

## **SHARED CARE IN SERIOUS MENTAL ILLNESS: CARING FOR CARERS**

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## **Introduction**

### ***Background***

Research examining families of people suffering from mental illness has historically focused on the family as a causative agent (for example parenting styles and more recently, genetics). While research into the family's role in causation, relapse and success of treatment in schizophrenia continues (eg. Battaglia, Gasperini et al. 1991; McCreddie, Phillips et al. 1991; Miklowitz, Velligan et al. 1991), other researchers have chosen to focus on the family as caregivers to the chronically ill (eg. Chakrabarti and Kulhara, 1999; Webster, 1992; Winefield and Harvey, 1993, 1994). Family caregiving of the mentally ill became particularly pertinent as health systems began the process of deinstitutionalisation in the 1950's and 1960's. While few would argue against the basic tenant of treatment within the community, removing mentally ill people from full time care in hospitals resulted in many families providing full time care at home. Studies conducted around this time confirmed that families suffered an increased burden as mentally unwell family members returned home (Grad and Sainsburg, 1963; Mandelbrote and Folkard, 1961).

### **Defining Family Burden**

As the body of research into family burden has increased, so the definitions of burden have gained complexity. This at least partially reflects the complex nature of the caregiving role and the uniqueness of each ill family member. In order to define burden, it is necessary to first examine what is meant by a caregiver. At the most basic level, caregiving implies that the responsibilities and tasks of one party in a relationship go beyond those customarily expected (Schofield, 1998). Carers of patients with serious mental illness may find themselves acting as pseudo case managers undertaking tasks such as supervision of medication compliance, coordination of services and provision of emotional and physical support. Burden occurs, in part, from the stress that is frequently experienced as a result of these intense demands (Fadden, Bebbington et al. 1987; Johnson, 1990; Winefield and Harvey, 1993). Studies have identified four main sources of burden, namely restrictions on the carer's social and leisure activities, the strains placed on finances and employment, the emotional impact the illness has on the carer, and the difficulty in dealing with dysfunctional and bizarre behaviours (Kuipers, 1993).

A distinction has been made between objective and subjective levels of burden (Hoenig and Hamilton, 1966). Objective burden relates to quantitatively measurable outcomes, such as the financial costs of caregiving, and costs to the carer's mental and physical health. Subjective burden, on the other hand, refers to the individual carer's perception of the burden that they are experiencing. While the two are frequently related, it is possible for them to act independently, highlighting the need for careful measurement of both.

### **Correlates of carer burden**

Literature evaluating burden includes carers of people with psychiatric and physical illnesses, such as dementia, physical disability and schizophrenia (Chakrabarti, Kulhara et al. 1993; Hodgson, Wood et al. 1996; Kramer, 2000; Winefield and Harvey, 1993, 1994). The burden reported by these carers ranges from an increased prevalence of psychiatric conditions (especially depression and anxiety) to financial difficulties and disruption of leisure activities (Chakrabarti, Kulhara et al. 1993; Cochrane, Goering et al. 1997; Gallagher, Mechanic et al. 1996; Haley, Levine et al. 1987; Livingston, Manela et al. 1996).

Literature focusing on carers of patients with serious mental illness has frequently utilised the model of subjective and objective burden, finding both types of burden to be highly prevalent in these carers. These high levels of burden often have negative consequences for the carer's mental health. For example, Bibou-Nakou, Dikaiou et al. (1997) found that high levels of objective and subjective burden were significantly associated with lower levels of psychological wellbeing. Levels of depression in carers appears particularly high, with Winefield and Harvey (1993) finding almost double the rates in a carer sample compared with a representative Australian community sample. To a lesser extent, high levels of burden may also have negative effects on the carer's physical health (Cochrane, Goering et al. 1997), although this has been examined less frequently than the impact that burden has on mental health.

Carer burden has also been linked to a number of patient and carer specific factors. Patient factors such as frequency of behavioural problems, length of illness and severity of illness have been positively related to carer burden (Biegel, Milligan et al. 1994; Chakrabarti, Kulhara et al. 1992). Carer factors and qualities such as coping style, motivation and perceived level of support have also been linked to the level of burden experienced (Biegel, Milligan et al. 1994; Duijnste, 1994).

### ***Rationale for the current study***

While numerous studies have examined psychological wellbeing in carers, very few have compared rates of burden related factors, such as depression, to population base rates. The majority of literature, therefore, has tended to either report results as proportions without comparison to the general population, or has compared wellbeing variables between carers with high versus low burden. One Canadian study (Cochrane, Goering et al. 1997) did compare the rates of depression in carers to those found in a major epidemiological survey and indeed confirmed higher levels of distress in the carer sample. This sample, however, was compiled of people caring for the mentally ill, disabled and elderly. A study examining prevalence rates of burden related factors such as physical and mental health problems in carers of patients with serious mental illness, in relation to known epidemiological data has yet to be conducted. This may in part be due to the difficulty in obtaining reliable population data, but the availability of Australian population data from the National Survey of Mental

Health and Wellbeing (NSMHWB; Andrews, Henderson et al. 2001) has provided an opportunity to conduct this type of research within Australia.

