respect for parents, school performance, resentment of interpreting, and conflict between their parents culture and their peer group can all be negatively effected by the presence of a mentally ill parent. Children's future marriage chances can be affected by having mental illness in the family. They may face exclusion, or gossip about their parents from within the community, or they may worry about developing mental illness themselves. The needs of the children of mentally ill Portuguese appear to be more neglected than the needs of carers.

The carers and children of the Portuguese mentally ill examined in this study were more negatively effected socially and/or interpersonally than they were financially,

materially, or physically. Some carers suffered more than others, due mainly to their lack of support. Community problems such as domestic violence and male alcoholism were also factors affecting the quality of life of carers. Alcoholism particularly affects the families of the mentally ill because the affected spouse appears to remain chronically mentally ill.

The need for a reorientation of mental health service delivery so that the needs of carers and children as well as mentally ill clients are incorporated into assessment and care plans would appear to be a positive step towards improving the support for families.

Advocacy for the establishment of community focused Alcohol and Domestic violence support programs to which affected carers and children could be referred would also be of considerable benefit for the families of the mentally ill.

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APPENDIX A

CLIENT AND CARER INFORMATION

Carer Interview Information

No 1 sex f age 50 R/ship wife M/st m Emp/st p/t Ocp cleaner u/sk

No 2 sex f age 21 R/ship niece M/st s Emp/st u/e Ocp sales u/sk

No 3 sex f age 52 R/ship s/law M/st m Emp/st h/d Ocp n/applicable

No 4 sex m age 49 R/ship b/law M/st m Emp/st f/t Ocp laborer u/sk

No 5 sex f age 41 R/ship wife M/st m Emp/st h/d Ocp n/applicable

No 6 sex m age 49 R/ship husb M/st m Emp/st f/t Ocp trade s/sk

FILE BASED INFORMATION

M.I. Relative of Carers

No 1 sex f age 45 R/ship wife M/st m Emp/st p/t Ocp cleaner u/sk

No 2 sex m age 51 R/ship husb M/st m Emp/st f/t Ocp factory u/sk

No 3 sex f age 46 R/ship sist M/st m Emp/st p/t Ocp child/c u/sk

No 4 sex m age 53 R/ship husb M/st m Emp/st u/e Ocp labour u/sk

M.I. Clients

No 1 sex m age 48 R/ship bro M/st dv Emp/st utw Ocp cleaner u/sk

No 2 sex f age 52 R/ship wif M/st m Emp/st f/t Ocp cleaner u/sk

No 3 sex f age 57 R/ship mot M/st sp Emp/st utw Ocp child/c u/sk

No 4 sex f age 56 R/ship mot M/st dv Emp/st utw Ocp home duties

APPENDIX B

TABLE 7: Total Number of Portuguese Speaking Person in Australia, NSW And Sydney

LANGUAGE	SYDNEY	NSW	AUSTRALIA
Macedonian	15,941	25,945	64,498
Maltese	19,332	20,925	53,052
Mandarin	22,347	23,372	55,454
Maori	1,461	1,720	4,070
Norwegian	289	458	1,436
Oceanic Languages N.E.I	5,249	6,142	14,398
Polish	16,027	19,820	67,256
Portuguese	11,918	14,126	25,610
Romainian	1,849	2,058	7,867
Romany	8	12	37
Russian	9,780	10,474	24,411
Serbian	9,409	11,024	24,425
Sinhabese	2,518	2,817	10,222
Slovak	783	891	3,373
Slovenian	1,522	1,904	6,194
Spanish	43,703	48,487	91,117
Swedish	1,332	1,710	4,669
Tamil	5,110	5,372	12,204
Tetum	335	354	732
Tha	3,820	4,292	9,805
Tongan	4,355	4,696	6,549
Turkish	15,040	16,552	42,067
Ukrainian	3,038	3,840	12,533
Urdu	2,530	2,763	4,500
Vietnamese	41,111	42,609	110,637
Welsh	264	376	1,323
Yiddish	2,496	2,580	10,122
Yugoslav N.E.I	11,885	15,701	43,253
Other Languages N.E.I	456	515	4,110
Inadequately Described	12,487	14,781	39,650
Not Stated	109,617	153,727	420,804
Total	3,538,749	5,732,032	16,850,330

