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# Giving Care to Men and Women with Mental Illness

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## Abstract

Caregivers are a largely understudied, unsung population who shoulder many of the social and psychological costs of mental illness. This study examines the load of caregiving during symptomatic and stabilised phases of the mentally ill and the various ways in which family members adapt themselves to give care. Drawing its data from 200 families with mental illness in Andhra Pradesh and Karnataka, the study diffuses the notion of care as physical, medical, psychological and social. The article focuses on how the gender of the affected person affects caregiving and underlines the indispensability of the family. Used to giving credit for any improvement to doctors and medicines, the study records the

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incredulous gratitude of caregivers at being acknowledged for the work they do, providing a boost to the morale of tired, unacknowledged caregivers.

### **Keywords**

Caregivers, caring for the mentally ill, gender and caregiving

### **Introduction**

Caring is a fundamental issue in the rehabilitation of a person with mental illness. There is a need for constant caregiving to motivate people with mental illness so that they can get better and/or lead a life with dignity. The family provides a considerable amount of caregiving to their mentally ill relatives even though they experience it as a significant burden (Bulger, Wandersman and Goldman, 1993; Leff, 1994). Families view caregiving as their responsibility towards their offspring and their ill parents. In India, the majority of people with severe mental illness live with their families (Thara, Padmavathi, Kumar and Srinivasan, 1998; Murthy, 2006), as we do not have adequate government-run services. The paucity of mental health care has resulted in families having to shoulder greater responsibilities of caring for their mentally ill family member; it is difficult to conclude whether this is by choice, cultural influence or lack of facilities, though there is some evidence to support the fact that family involvement in care was and continues to be a preference of families (ICMR, 1988; Kulahara and Wig, 1978). It is unfortunate that the experiences of the families have not been adequately studied and their strengths not optimally utilised in the recovery of people with mental illness.

The notion of 'family' caregiving obscures the fact that women do most of the caregiving work. Gender norms that prescribe nurturing and domestic roles for women naturally assign to women the responsibility of caring for sick family members at home (Gerstel and Gallagher, 1993). In some cultures male caregivers are denigrated; for example, a study of caregiving in South Asian communities found that men who took on the role of caregivers, especially those who quit their jobs to do so, were stigmatised and seen as unworthy of respect.

The caregiver's productivity is affected by caring for a person with mental illness. It is not only a burden for the family but also affects the caregiver's social interactions within the family and community. Caregiving involves a significant expenditure of time, energy and emotion over extended periods of time, involves tasks that may be unpleasant and uncomfortable and is often a role that had not been anticipated by the caregiver. When these unanticipated roles are incongruent with stereotypical gender expectations, as when a male caregiver must attend to the physical hygiene of a woman who is mentally ill, or when a woman caregiver is responsible for controlling a violent, mentally ill relative's dangerous behaviour, the stress can be exacerbated (Tessler and Gamache, 2000).

Caring for people with severe mental illness, particularly in the family and in the community, carries a heavy burden. Such a burden manifests itself in reduced well-being of the caregiver (Jungbauer and Angermeyer, 2002), which admittedly depends in part on caregiving style (Stengard, 2002). In turn, as caregivers are less able to provide support to their ill relatives, their relatives' well-being and their ability to remain in the community suffer (Leff and Vaughn, 1985; Song, Biegel and Milligan, 1997).

## **Methodology**

There have been no systematic scientific Indian studies to understand the types of caring required for persons with mental illness during their acute phase of illness and during their recovery phase. The study aims to understand caregivers and the roles they play in the recovery of mentally ill family members. The population for the study comprises the caregivers of people with severe mental illness in the Community Mental Health and Development programme of Basic Needs India (BNI)<sup>1</sup> implemented in partnership with two NGOs in Karnataka and one NGO in Andhra Pradesh. The Community Mental Health programme has been integrated in the Community Based Rehabilitation (CBR) programme of the organisation.<sup>2</sup> The primary partners of BNI are SACRED<sup>3</sup> (Ananthpur) in Andhra Pradesh; GASS<sup>4</sup> (Doddaballapur) and Narendra Foundation (Pavagada)<sup>5</sup> in Karnataka. Two hundred and one persons with mental

illnesses in the programme area of the two partners of BNI and their primary caregivers were identified to form the sample in the present study. Patients receiving care were coded as 1 and those not being given care were coded as 0.

All the life stories written by BNI were reviewed, culling out the roles of caregivers during the acute phase of illness and later during recovery. A list of caregiving duties was prepared and circulated among the research team for their comments. The partner organisations and Mental Health Coordinators were contacted and the research team had a brainstorming session with them to prepare a list of caregiving activities of family members. Both the lists were reviewed and a final list emerged of the tasks undertaken by caregivers. An interview schedule was developed for collecting information about individual caregivers' efforts and their role in the well-being of their wards. The schedule has four sections: the first section fills in the socio-demographic details of the person with mental illness; the second section collects the socio-demographic particulars of the caregiver. The third section elicits information on the caregiver's capacity to act as a resource person and the fourth section lists the tasks of caregiving, that is, the different types of caregiving activities classified as physical care, psychological care, medical care and social care.

