

## Care-giving and the impact on carers of a community mental health service

PRiSM Psychosis Study 6

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**Background** We examined: care-giving activities in a population-based sample of carers of sufferers from psychotic disorders; putative determinants of care-giving; and changes in care-giving in an intensive community psychiatric service.

**Methods** In the PRiSM interview sample 170 people had a carer; 124 were interviewed. Care-giving activities, dissatisfaction with these, and carers' General Health Questionnaire (GHQ) scores were measured. Patient and illness characteristics were examined as predictors of the carer measures. The carer measures were reassessed for 62 carers after two years in two service sectors, one with an intensive community service, the other with a standard service.

**Results** Overall, 36% of carers were engaged in no, or only occasional care-giving activities. Fifty per cent expressed no dissatisfaction with their care-giving role. Patient and illness characteristics predicted care-giving poorly. Carers in the intensive community treatment sector did not experience significantly different care-giving demands or distress than those in the standard sector.

**Conclusions** A significant proportion of carers of sufferers from psychosis do not engage in common care-giving activities, and are not dissatisfied with their role. An intensive community service did not affect the impact of the illness on carers.

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Informal carers are pivotal to a successful policy of community care for people with severe mental illness. They are the primary care-givers for the majority of sufferers. Despite this, research into the determinants of their experiences and their needs has only recently commenced in earnest.

### EXPERIENCE OF CARE-GIVING

The conceptualisation of care-giver 'burden' presents major difficulties (Schene, 1990; Szmukler, 1996). As a consequence there has been little agreement on the best instruments for measuring care-giver experiences and distress (Schene *et al*, 1994). However, most workers conclude that care-giving is multi-dimensional in nature, and that among its major determinants are the severity of the individual's mental disorder and associated disability (Perring *et al*, 1990).

A number of studies evaluating community alternatives to hospitalisation for people with mental illness have assessed the impact on carers. These have shown that care-giver 'burden' is either less severe (Hoult *et al*, 1981, 1984; Dean *et al*, 1993) or no different (Test & Stein, 1980; Fenton *et al*, 1982; Burns *et al*, 1993) for those people treated in the community compared with hospital. Hoult *et al* (1984) and Muijen *et al* (1992)/Marks *et al* (1994) (same study) found that care-givers of those treated at home were more satisfied than carers of those hospitalised. However, these encouraging results require qualification. They all involved people entering the study at a time when admission was being considered. They also involved enthusiastic experimental teams engaging in an exciting new form of care. Whether carers are as satisfied with a community-oriented service when people are in a stable state as well as during crisis, and when the service provided is

routine and long established, is an open question.

The PRiSM Psychosis Study provides an opportunity to extend our knowledge of care-giving in a number of important respects. A population-based sample of carers of sufferers from psychosis was the subject of the study, rather than selected samples as in most other investigations. Unlike most other studies, the detailed assessments of the people's illness and psychological and social functioning were made by mental health professionals engaged in treating the person or by independent researchers, rather than by the carers themselves. This provided an opportunity to examine some major putative determinants of care-giving. Finally, the study allowed us to assess changes in care-giving following the introduction of an intensive community psychiatric service over a two-year period.

The aims of the study were thus:

- to examine the range of care-giving activities in a population-based sample of carers of sufferers from psychosis;
- to examine some putative determinants of care-giving activities, especially individual and illness characteristics; and
- to assess changes in care-giving following the introduction of an intensive community psychiatric service.

### METHOD

#### Subjects

In the PRiSM interview sample 170 people were known to have a carer; 124 of these carers were interviewed. In the remaining 46 cases, either the patient or the carer refused consent. The background characteristics of the individuals whose carer was interviewed were compared with those where the carer was not interviewed. The two groups differed significantly on only two of 25 background characteristics examined – people in the interview sample had been in contact with the services longer (17.2 *v.* 12.3 years) than those not interviewed ( $P=0.02$ ), and more people in the interview sample had received a domiciliary visit in the previous year ( $P=0.05$ ). The two groups did not differ significantly in terms of basic socio-demographic details, ethnicity, past admissions, diagnosis, measures of social functioning, or on a range of variables describing service use in the previous year.