Since 1997, the research team have been systematically investigating the experience of carers through a General Practice Evaluation Program funded project (GPEP 518): "General Practitioners caring for the long term mentally ill: is shared care quality care?" (Meadows, Harvey et al. 2003). The data from GPEP 518 revealed moderate objective burden and high subjective burden in carers. The research team hypothesised this as possibly indicative of high rates of major depression and/or anxiety disorders in those caring for patients with a serious mental illness, however this study did not specifically examine this. Certainly, community-based studies suggest that the majority of major depression and other psychiatric disorders remain undiagnosed and are consequently not treated. This raises the distinct potential that this low recognition may be repeated in the carer sample of GPEP 518 and others like them. This study, therefore, aimed to report levels of depression and anxiety in carers and compare these to population base rates. In addition to examining these prevalence rates, two models of patient care were evaluated, to assess whether the type of mental health intervention available to the patient had any effect on carer burden. These two models are the current conventional care provided by Area Mental Health Services (AHMS), which is case management based, and a shared care model (Consultation Liaison in Primary Care Psychiatry; CLIPP) designed to more heavily involve General Practitioners (GPs) in the care of the mentally ill.

### **Shared Care Programs**

As previously mentioned, the process of de-institutionalisation and the main-streaming of mental health services has shifted the locus of care for patients with severe mental health disorders in great measure from specialist services, including hospitals, to the wider community. Not only has this potentially increased the burden placed on carers and family, but also potentially the burden on GPs to provide ongoing care to the mentally ill and their family members. The motivation for this study was to determine whether the introduction of shared care promoted helpful and productive interaction between GPs and carers of patients with serious mental illness. It also hoped to clarify whether the introduction of a shared care model shifted the burden from mental health services to families. Literature searches have demonstrated that currently no reports exist investigating the burden in carers of patients with mental illness whose care has been shared with general practitioners. This is despite some authors (Lefley, 1990; Smith and Birchwood, 1990) suggesting that collaboration between those who care for the patient and those who care for the relatives may be beneficial to all parties.

## **The CLIPP Shared Care Model**

A GP shared mental health care initiative was developed in Victoria over the last eight years by the Northwest AMHS, the North West Melbourne Division of General Practice and the University of Melbourne. This model of service delivery provides a supportive mechanism for mental health service patients to be reintegrated into general health care within a seamless service delivery structure. It attempts to synthesise three major elements; consultation liaison in general practice, defined transfer protocols facilitated by a specialist staff member and case registration to support continuity of care.

The program processes have been comprehensively reported elsewhere (see <http://www.health.vic.gov.au/mentalhealth/publications/clipp/>)

## **Aims**

### ***Overview***

The overall aims of this project were to assess whether carers of people suffering continuing and serious mental illness have increased prevalence of psychiatric morbidities compared to the general population, whether carers of patients with serious mental illness who are managed in the shared care setting consult with GPs more than carers of patients who are managed by conventional case management and whether in the shared care setting the GPs are successful at detecting and treating psychiatric morbidity amongst carers. These central propositions were operationalised by the following set of research hypotheses.

### ***Hypotheses***

When compared with the general population, there will be an increased rate of depressive disorders in the carers of patients with serious mental illness who are managed in the shared care setting and by conventional case management.

When compared with the general population, there will be an increased rate of anxiety disorders in the carers of patients with serious mental illness who are managed in the shared care setting and by conventional case management.

When compared with the general population, there will be an increased rate of neurasthenia (a condition characterised by general lassitude, irritability, lack of concentration, worry, and hypochondria; Bartelby, 2003) in the carers of patients with serious mental illness who are managed in the shared care setting and by conventional case management.

When compared with the general population, there will be an increased rate of physical disorders in the carers of patients with serious mental illness who are managed in the shared care setting and by conventional case management.

Carers of the patients with serious mental illness who are managed in the shared care setting will consult with general practitioners more than carers of patients who are managed by conventional case management.

Carers of the patients with serious mental illness who are managed in the shared care setting will see their needs for mental health care as being met to a greater extent than carers of patients who are managed by conventional case management.

Carers of the patients with serious mental illness who are managed in the shared care setting will see their needs for physical health care as being managed to a greater extent than the carers of patients who are managed by conventional case management.

## **Method**

### ***Setting***

The model of shared care that was examined in this study was the CLIPP Shared Care Model which has successfully implemented, and sustained, psychiatric liaison attachments to 12 general practices. It has transferred over 160 patients from the local AMHS into shared care with GPs using the channels of communication and collaboration developed within the liaison attachments.

### ***Participants***

The study plan involved the use of two quasi-experimental designs:

#### ***1. Comparison of the prevalence of disorder in each of two groups of carers with the prevalence in appropriately matched groups drawn from a national community survey data set.***

This first quasi-experimental design addressed hypotheses 1, 2, 3 and 4 outlined above.