* ABS Census 1991. Sydney Statistical Division

APPENDIX C

TABLE 5: Number (%) of Portuguese born in Local government Area of NSW

Area	Number	(%)
Marrickville	3036	(34)
Wollongong	1168	(13)
Sydney	755	(9)
Canterbury	568	(6)
Randwick	363	(7)
Leichhardt	280	(3)
Waverley	251	(3)
Rockdale	250	(1)
Fairfield	222	(3)
Ashfield	209	(2)
Rest of NSW	1608	(18)

Total in NSW	8876	(100)

* ABS Census 1986

TABLE 6: Age distribution by sex of Portuguese residents in Metropolitan Sydney.

Age in Years	Males		Females	
	n	(%)	n	(%)
0 - 14	382	(10)	347	(10)
15 - 29	895	(24)	961	(28)
30 - 54	2091	(56)	1830	(52)
55 - 64	261	(17)	216	(6)
65+	103	(3)	134	(4)

Total	3732	(100)	3488	(100)

* ABS Census 1991

APPENDIX D

Central Sydney Community Health Services.
 Adult Mental Health Client Registrations. 1/7/92 to 30/6/93.
 Persons with Portuguese Language, Ethnicity or Portugal as
 Country of Birth.

TABLE 1

<u>Total No. registered.</u>	<u>No.</u>	<u>%</u>
Marrickville C.H.C	48	92.4
Glebe/Redfern: Ashfield C.H.Cs.	4	7.6
<hr/>		
Central Sydney C. H. S.	52	100.0
<hr/>		
<u>Place of Birth.</u>		
Portugal	51	98.0
Brazil	1	2.0
<hr/>		
	52	100.0
<hr/>		
<u>Language.</u>		
Portuguese	45	86.5
English	7	13.5
<hr/>		
	52	100.0
<hr/>		
<u>Language spoken at home.</u>		
Portuguese	47	90.3
English	5	9.7
<hr/>		
	52	100.0
<hr/>		
<u>Interpreter Usage.</u>		
Yes	22	42.3
No	30	57.7
<hr/>		
	52	100.0
<hr/>		
* Portuguese Bi-lingual Social Worker at M.C.H.C.		
<u>ex.</u>		
Female	32	61.5
Male	20	38.5
<hr/>		
	52	100.0
<hr/>		

TABLE 2

Age.

19 - 29	8	15.3
30 - 39	11	21.2
40 - 49	13	25.0
50 - 59	11	21.2
60 - 69	5	9.6
70 - 79	1	1.9
80 - 89	0	0.0
90 - 99	3	5.8

	52	100.0

Age by 20 year intervals.

* 19 - 39	19	36.5
* 40 - 59	24	46.2
* 60 - 79	6	11.5
* 80 - 99	3	5.8

	52	100.0

Employment.

Fulltime (8) Part time(4)	12	23.1
Retired/ Age pension	8	15.4
Other benefits	5	9.6
Home duties	17	32.7
Unemployed	10	19.2

	52	100.0

Occupation.

Prof/ Tech/Admin	4	7.7
Trades	3	5.8
Semi/unskilled	25	48.0
Service/transport	5	9.6
Unknown/never	5	9.6

	52	100.0

Pension/benefits.

Age/ invalid	4	7.7
Other	7	13.4
Unemployment	2	3.8
Widows/wives	2	3.8
Not/applicable	37	71.1

	52	100.0

TABLE 3

Living Arrangements.

Alone	9	17.3
Partners+ dependents	38	73.1
Family/friends	2	3.8
Unknown	3	5.8
	-----	-----
	52	100.0
	-----	-----

Marital Status.