Eighty-seven per cent of the carers were relatives, 28% being parents and 29% a spouse; 54% of the carers lived with the person. The median number of hours spent by the person and carer together was 50 per week.

Of the 124 carers interviewed at the beginning of the project, 62 were re-interviewed two years later. Those interviewed twice were compared on the same background characteristics mentioned above with the remainder of the carers ( $n=108$ ). They again differed significantly on only two variables: carers interviewed twice were more likely to look after a person with a diagnosis of schizophrenia ( $P=0.03$ ) and a domiciliary visit was more likely to have occurred in the year before entry to the study ( $P=0.04$ ). No significant differences were found on the other 23 variables.

## Measures

### Carer measures

A measure of care-giving activities based on that used by Creer *et al* (1982) was administered by interview. This covers activities in seven domains of care-giving: self-care, household chores, money, child care, socially embarrassing behaviour, other difficult behaviours, and requirement for general supervision. Carer's dissatisfaction (including resignation) with their care-giving activities in each domain was also rated as present or not. All carers completed the 28-item General Health Questionnaire (GHQ; Goldberg & Hillier, 1979).

### Subject measures

A note was made whether the person lived with the carer. Illness-related variables used in this study included age of onset, course of illness, history of suicide attempts, history of violence, response to neuroleptic treatment and family history of schizophrenia or affective disorder. The person's current symptoms were measured using the Brief Psychiatric Rating Scale (BPRS; Ventura *et al*, 1993). Social functioning was measured using the Social Behaviour Scale (SBS; Wykes & Sturt, 1986). The person's met and unmet needs were assessed using the Camberwell Assessment of Needs (CAN; Phelan *et al*, 1995). The family relation scale of the Lancashire Quality of Life Questionnaire (Oliver, 1991) was also included, as was

**Table 1** PRISM carers study: care-giving activities engaged in by carers ( $n=124$ )

Care-giving activity	% +++	% ++	% +	% NIL	% 'dissatisfied' with their care-giving contribution
<b>Self-care</b>					<b>22</b>
Hygiene	10	7	6	77	
Toilet	1	1	1	97	
Medication	7	9	15	69	
Eating	7	7	9	77	
Getting up	5	7	11	77	
<b>Household chores</b>					<b>24</b>
Need for prompting	7	21	17	55	
<b>Money</b>					<b>8</b>
Carer takes responsibility	15	6	9	70	
<b>Child care</b>					<b>2</b>
Carer takes responsibility	1	3	2	94	
<b>Socially embarrassing behaviour</b>					<b>18</b>
Inappropriate socially	7	5	15	73	
Attention-seeking	6	2	12	80	
Inappropriate sexually	2	1	4	93	
Stealing; begging	1	2	1	96	
Threatening; violent	3	2	7	88	
<b>Other behaviour</b>					<b>22</b>
Supervision at night	3	2	8	87	
Self-harming behaviour	1	1	5	93	
Other difficult behaviour	17	11	9	63	
<b>General supervision</b>					<b>18</b>
Interferes with social life, leisure	7	18	11	64	

+++ , most of the time; ++, often; +, sometimes; NIL, rarely or not at all.

the Verona Service Satisfaction Scale (patient version) (Ruggeri & Dall'Agnola, 1993). These measures were used in the part of the study assessing determinants of care-giving activities and care-giver distress.

### Services compared

Details are presented by Becker *et al* (1998, paper 2 of this series). Two sectors in the Maudsley catchment area with very similar indices of social deprivation were compared. The intensive sector aimed to offer extended-hours acute, home-based care; to provide continuing care and assertive outreach (with access to non-hospital crisis and respite beds); and to develop inter-agency and primary care liaison. Separate acute and rehabilitation teams were established, both with a strong community outreach focus. The standard sector had more limited aims providing a generic community mental health team

providing emergency services during office hours as well as case management of people with severe mental illness. The team made use of the local psychiatric emergency clinic and local, accessible resources but deployed a narrower range of service interventions. In the intensive sector attempts were made to involve carers in developing treatment plans and they were more likely to be seen at home than in the standard sector. Both sectors organised relatives' groups.