The two "exposed" groups, each with one of two different exposures, were:

39 carers of people with serious mental illness, where the care of the person with serious mental illness had been transferred into the CLIPP Shared Care Model with general practitioners from the North West of Melbourne.

19 carers of people with serious mental illness, where the care of the people with serious mental illness was being managed in the conventional AMHS setting under case management.

Recruitment into this study was dependent on informed consent. All patients where the carer was approached had been in their particular care setting for at least twelve months.

The matched "non exposed" subjects were drawn from the Confidentialised Unit Record File of the NSMHWB (Andrews, Henderson et al. 2001). This data had already been collected and hence, the subjects did not need to be approached further for this purpose. The chosen case data was matched for age, sex, socio-economic status of area and state of residence. The data set from the survey did not enable us to exclude the possibility that some participants may also have been carers of people with serious mental illness, however the prevalence of this kind of disorder in the community meant that this could be judged to be a low frequency event. The data sets from this survey were fully anonymised under the legal statutes

governing the functioning of the Australian Bureau of Statistics so individual subjects could not be identified.

## ***2. Comparison of two groups of carers for retrospective report of service use and perceived met need for mental health care.***

This part of the study involved collection of retrospective self-report data of service utilisation and perceived met need on the part of the above identified groups of carers. In contrast to the above section, this part of the study addressed hypotheses 5, 6 and 7 above and therefore involved comparisons between the two groups of carers. Hence, in this quasi-experimental design the "exposures" were differently conceptualised, with the CLIPP linked carers (Group 1 above) being the "exposed" group and the AMHS linked carers (Group 2 above) being the "non-exposed" group. Given the concern that a close matching strategy might have rendered recruitment of the desired numbers impossible, the available sample frames were identified and subjects were recruited according to a feasible matching strategy that accounted for features such as relationship to patient, sex and broad age strata.

### ***Measures***

The instruments used in this study were the same as those used in the NSMHWB (Andrews, Henderson et al. 2001), with some minor modifications to make them suitable for this purpose. Several sections of the NSMHWB field questionnaire (Andrews, Henderson et al. 2001) were not considered (eg. manic and bipolar disorders, psychotic disorders, organic mental disorders and personality disorders) in the interests of maintaining the interview time frame judged acceptable for the NSMHWB (that is, 1hour; Andrews, Henderson et al. 2001).

### **Demographics**

Demographics collected about the carer included age, country of origin, language spoken, education level, marital status, children, employment details, sources of income, housing, relationship to the patient and time spent in the caring role.

### **Physical Disorders Self Report**

Carers were provided with a list of common physical disorders and asked to confirm any specific disorders that they had experienced.

### **Neurasthenia**

Neurasthenia is characterised by mental or physical fatigue. The occurrence of symptoms such as low energy, dizziness, headache, disturbed sleep, inability to relax, muscle aches and pains, irritability, poor memory and concentration were assessed.

### **Sections of the Composite International Diagnostic Interview (CIDI-Auto; World Health Organisation, 1993a).**

The CIDI-Auto is a computerised version of the CIDI (World Health Organisation, 1993b). It is a fully structured diagnostic interview for the assessment of mental disorders which

provides lifetime and current diagnosis according to the accepted criteria of the International Classification of Diseases (ICD-10; World Health Organisation, 1993c) and Diagnostic and Statistical Manual for Mental Disorders (DSM-IV; American Psychiatric Association, 1994). The sections considered for this protocol included anxiety disorders, depression and dysthymic disorders, alcohol and substance abuse. The inter-rater and test-retest reliability of the CIDI-Auto is considered excellent because the scoring does not allow field researchers judgement to intervene, but rather is based solely on carer's responses (World Health Organisation, 1993d). The instrument has also demonstrated acceptable validity (Peters and Andrews, 1995).

### **Brief Disability Questionnaire**

The BDQ is a self rating scale which asks respondents whether specific activities have been affected by their health state (eg. climbing stairs). It assesses whether they have cut down or stopped routine activities (eg. efficiency at home, school or work).

### **Perceived Need for Care Questionnaire (PNCQ) (Meadows, Harvey et al. 2000a,b).**

This questionnaire is fully structured and has a branching format that systematically explores perceptions of receiving mental health care, including adequacy of service response. The enquiry proceeds along five branches, probing for consumer perceived need relating to information, medication, counselling, social interventions and skills training. Reliability and validity are adequate.

### **General Health Questionnaire (GHQ) (Goldberg, 1972)**

This questionnaire is a measure of psychological disturbance validated for Australian community populations. It asks respondents how their general health has been over the few weeks prior to interview.

## ***Procedures***

### **Inclusion Criteria**

To be considered for the project, patients were required to be:

Either in long-term shared care within the CLIPP program, or under case management by an Area Mental Health Service that does not have an active shared- care program.