Married/defacto	33	63.5
Divorced/separated	8	15.4
Single	8	15.4
Widowed	3	5.7
	-----	-----
	52	100.0
	-----	-----

Local Government Area.

Marrickville L.G.A.	42	80.7
Glebe/Leichhardt/Redfern	10	19.3
	-----	-----
	52	100.0
	-----	-----

Year of First Contact.

1978 -79	4	7.7
1980 -89	12	23.0
1990 -91	3	5.8
1992 -93	33	63.5
	-----	-----
	52	100.0
	-----	-----

Referral Source.

Gov/Med	14	27.0
Pri/Med	5	9.6
Gov/Welfare	7	13.4
Other	5	9.6
Family/friends	8	15.4
Self	13	25.0
	-----	-----
	52	100.0
	-----	-----

TABLE 4

<u>Presenting Problems.</u>	<u>NO.</u>	<u>%</u>
1. Marital Conflict/violence	8	8.9
2. Depression	7	7.8
Depressive states	7	7.8
Anxiety/anxiety states	7	7.8
Intrapersonal problems	7	7.8
3. Physical Health problems	6	6.7
Work related problems	6	6.7
Cultural isolation/conflict	6	6.7
4. Alcohol related problems	5	5.6
Psychosis	5	5.6
Schizophrenia	5	5.6
5. Paranoid States	4	4.4
Services Access problems	4	4.4
6. Manic Depressive Psychosis	3	3.3
Family Circumstances	3	3.3
Financial Problems	3	3.3
7. Interpersonal Problems	2	2.2
8. Personality Disorders	1	1.1
Housing	1	1.1
	90	100.1

APPENDIX E

Table 8: Adult Mental Health Registration by Country of Birth of Clients Registered Between 1/7/92 - 30/6/93

<u>COUNTRY OF BIRTH</u>	<u>PERCENTAGE</u>
Australia	44%
Vietnam	11%
Greece	7%
Portugal	6%
New Zealand	2%
Unknown	4%
Other	22%

Source: Central Sydney Community Health Services
Information Systems

Table 9: Crisis Team Registration By Country of Birth of Clients Registered Between 1/7/92 and 30/6/93

<u>COUNTRY OF BIRTH</u>	<u>PERCENTAGE</u>
Australia	55%
Greece	6%
Vietnam	4%
Portugal	3%
Yugoslavia	2%
Italy	2%
Lebanon	2%
Other	24%

Source: Central Sydney Community Health Services
Information Systems

APPENDIX F

INFORMATION SHEET FOR PARTICIPANTS.

Chronic Mental Illness and its effect on the Portuguese Family.

My Name is Ms Deborah Wenham and I am doing a study concerning the Effects of mental Illness on Portuguese families. The aims of my study are as follows.

1. To reveal the experiences of Portuguese people who care for a person who is mentally ill and Portuguese.
2. To reveal the experiences of health workers involved with persons who care for persons who are mentally ill and Portuguese.

To do my study I would like to visit you and ask you and/ or other family members about your experiences. This should take no more than One Hour of your time and I will be bringing an interpreter to help me talk to you should you agree to participate. You should also know that I will be writing down your answers.

I would like to assure you, that you will not be identified in any way, and no information you give will be used without your permission. You also have the right to question any part of the procedure and you can withdraw your participation at any time.

Should you agree to participate and are interested in the completed work.

I will be calling you on the telephone to answer any further questions and confirm if you are interested in participating.

You are also invited to contact either myself or Mr. Ray Miletic my supervisor, at the times and phone numbers listed below.

Thank You for your kind attention.

Mrs. Deborah Wenham.

Available Monday to Friday on 5604500.

Project Supervisor. Mr. Ray Miletic.
Available Monday to Friday on 6466127.

APPENDIX G

QUESTIONS ADDRESSED TO HEALTH WORKERS ONLY

INTERVIEW QUESTIONS HEALTH WORKER

Health worker details.