Physical, medical, psychological and social care are defined as follows:

**Physical care**—One of the major symptoms of a person with severe mental illness is deterioration in appearance, hygiene or personal grooming. This affects many social aspects, as many people would rather alienate themselves from someone who has poor personal hygiene than tell them how they could improve. Thus, caregivers play a major role in assisting them and caring for their personal hygiene so as to minimise social stigma. The types of physical care mentioned in the questionnaire were: bathing/brushing and combing hair, helping in the washroom, haircutting and feeding, ensuring that the person wears clean clothes.

**Medical care**—Psychotropic medications (psychiatric drugs) are often very useful in helping the patient think more clearly, gain control of his/her own thoughts and actions, and bring his/her emotional state back into normal range. These medications produce both beneficial effects and undesirable side effects. Persons under treatment are often

not compliant in taking prescribed medications and caregivers have to constantly monitor them to check if the medicines have been taken or not in order to avoid relapses. To recognise the types of medical care provided, the schedule included questions on the types of care that caregivers provided, such as bringing the patient to the camps regularly, seeing him/her through admission and hospitalisation, ensuring that medicines are taken regularly, noting side effects and reporting the same to the field staff.

**Psychological care**—Changes in thinking, perception, mood and behaviour are characteristic of Severe Mental Disorder (SMD). It is very important to manage the person with mental illness when she or he is psychologically and emotionally disturbed with love and affection, without impatience and anger. The mentally ill person must not be confined, isolated or chained, needs to be engaged in small tasks and conversation, and most importantly, given full attention, the caregiver not comparing him/her to a (so-called) sane person.

**Social care**—The stigma and discrimination associated with mental illness is huge and is manifested in the form of denial of illness, harmful treatment, social boycott of the entire family, denial of property rights, marital discord and legal separation and ineligibility for marriage. Caregivers, especially among the poor, suffer much more as they have to cope with the necessity of having to earn a living while caring for and managing a person with mental illness. For information on the scope of social caregiving, the questionnaire sought responses to the following: educating the community about the illness, preventing the community from abusing the person with mental illness, physically, mentally and sexually, helping in the social integration of the person concerned, taking her/him along with them to functions and celebrations, respecting his/her property rights, paying due attention to the wishes of the person to get married and informing the prospective bride and the family about the illness and encouraging the person with mental illness to mingle with peers and friends.

As a preliminary step, care was taken to build the capacities of the partner staff in understanding the interview schedule. First, the partners were consulted about the research study and discussions were held on the importance of recognising the role of the caregiver and using them as resource people in the Community Mental Health and Development programme. The research team then trained Mental Health Coordinators

to understand the interview schedule to administer it at the field level, understand the concept of caring, and the different levels of caring required for people with mental illness during the acute phase of illness (symptomatic phase) and the stabilised phase (recovery phase) (see Table 1). The training also included role plays and a demonstration of

**Table 1.** Definition of Symptomatic and Stabilised Phases

<p><i>Symptomatic Phase:</i> During the symptomatic phase a person exhibits gross dysfunction in physical, psychological and social functioning.</p>	<p><i>Stabilised Phase:</i> The indicators for stabilisation can be seen at two levels, that is, at the personal level and the family level.</p>
<p><i>Physical symptoms:</i> Dramatic changes in eating and sleeping habits, bowel and bladder disturbances, sexual disturbances and many unexplained physical problems.</p>	<p><i>At the individual level:</i></p> <ol style="list-style-type: none"> <li>1. Reduction of symptoms to a large extent for not less than three months, with or without treatment.</li> <li>2. Attending to self-care, personal hygiene and daily activities.</li> <li>3. Greater understanding of the situation and voluntarily taking the prescribed dose of medication.</li> <li>4. Regaining insight and judgement.</li> <li>5. Showing interest in participating and involving themselves in the activities of family and community.</li> <li>6. Beginning to take responsibilities voluntarily and exploring gainful occupations.</li> </ol>
<p><i>Psychological symptoms:</i> Irritability/ anger; excessive fear, worry, anxiety and sadness; extreme highs and lows in mood; thought disturbances, confused thinking, delusions, illusions, perceptual abnormalities, memory disturbances, difficulty in concentration and holding attention and in judging situations.</p>	
<p><i>Social symptoms:</i> Social withdrawal, difficulty in maintaining personal hygiene, increasing inability to cope with daily problems and activities.</p>	<p><i>At the family level:</i></p> <ol style="list-style-type: none"> <li>1. The caregiver is relieved of the burden and finds time to engage in her or his own work, and</li> <li>2. shows increased understanding of the illness and its management resulting in appropriate support to the affected person.</li> </ol>

**Source:** Janardhana et al. (2008).



how to administer the interview schedule. They were also trained in the local language for at least two days.