Aged 18 to 65 years and suffering from a chronic mental illness.

They needed to have been diagnosed more than three years ago and preferably not hospitalised within the twelve months prior to participation in the project.

In some instances the last criteria was not rigidly enforced if a very brief hospitalisation was considered unlikely to have impacted on the levels of burden experienced by the carer.

Carers of eligible patients were nominated by the patients and defined as "someone who had a particular interest in their well-being and gave practical or emotional support." Carers were

considered eligible for the project regardless of their relationship with the patient or current living arrangements, but they were required to be over 18 years of age.

### **Recruitment of carers and patients previously known to the team**

Where carers and patients had a previous relationship with the research team through being involved with GPEP 518, they were approached directly and invited to participate in the study.

### **Recruitment of carers and patients not previously known to the team**

The research team marketed the project to clinical teams within participating services and invited case managers and clinicians to identify appropriate patients whose carers might be willing to participate in the study. The case managers and clinicians undertook an initial exploratory approach with patients to gauge their level of interest. Upon confirmation of interest, contact details for the patients were provided to the research team and the formal consent process undertaken. Patients nominated their appropriate carers, who were subsequently contacted by the research team. They were provided with an explanation of the aims of the project and invited to participate.

### **Testing**

Participation in the study involved an interview session with carers conducted by experienced field researchers using the composite interview described above. The interview was generally conducted in a place most suitable to the carer (eg. their home, office, AMHS or GP surgery) and without the patient present.

### **Ethical Considerations**

The principle participants for this study were carers, however, and as developed within the guidelines for ethical approval within the applying Mental Health Ethics approval committee<sup>1</sup>, informed consent was also obtained from patients prior to their carers being approached. Each participant, regardless of their status as a patient or carer, was given a copy of their respective plain language statements and upon agreeing to participate, their consent form. They were informed about the purpose of the study, what would be involved and the estimated duration of the interview. They were also made aware that debriefing would be available to them, should it become necessary as a result of their involvement. Participation was voluntary and could be withdrawn at any time, without any adverse affect. All information provided by participants remained confidential, and remains in archive in line with relevant ethics approval procedures.

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<sup>1</sup> Ethics approvals were granted from NorthWestern Mental Health and Southern Health (Melbourne), also from SouthWest Health Care (Warrnambool).

## **Results**

### ***Sample***

#### **Carer and Control Characteristics**

In total carers 58 (18 males and 40 females) completed the structured interview. The carer sample was divided into two groups, 39 who had cared for patients within the CLIPP Shared Care model and 19 who had cared for patients receiving care from an AMHS. Each carer was matched randomly by age group, gender and socio-economic status to four controls gained from the NSMHWB. This provided a total of 232 participants in the control group. The larger control sample was utilised to assist with statistical power for analysis.

The demographics for the carers and control group are provided in Table 1.

**Table 1: Demographics of Carer vs Non-carer control samples**

	Carers total (%)	Control (%)
Marital Status		
Married/Defacto	67.2	53.0
Not - married	32.8	47.0
Country of Birth		
Australia	50.0	71.6
Other English speaking	3.4	13.8
Non-English speaking	46.6	14.7
Language spoken at home		
English	63.8	91.8
Other	36.2	8.2
On a government allowance	72.7	47.9

From this table we can see that, when carers are compared to the control group, more carers were from a non-English speaking country of birth and more carers were on government allowance than non-carers.

The CLIPP and AMHS carers were compared on demographic variables. The two groups did not differ on the variables of age ( $t(19) = -1.566$ ;  $p > 0.05$ ), marital status ( $\chi^2(1) = 1.121$ ;  $p > .05$ ), country of birth ( $\chi^2(1) = 4.253$ ;  $p > .05$ ) or language spoken at home ( $\chi^2(1) = 2.809$ ;  $p > .05$ ). There were more CLIPP carers on government allowance than AMHS carers ( $\chi^2(1) = 4.856$ ;  $p < .05$ ). There were also no males in the AMHS sample, as opposed to the CLIPP sample, which was made up of 46% males ( $\chi^2(1) = 12.715$ ;  $p < .01$ ). The demographic variables for the CLIPP and AMHS carers are contained in Table 2.