Sex_____ age___ Relationship to clients._____

Professional type?

Years experience?

Where are clients usually seen?

Portuguese speaker?

Average % of case load Portuguese?

Services performed for clients?

Interpreter usage?

Do you think projecting a 'professional image' is essential for Portuguese Clients?

Could you describe 'Professional image' in this context?

What other attributes do you think help with engaging Portuguese clients?

Have you ever had to use family or friends to act as interpreters?

Describe the reasons for this?

Do you think your M.I. clients usually speak for themselves?

Have you noticed differences between males and female clients in this regard?

What language do your clients speak at home?

If you home visit your clients at home have you noticed common features in their home environments?

Have you noticed any formalities which are usually observed when you visit a Portuguese household?

Do you think the region of Portugal or it's territories is an important consideration when assessing your Portuguese M.I. clients?

Do you think the social class of your Clients before they came to Australia is an important consideration when assessing your Portuguese clients?

Would you list the advantages and disadvantages of either being or using a Portuguese speaking health worker with your Portuguese clients?

Do you think it is important for the health worker to be the same sex as the client?

Do you think the family has a strong influence over the clients?

Have you discovered or suspected domestic violence to be an prevalent issue in the lives of your clients?

INTERVIEW QUESTIONS

HEALTH WORKERS AND CARERS

FAMILY COMPOSITION

M.I. person usually live with their family /friends?

Average number of others in the home?

Are there usually other ill persons in the home needing care?

Are there usually persons under 18 living at home?

Has any of the persons you care for been subject to criminal charges?

Is it common for the person you care for, or any of their family to have made any compensation claims?

MIGRATION HISTORY

Did the M.I. person have their illness before they came to Australia?

If not, how long after arriving here did they become ill?

Did the M.I. person have friends and relatives already in Australia?

Reasons for coming to Australia?

HISTORY OF CARING PERIOD

Usual Length of time they have cared for the M.I. Person/s?

How did they become the M.I. person's carer?

Who else helps them care for the M.I. person?

If any, How do they help out?

CARER'S LEISURE TIME

What do your clients usually do for leisure?

How often?

Does the M.I. person go out alone?

Do your clients attend church regularly?

CARER'S EMPLOYMENT/ FINANCIAL HISTORY

Has having a M.I. stopped your clients seeking or keeping employment?

How has their employment been affected?

Has caring for the M.I. person caused financial difficulty for their carers?

How?

CARER'S HEALTH STATUS

Do your clients carer/s have an illness themselves?

Who do they go to see to help with their illness?

How often do they seek treatment for themselves?

Does the carer take medicine themselves?

Has the carer ever had to take medicine for sleeping?

Has the carer ever taken medicine for depression or nerves?

SMOKING AND ALCOHOL HISTORY

Does the M.I. person have a problem with alcohol?

Do other persons in the client's family have a problem with alcohol?

Does the M.I. person smoke?

Do other people at home smoke?

Are the clients and their family bothered by smoking?

TREATMENT IN PORTUGAL

Does the M.I. person go on holiday?

Has the carer taken the M.I. person back to Portugal for holiday?

Did the M.I. person take medication when in Portugal?

Did your clients believe their M.I. was improved in Portugal?

Did their carers think the M.I. person's illness was better in Portugal?

Have your clients had to get treatment for their M.I. in Portugal?

How do they get treatment for the M.I. person's illness in Portugal?

Do the clients find treatment better in Portugal than Australia?

How?

TREATMENT PREFERENCES

Do your clients know their diagnosis?

Do they accept their diagnosis?

Do you accept their diagnosis?

Should the M.I. person you care for become mentally ill where do they prefer have treatment?

If hospital, why do they prefer this?

If home, why do they prefer this?

Would you like to suggest some ways treatment for the persons you care for could be improved?

Do your clients take responsibility for their medication?

Does the carer give the M.I. person their medication?

Do your clients attend appointments with you or their doctors alone?