## RESULTS

### Care-giving activities

Care-giving activities engaged in by the 124 carers interviewed at Time 1 are shown in Table 1. Also shown are the percentages of carers 'dissatisfied' with their care-giving contribution in each of the seven domains. The majority of care-givers were not engaged in most of the

**Table 2** Care-giving activities, 'dissatisfaction with care-giving', and carers' GHQ. Changes over time in the 'standard' and 'intensive' community service sectors

Sector	Carer measure	Time 1 mean	Time 2 mean	Change (T2-T1)	95% CI	<i>p</i> <sup>3</sup>
Intensive <sup>1</sup>	Care-giving activities	7.47	6.71	0.76	-1.43-2.96	0.48
	Dissatisfaction with care-giving	1.15	0.82	0.32	-0.21-0.86	0.23
	Carers' GHQ	17.6	17.0	0.53	-2.8-3.9	0.75
Standard <sup>2</sup>	Care-giving activities	6.57	6.50	0.07	-1.73-1.87	0.94
	Dissatisfaction with care-giving	1.24	1.04	0.20	-0.33-0.73	0.45
	Carers' GHQ	16.0	16.2	-0.2	-4.4-3.9	0.89

GHQ, General Health Questionnaire.

1. *n*=34, Time 1-Time 2 pairs.

2. *n*=28, Time 1-Time 2 pairs.

3. Paired *t*-test; see text for significance of overall sector, time and sector × time effects.

potential care-giving tasks. In each of the domains the number of care-givers dissatisfied with their contribution was relatively small.

Overall, 19% of care-givers were not engaged in any care-giving activities and a further 17% were involved no more than occasionally in any task. Fifty per cent of the carers expressed no dissatisfaction with their care-giving role in any domain. Twenty-three per cent of the carers scored as a 'case' on the GHQ (cut point 4/5).

### Determinants of care-giving

These were examined for the 124 carers at Time 1. The following were significantly associated with the number of care-giving activities using univariate analyses: living with the person (*P*=0.001); total BPRS score (*r*=0.25; *P*=0.005); SBS - total behaviour score (*r*=0.33; *P*<0.001); Social Network Scale - total number of friends (*r*=-0.22; *P*=0.02); age of onset of illness (*r*=-0.22; *P*=0.017); chronic course of the disorder (*P*=0.002); and, family history of schizophrenia (*P*=0.02). These variables were entered into a multiple regression model to see how well they predicted care-giving activities, as a group. Using the 'enter' method 13% of the variance was accounted for (*R*=0.439; *R*<sup>2</sup>=0.193; adjusted *R*<sup>2</sup>=0.126; *F*<sub>(7,91)</sub>=2.87; *P*=0.010). No variable was significant adjusting for the others. A stepwise regression analysis produced a simpler model accounting for 10% of the variance in care-giving activities (*R*=0.328; adjusted *R*<sup>2</sup>=0.098). The only variable

retained in this model was SBS - total behaviour score (*B*=0.753, 95% CI 0.306-1.20; *t*=3.30; *P*=0.001). Thus, only a small percentage of the variance in care-giving activities was accounted for by independent measures of the person's illness, social functioning, met or unmet needs, self-rated quality of life, social networks, and satisfaction with services.

'Dissatisfaction with care-giving' was highly correlated with the number of care-giving activities engaged in by the carer (*r*=0.71; *P*<0.001). However, carers' GHQ scores were weakly predicted by the number of care-giving activities (*r*=0.18; *P*=0.05).

### Impact of an intensive community mental health service on carers

Sixty-two carers were interviewed before and after the introduction of the intensive service. Thirty-four were in the intensive treatment sector and 28 in the control sector. Three carer measures were compared: the number of care-giving activities,

'dissatisfaction with care-giving', and GHQ. The results are presented in Tables 2 and 3. Table 2 shows changes over time in these variables in the two sectors. There was no significant change over time in either sector. Table 3 shows the results of an ANCOVA with scores at Time 2 as the dependent variable, and with scores at Time 1 and 'sector' (intensive *v.* standard) entered as independent variables. There was no significant difference on any of the measures between the two sectors over the two-year period of the study.