**Table 2: Demographics of CLIPP and non-CLIPP groups (percentages)**

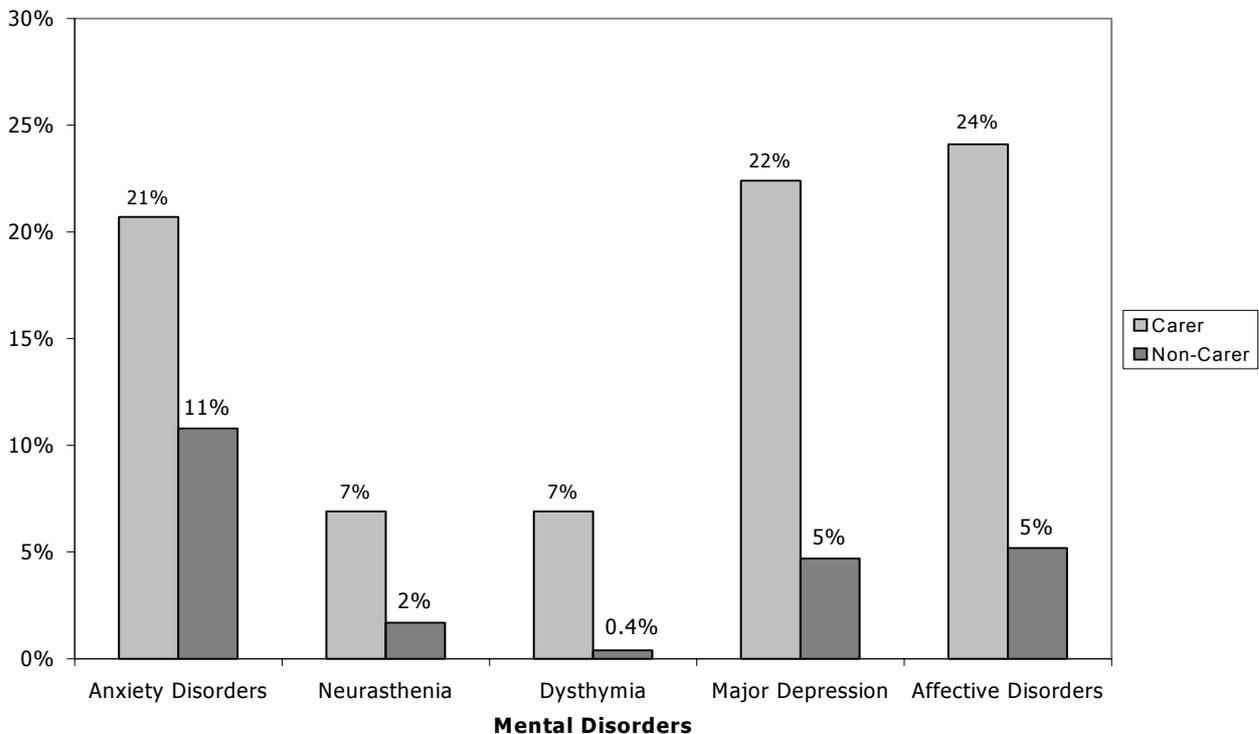
	CLIPP group (n=39)	Non-CLIPP group (n=19)
Mean Age (SD)	57.3 ( $\pm 16.4$ )	50.7 ( $\pm 11.7$ )
Gender		
Female	53.8	100
Male	46.2	0
Marital Status		
Married/Defacto	71.8	57.9
Not - married	21.2	42.1
Country of Birth		
Australia	41	68.4
English speaking	5.1	0
Non-English speaking	53.8	31.6
Language spoken at home		
English	56.4	78.9
Other	43.6)	21.1
On a government Allowance	81.6	52.9

## ***Prevalence rates of mental and physical conditions in the carer sample compared to controls***

### **Mental disorders**

Overall, the carer group had a high morbidity of mental disorders, with 29.3% fulfilling criteria for at least one disorder. The most common psychiatric conditions were affective disorders (24.1%) followed by anxiety disorders (20.7%). Figure 1 presents the prevalence rates of mental disorders in the carer and control groups.

Figure 1: Prevalence rates of mental disorders in the carer and control sample



### **Physical Conditions**

Overall, 53.4% of the carer group suffered from one or more physical condition, a very similar rate to that suffered by the control group (53.9%).

### ***Hypothesis testing for Carer vs Non-Carer groups***

Conditional logistical regression was used to estimate the strength of association between psychiatric and physical conditions in the carer group as opposed to controls. Table 3 presents the odds ratios and significance levels for psychiatric and physical variables

examined. A significantly greater number of carers suffered from anxiety and affective disorders than the control group. More specifically, a larger proportion of carers suffered from neurasthenia, dysthymia and depression than controls. The carer group did not suffer from increased physical conditions when compared to controls.

**Table 3: Results of Conditional Logistical Regression analysis between the binary variables and group (carer vs non-carer).**