Does the carer take the M.I. person to doctors appointments?

Do your clients see other psychiatrists or doctors at the same time?

Does the carer take the M.I. person to other doctors or psychiatrists at the same time?

Does the carer act as interpreter for the M.I. person?

How often?

Are they bothered by this?

Does the carer or client prefer to pay for medical services?

If yes, why?

What other tasks do you think carers do for the M.I. client?

List. _____

Have your clients ever used the church, folk healers or clairvoyants to try and help themselves with their illness?

Do you think this is a common practise with Portuguese clients?

Can you list any other services that you have used to help care for the M.I. person?

Have you ever explained the M.I. person's medication to them?

Have you ever explained the M.I. person's medication to their carers?

Have you told them about the possible side effects of their medication?

Have you told the same to their carers?

Have you ever discussed what causes mental illness with the M.I. person?

With their carers?

Have you ever discussed the symptoms of mental illness with your clients?

With their carers?

Do you think they accept what you tell them?

Do you think their carers accept what you tell them?

Do you think they have problems understanding what you have told them?

Could you describe why you think this?

Do you think their carers have similar problems?

What do you think they believe mental illness is?

Do you think their carers have similar views?

Have they changed what they think about mental illness during the time you have cared for the M.I. person?

If yes, How?

Do you think the same has occurred with their carers?

Do you discuss their illness with the M.I. person you care for?

Do you discuss the M.I. . of your clients with their families if they permit it?

Can your clients tell when they are becoming mentally unwell?

Can your clients carers usually tell when the M.I. person is becoming unwell?

What behaviors are usually the most bothersome to the M.I. person?

What behaviors usually bothers the carers most?

What forms of medication do you think they prefer?

Do they expect the medicine to work immediately?

Do the carers expect the medicine to work immediately?

Should the M.I. person you care for become mentally ill, who usually contacts you?

CARER'S AND THEIR COMMUNITY

Has having a M.I. affected how other members of the Portuguese community treat your clients?

If yes, how?

Do you think the person's carers have been similarly affected?

Do you think there are differences in this regard between male and female clients?

CARER'S OPTIONS FOR THE FUTURE

Do your clients intend to return to live in Portugal eventually?

If no, has the M.I. person's condition influenced their decision to stay in Australia?

What concerns you the most about the future of the person you care for?

Does the M.I. of the person you care for affect other members of their family?

If yes, How?

Would you like to suggest some ways that would make caring

for your M.I. Portuguese clients easier for you?

Do your clients carers ever express an inability to cope with the person they are caring for?

Do you think carers ask for help when necessary?

If not, why do you think they understate their problems?

Who in the family of the M.I. person do you think makes the final decisions concerning the treatment of your M.I. clients?

Are there any other matters or concerns you would to mention concerning the Portuguese clients you care for?

CARER INTERVIEW QUESTIONS.

Carer details see appendix A

Residence type?

What region of Portugal do you come from?

Interpreter need?

English Skills?

Language spoken at home?

FAMILY COMPOSITION.

Person cared for live with them?

Number of others in the home?

Do they belong to one family?

Any other ill persons in the home needing care?

List.

Are there persons under 18 living at home?

Has the person they care for been subject to criminal charges?

Has the person they care for made any compensation claims?

MIGRATION HISTORY

Did the M.I. person have their illness before they came to Australia?

If not, how long after arriving here did they become ill?

Did the carer come to Australia before the the M.I. person?

Did the M.I. person have friends and relatives already in Australia?

Did the carer have friends and relatives already in Australia when they came?

Reasons for coming to Australia?

M.I.P.

Carer.

HISTORY OF CARING PERIOD.

Length of time they have cared for the M.I. Person/s?

How did they become the M.I. person's carer?

Who helps them care for the M.I. person?

If any, How do they help out?

CARER'S LEISURE TIME

What do they do for leisure?

How often?

Does the M.I. person go with them when they go out?

Has caring for the person made leisure time difficult to achieve?

Do you attend church regularly?