## DISCUSSION

### Care-giving activities in a population-based sample of carers

This study provided an opportunity to assess the extent of care-giving by informal carers in a population-based sample of people with a psychotic illness. Most previous studies have reported on carers selected by membership of carers' organisations, or by their relative being a recent in-patient or by their willingness to participate in a survey. The carers in our study engaged in a wide range of activities but 36% were involved in no or only occasional care-giving. Fifty per cent were not dissatisfied with their care-giving role. These data are useful in estimating population-based needs of carers in planning services.

### Predictors of care-giving and carer distress

The ability of a wide range of individual characteristics (including socio-demographic variable, features of the illness, symptomatic state, met and unmet needs, person's social networks, and social functioning) to predict care-giving activities and care-giver distress was poor. In a stepwise multiple regression model only a measure of poor social functioning significantly predicted the number of care-giving activities,

**Table 3** Effect on carer outcomes of service provision (intensive compared to standard sector)

Variable	<i>n</i>	<i>R</i> <sup>2</sup>	Adjusted mean difference <sup>1</sup>	95% CI	<i>P</i>
Care-giving activities	62	0.50	0.39	-2.19-2.98	0.76
Dissatisfaction with care-giving	59	0.27	0.17	-0.48-0.82	0.60
GHQ	59	0.16	-1.30	-5.65-3.06	0.55

GHQ, General Health Questionnaire.

1. Adjusted for Time 1 value using analysis of covariance; intensive compared with standard sector.



and then only weakly, accounting for 10% of the variance. Carers' GHQ was poorly predicted by care-giving activities, which accounted for about 4% of the variance.

Previous studies have reported people's symptomatic state and poor social functioning as variably determining carer 'burden' (Perring *et al*, 1990). Where the relationship has been strongest, the assessment of the person's state has been made by the carer rather than independently as in the present study (Gubman *et al*, 1987; Winefield & Harvey, 1993; Solomon & Draine, 1995; Jones *et al*, 1995; Szmukler *et al*, 1996). There are two possible explanations which at this stage are impossible to disentangle. First, carers who feel more distressed by their care-giving role or who cope poorly with it, may, as a consequence, see their relative as more disturbed or disabled. Or, second, carers' closer contact with their ill relative may result in a more accurate picture of the illness. Whatever the explanation, this study indicates that a clinician's assessment of the person's symptoms and disability will not be very indicative of the nature of a carer's role nor of their distress. Only the carer can provide this information.

### Impact of an intensive community service on care-giving

Many carers have feared that a policy of community care will transfer major responsibilities for looking after their relative from health services to them. As mentioned above, previous research tends to be reassuring on this point – 'burden' has not been shown to increase, and if anything to decrease, and some studies also show that relatives' satisfaction with community-based treatment exceeds that with traditional care.

In this study an intensive community service did not significantly affect care-giving activities, carer dissatisfaction with these, or care-giver distress. Nor were there significant changes over time across the experimental and control sector, worth examining since even the control sector had changed towards a stronger community orientation over the two years of the study.

As mentioned earlier, the service evaluated in this study differed from previous studies in a number of respects. First, it examined a population-based sample of carers in a defined locality with 45 000 population. Second, people were at varying phases of their psychotic illnesses, not

### CLINICAL IMPLICATIONS

- Fifty per cent of carers of patients suffering from a psychosis were dissatisfied with their caring role.
- Characteristics of the patient's illness, including disability, predicted care-giving activities weakly, while these activities predicted carers' psychological morbidity even less.
- An intensive community mental health service had no significant effect on care-giving or carers' distress compared to a standard service.

### LIMITATIONS

- Measures of care-giving were limited in range.
- Fifty per cent of carers could not be reassessed at two years' follow-up.
- Neither the intensive community service nor the standard service focused strongly on carers' needs.

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comprising solely those presenting for admission with an acute episode. Third, the service was studied over a two-year period, reducing the influence of an experimental team's initial enthusiasm; by the follow-up evaluation the intensive community service had become quite routine.

On the one hand, carers may be reassured by the results of our study that a community service does not increase care-giving requirements or distress. On the other hand, some might be disappointed that a service aspiring to support people more comprehensively in the community and aiming to work jointly with carers, in this regard did not improve outcomes for those carers. It remains possible that during acute illness episodes carers might have been more helped in the intensive sector and that this effect was diluted by including the whole group of people with psychosis.

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