<b>Variable</b>	<b>Odds Ratio (95% CI)</b>	<b>Wald Chi-square (df)</b>	<b>P Value</b>
Physical Conditions	0.98(0.52 to 1.85)	0.00(1)	0.9479
Agoraphobia	2.00 (0.37 to 10.92)	0.64(1)	0.4235
GAD	2.22 (0.68 to 7.17)	1.77(1)	0.1835
OCD	1.33 (0.14 to 12.8)	0.06(1)	0.8033
PTSD	1.26 (0.38 to 4.10)	0.14(1)	0.7038
Anxiety Disorders	2.23 (1.02 to 4.89)	4.02 (1)	0.0450*
Neurasthenia	4.00 (1.00 to 15.99)	3.84(1)	0.0499*
Dysthymia	16.00 (1.79 to 143.15)	6.15(1)	0.0131*
Depression	5.34 (2.27 to 12.58)	14.71(1)	0.0001**
Affective Disorders	5.21 (2.30 to 11.8)	15.68(1)	0.0001**
Alcohol Dependence	2.17 (0.35 to 13.47)	0.69(1)	0.4043
Drug Use Disorder	1.33 (0.14 to 12.81)	0.06(1)	0.8033
Substance Use Disorders	0.88 (0.18 to 4.23)	0.02(1)	0.8774
Total Mental Disorders	2.21 (1.14 to 4.29)	5.52(1)	0.0188*
Mental Health Service Utilisation	0.89 (0.37 to 2.12)	0.07(1)	0.7971
All Mental Disorders	2.07 (0.77 to 5.58)	2.08(1)	0.1487
Comorbid Mental and Physical Disorders	2.05 (0.91 to 4.58)	3.05(1)	0.0818

Note: Chi-Squared results were not calculated for the variables of *Panic Disorder*, *Depressive disorder not otherwise specified* and *Harmful alcohol use* as there were insufficient positive numbers for statistical analysis.

\*p<0.05 \*\*p<0.01

Conditional logistic regression was also conducted to more closely examine the individual contribution of each disorder to the overall greater rates of mental disorders in carers. In order to do this, combined co-morbid variables were calculated. These results can be found in Table 4.

**Table 4: Results of Conditional Logistical Regression analysis between the categorical variables and group (carer vs. non-carer).**

<b>Variable</b>	<b>Odds Ratio (95% CI)</b>	<b>Wald Chi-square (df)</b>	<b>PValue</b>
Comorb2		18.37(9)	0.0311*
Physical only	0.80 (0.39 to 1.65)	0.37(1)	0.5431
Anxiety only	0.88 (0.89 to 8.63)	0.01(1)	0.9128
Affective only	1.92 (0.16 to 22.5)	0.27(1)	0.6042
Substance abuse only	(0.00 to inf)	0.00(1)	0.9892
Combination Mental only	4.01 (1.11 to 14.50)	4.49 (1)	0.0341*
Anxiety and Physical	0.33 (0.04 to 2.87)	0.99(1)	0.3187
Affective and Physical	7.31 (1.31 to 40.87)	5.14(1)	0.0234*
Substance Abuse and Physical	(0.00 to inf)	0.00(1)	0.9866
Combination Mental and Physical	5.91 (1.33 to 26.22)	5.47(1)	0.0194*
Comorb3			0.1300
Physical Disorders Only	0.87 (0.41 to 1.80)	5.65	0.6973
Comorbid mental and physical	2.02 (0.82 to 4.95)	(3)	0.1257
Mental disorders only	2.16 (0.77 to 6.04)	0.15(1)	0.1438
		2.34(1)	
		2.14(1)	
Comorb4			0.0037**
Anxiety only	0.57 (0.12 to 2.63)	0.52 (1)	0.4705
Affective only	5.22 (1.37 to 19.78)	5.90 (1)	0.0151*
Substance abuse only	(0.00 to inf)	(1)	0.9832
Anxiety and affective	5.96 (1.91 to 18.62)	9.43 (1)	0.0021**
Substance abuse and other	3.89 (0.55 to 27.64)	1.84 (1)	0.1749

\*p<0.05 \*\*p<0.01

Due to low numbers in the substance abuse categories, the analysis of co-morbidity was reconducted excluding substance abuse. This found that significantly more carers suffered

from co-morbid anxiety and affective disorders than the controls. These results are contained in Table 5.

**Table 5: Results of Conditional Logistical Regression analysis examining co-morbidity in the carer vs non-carer groups, excluding substance abuse.**

<b>Comorbid disorders (excluding substance abuse)</b>	<b>Odds Ratio (95% CI)</b>	<b>Wald Chi-square (df)</b>	<b>PValue</b>
Anxiety only	0.87 (0.24 to 3.18)	0.04(1)	0.8328
Affective only	5.39(1.43 to 20.27)	6.20(1)	0.0128*
Anxiety and affective	5.04 (1.84 to 13.78)	9.93(1)	0.0016**