CARER'S EMPLOYMENT AND FINANCIAL HISTORY

Has caring for the M.I. person stopped the carer from seeking or keeping employment?

How has their employment been affected?

Has caring for the M.I. person caused financial difficulty for the carer?

How?

CARER'S HEALTH STATUS

Does the carer have an illness themselves?

Who do they go to see to help with their illness?

How often do you seek treatment for yourself?

Does the carer take medicine themselves?

Has the carer ever had to take medicine for sleeping?

Has the carer ever taken medicine for depression or nerves?

Have the carer's or are the carers involved in compensation claims?

SMOKING AND ALCOHOL HISTORY

Does the M.I. person cared for have a problem with alcohol?

Do other persons in the family have a problem with alcohol?

Does the M.I. person smoke?

Does the carer smoke?

Do other people at home smoke?

Does smoking bother the carer?

If yes or no, how?

TREATMENT IN PORTUGAL

Does the carer take holidays?

Does the M.I. person go on holiday with them?

Has the carer taken the M.I. person back to Portugal for a holiday?

Did the M.I. person take medication when in Portugal?

Did the carer think the M.I. person's illness was better in Portugal?

Have you had to get treatment for the M.I. person in Portugal?

How do you get treatment for the M.I. person's illness in Portugal?

Do you find treatment better in Portugal than Australia ?.

How?

TREATMENT PREFERENCES

Do you know the diagnosis of the M.I. person you care for?

Do you accept this diagnosis?

Should the M.I. person you care for become mentally ill where would you like the person to have treatment?

If hospital , tell me how you think this is better?

If home, tell me how you find this better?

Would you like to suggest some ways treatment for the person you care for could be improved?

Does the carer give the M.I. person their medication?

Does the carer take the M.I. person to doctors appointments?

Does the carer take the M.I. person to other doctors or psychiatrists at the same time?

Does the carer act as interpreter for the M.I. person?

How often?

Are they bothered by this?

Does the carer prefer to pay for medical services?

If yes, why?

What other tasks do you do for the M.I. client?

List. _____

Have you ever used the church, folk healers or clairvoyants to try and help the person they care for?

Can you list any other services that you have used to help care for the M.I. person?

Have you ever had the M.I. person's medication explained to you?

Have you been told about the possible side effects of their medication?

Have you ever discussed what causes mental illness with the person's doctor or case manager?

Have you ever discussed the symptoms of mental illness with a doctor or case manager?

What do you think mental illness is?

Have you changed what you think about mental illness during the time you have cared for the M.I. person?

If yes, How?

Do you discuss their illness with the M.I. person you care for?

Can you tell when the person you care for is becoming mentally unwell?

What behaviors do they have that are bothersome to you?

Is violence a problem with the person you care for?

Are there problems with violence from other family members?

What forms of medication do you think are better?

Do you expect the medicine to work immediately?

Should the M.I. person you care for become mentally unwell who do you contact first?

Have you ever felt you could not cope with the M.I. person?

How often?

Can you share these feelings with others?

If no, how do you deal with these feelings?

If yes, Who helps you?

CARER'S AND THEIR COMMUNITY

Has having a M.I. person in your care/ family affected how other members of the Portuguese community treat you?

If yes, how?

CARER'S OPTIONS FOR THE FUTURE

Do you intend to return to live in Portugal eventually?

If no, has the M.I. person's condition influenced your decision to stay in Australia?

What worries you the most about the future of the person you care for?

Does the M.I. of the person you care for affect other members of your family?

If yes, How?

Would you like to suggest some ways that would make caring for the M.I. person easier for you?

Would you be prepared to meet other Portuguese carers of mentally ill persons in a group to discuss your experiences and problems?

Who in the family makes the final decision in regard to family matters?

Who has the final say about what the family does in regard to the person you care for?

Are there any words and phrases in Portuguese that you use to describe or name mental illness?

Are there any other matters or concerns you would to mention concerning the person you care for?