\*p<0.05 \*\*p<0.01

## ***Prevalence rates for CLIPP vs AMHS carers***

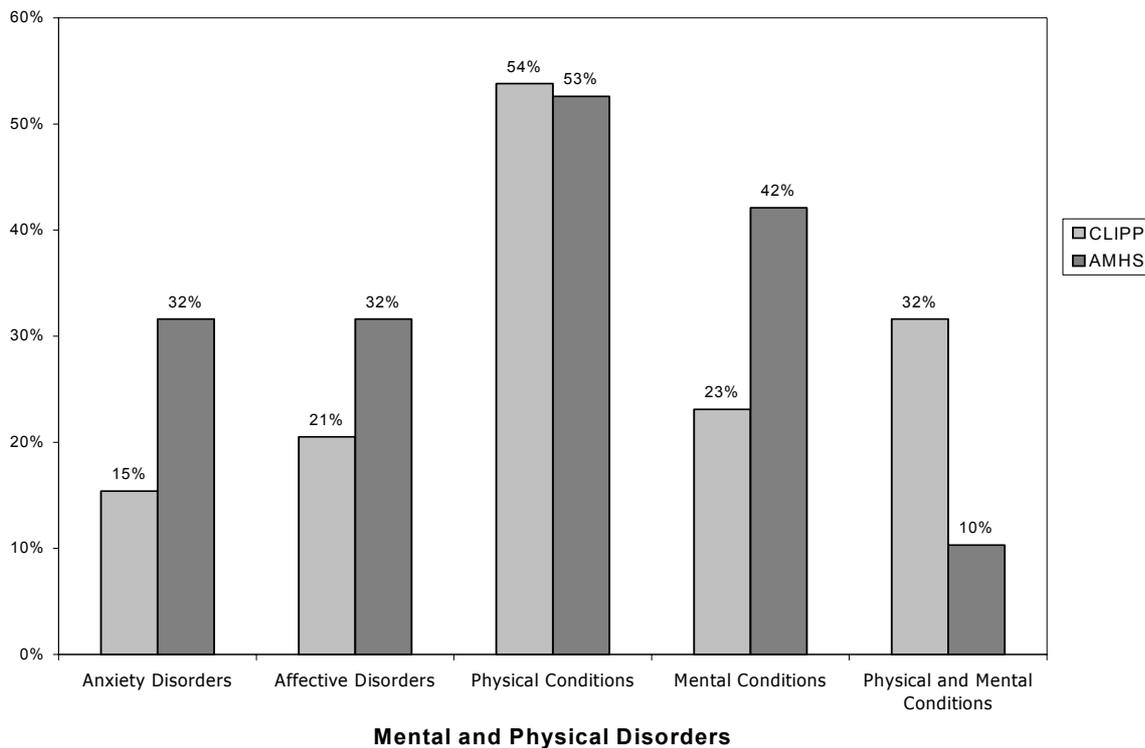
### **Mental disorders**

CLIPP and AMHS carers suffered similar rates of mental conditions. Qualitatively, AMHS carers appeared to have higher rates of mental disorders (42.1%) than CLIPP carers (23.1%). AMHS suffered double the rate of anxiety disorders (31.6%) compared to CLIPP carers (15.4%). AMHS also had higher rates of depressive disorders than CLIPP carers (31.6%vs 20.5%).

### **Physical conditions**

Almost forty four percent of CLIPP carers endorsed self-report of the specified physical conditions. This is opposed to only 21.1% of AMHS carers who reported these physical conditions.

**Figure 2: Percentage of mental and physical condition in CLIPP vs. AMHS carers**



### ***Hypothesis testing for CLIPP vs AMHS groups***

#### **Mental and physical disorders**

Chi-squared analyses were conducted to examine the rates of mental and physical disorders within the CLIPP and AMHS groups. The results of these analyses are contained in Table 6. There was a trend for CLIPP carers to report physical conditions with greater frequency than did AMHS carers. When comorbid mental and physical disorders were examined, AMHS carers had significantly greater comorbidity than CLIPP carers.

**Table 6: Chi-Squared analyses comparing AMHS and CLIPP carers on mental and physical disorders.**

	<b>AMHS (%)</b>	<b>CLIPP (%)</b>	<b>Chi-sq(df)</b>	<b>p</b>
Mental Disorders Only	2 (10.5)	5 (12.8)	.063(1)	.801
Physical conditions only	4 (21.1)	17 (43.6)	2.809(1)	.094
Mental and physical disorders	6 (31.6)	4 (10.3)	4.071(1)	.044*
Any mental or physical disorder	12 (63.2)	26 (66.7)	.070(1)	.792
One or more mental disorders	8 (42.1)	9 (23.1)	2.233(1)	.135
One or more physical conditions	10 (52.6)	21 (53.8)	.008(1)	.931
Anxiety Disorders	6 (31.6)	6 (15.4)	2.042(1)	.153
Affective Disorders	6 (31.6)	8 (20.5)	.854(1)	.355
Substance Abuse Disorders		2 (5.1)	1.009(1)	.315
Mental Health Related Service Use (last 12 months)	3 (15.8)	4 (10.3)	.369(1)	.544

\*p<0.05

#### **Patterns of health consulting and satisfaction**

Chi-squared analyses were carried out to examine the frequency of contact carers had with health professionals. These results are contained in Table 7. As expected carers of patients within the CLIPP setting consulted with general practitioners more than carers of patients in the AMHS did.

**Table 7: AMHS vs CLIPP consultations with health professionals**

<b>Consultations in the last 12 months</b>	<b>AMHS (%)</b>	<b>CLIPP (%)</b>	<b>Chi-sq(df)</b>	<b>p</b>
GP Mental Health Consultations	2 (10.5)	4 (10.3)	.001(1)	.975
GP Mental or Physical Consultations	14 (73.7)	37 (94.9)	5.404(1)	.020*
	<b>Mean (SD)</b>	<b>Mean (SD)</b>	<b>t(df)</b>	<b>p</b>
Total GP consultations	.8421(.8342)	1.8718(.9509)□	-4.02( 5)	.000**

\*p<0.05 \*\*p<0.01

We also examined the degree of satisfaction of carers to the level of health assistance provided to them. Only majority of carers reported that they did not require health services (65.5%), with slightly higher numbers of CLIPP (71.8%) than AMHS (52.6%) requiring no assistance. Further, 87.9% of the whole carer sample found no need for mental health services, with no differences between the groups. No carers felt that their need for information, medication or social support was unmet. Two carers (one each from CLIPP and AMHS) felt that their need for counselling was unmet. One carer (from CLIPP) felt that their need for skills to assist them with caring was unmet.

In summary, the majority of carers did not report high need for mental or physical support services for themselves. This was despite higher reported rates of physical and interview-diagnosed mental-conditions suffered by the carer group. Qualitatively, many of the interviewers involved in the project noticed that carers felt that their burden was inherent to caring for someone with mental illness. Carers frequently made comments indicating that these difficulties reflected 'their lot in life'.

## **Discussion**

### ***Overview***

In this study we have made use of the data resource of the National Survey of Mental Health and Wellbeing data set to contrast the diagnosed mental and self-reported physical morbidities of carers of people with mental health problems with those experienced by people in the community. The large size of the NSMHWB data set has enables us to draw large numbers of controls for these cases without the expense of community representative data collection for this specific study. This methodology has enabled us within reasonable resource limitations to derive estimates of the relative rates, and odds, for experiencing these

disorders as a carer compared to the rates found within a matched group in the community. There has been some comparison of morbidity rates between two care models, one an innovative shared-care model, and another that may be regarded as more of a 'Treatment as Usual' group, being conventional area mental health service case management. We selected the second group from settings without active shared care programs and sought to match these included patients and carers as far as reasonably possible with the clients recruited into GP shared care in the new model. We have also profiled service use for physical and mental health problems within these groups. The major findings could be summarised as follows:

The results of the current study provide a clear picture of the toll of caring for the chronically mentally ill.

They illustrate high levels of mental illness found in carers as opposed to a matched population sample.

Despite the high prevalence of mental disorders, few carers consulted GPs for mental health reasons, or felt the need to consult. These results suggest a 'stoic' model of response on the part of participating carers.

When comparing the CLIPP vs Non-CLIPP groups, many findings are not statistically significant, and here there is a limitation of low numbers in this aspect of the study. However, to the extent possible within these data, we may extract suggestions of differences between the two:

AMHS carers may be more likely to have mental conditions than the CLIPP group (in this study 42% vs 23%  $p=0.14$ ).

CLIPP carers made significantly more use of GP services than did non-CLIPP carers for mental and physical health consultations, but not for mental health consultations alone.

The AMHS carers appeared to have less physical conditions than the CLIPP group. The reason for this is unclear; it could reflect actual morbidity, or perhaps more diagnosis and recognition of existing morbidity, possibly related to the finding that CLIPP carers consult with GP's more frequently.

### ***Limitations of this study***

Notwithstanding our efforts to match as closely as possible, and our criteria for entry, the strategy for recruiting CLIPP and non-CLIPP included patient and carer subjects may not have entirely excluded the possibility of relative bias towards more serious cases within the AMHS. This limitation will be hard to thoroughly address without a full Randomised Controlled Trial (RCT) of the model. One attempt has been made to conduct such an RCT, in Queensland through the GPAPP model. Conference reports from that study suggest comparable outcomes within shared care and conventional case management. However it also appears that the presentation of this service development as a research endeavour slowed recruitment into clinical transfer with the model, and ultimately may have hindered full uptake of the shared care service on a continuing basis by the involved services.

### ***Implications for further research service delivery and policy***

This study should be considered along with the recently reported GPEP 518 as providing a detailed examination of the service delivery model provided through the CLIPP shared care program. Following from the outputs of GPEP 518 that showed good rates of clinical stability attained within the model for clients, this later study has explored the rates of morbidity and service use among carers within the CLIPP model. Although matching questions and limited numbers mean that the following conclusions must be somewhat tentative, there is a clear suggestion of relatively lower rates of psychiatric morbidity in the CLIPP carers than in AMHS carers. The developing picture from GPEP 518 and 858 is that this model may well be able to deliver comparable quality of care, with perhaps lower carer psychiatric morbidity associated. The finding of higher physical morbidity might be considered a negative, or perhaps a positive feature as the physical morbidities in these carers may have been recognised through higher GP consultation rates.

Given this evolving picture, there is a developing case for a full and adequately powered RCT of this model, with a view to supporting strategic initiatives including wider scale implementation of shared care models with the same essential features.

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