Further sessions were held with the field staff listing all the possible caregiving roles and categorising them. Then the interview schedule was reintroduced to them, and the Mental Health Coordinators and senior field staff (with experience of working in the community for more than five years) were trained in the various aspects of the interview schedule. Pilot interviews were conducted to help them familiarise themselves with the questionnaire. Finally, the Mental Health Coordinators and the senior field staff administered the interview schedule; the data collected was sent to BNI. The data was coded and entered in the Statistic Package for Social Sciences (SPSS) and used both descriptive statistics, parametric and non-parametric statistical analysis.

The research was an empowering experience for the field staff and for the caregivers who understood their vital role in the recovery process.

## Results

The sample had an almost equal number of men (101) and women (100).

Table 2 shows that nearly half (46.2 per cent) of the sample was in the age group 21–35 years and a third (31.9 per cent) of the sample was in the age group 36–50 years. About 15 per cent were over 51 years. Only 5 per cent were between 18 and 20 years of age. The findings confirm earlier research findings that mental illness affects those in their prime, diminishing occupational functioning, leading to disability.

There were a larger number of illiterates among women (40 per cent) which is somewhat similar to the figures in the Census of India 2001. The occupations of people with mental illness vary. The sample showed that they are engaged mainly in agriculture (farming), manual labour and domestic work. A small number was engaged in small businesses and weaving. Domestic work is dominated by women. Men tend to be engaged in agriculture and weaving more than women. Both men and women are almost equally engaged in coolie work or manual labour and small businesses. It is quite striking that among those not working, there are more men than women. This picture brings out a kind of hierarchy among occupations and in gender disparity.

**Table 2.** Distribution of People with Mental Illness against Socio-demographic Variables

	Male 101	Percentage	Female 100	Percentage	Total	Percentage
<b>Age group of persons with mental illness</b>						
18-20 years	3	1.5	7	3.4	10	4.9
21-35 years	54	26.9	39	19.4	93	46.2
36-50 years	32	16.0	35	17.4	67	31.9
51 years and above	12	6.0	19	9.4	31	15.4
<b>Total</b>	<b>101</b>	<b>50.4</b>	<b>100</b>	<b>49.6</b>	<b>201</b>	
<b>Educational qualification</b>						
Illiterate	17	8.4	41	20.3	58	28.9
Std I to VII	41	20.4	24	11.9	65	32.4
Std VIII to X	28	14.0	13	6.4	41	20.4
Std XI to XII	5	2.6	6	2.9	11	5.5
Above Std XII	4	2.0	0	0	4	1.9
Information not available	6	3.0	16	7.9	22	10.9
<b>Total</b>	<b>101</b>	<b>50.4</b>	<b>100</b>	<b>49.4</b>	<b>201</b>	<b>100</b>

<b>Occupation</b>									
Not working	11	5.4	2	0.99	13	6.4			
Agriculture	33	16.5	27	13.0	60	29.8			
Coolie, manual labour	24	11.9	23	11.5	47	23.4			
Domestic work	1	0.4	25	12.5	26	13.0			
Salaried work	3	1.6	0	0	3	1.4			
Business	5	2.5	4	2.0	9	4.4			
Weaving	9	4.5	0	0	9	4.4			
Student	0	0	1	0.4	1	0.4			
Others	7	3.6	1	0.4	8	4.0			
Not available	8	4.0	17	8.4	25	12.4			
<b>Total</b>	<b>101</b>	<b>50.4</b>	<b>100</b>	<b>49.6</b>	<b>201</b>	<b>100</b>			
<b>Marital status</b>									
Single	34	17.0	15	7.5	49	24.4			
Married	54	27.0	61	30.4	115	57.3			
Divorced	2	0.9	4	2.0	6	3.0			
Deserted	7	3.4	9	4.4	16	8.0			
Widowed	1	0.5	9	4.4	10	5.0			
Not available	3	1.6	2	0.9	5	2.4			
<b>Total</b>	<b>101</b>	<b>50.4</b>	<b>100</b>	<b>49.6</b>	<b>201</b>	<b>100</b>			

(Table 2 continued)

(Table 2 continued)

	Male 101	Percentage	Female 100	Percentage	Total	Percentage
<b>Diagnostic categories</b>						
Schizophrenia	52	25.7	41	20.2	93	46.2
Psychosis—Not Otherwise Specified	32	16.0	21	10.7	53	26.4
Affective disorder	17	9.0	38	18.9	55	27.4
<b>Total</b>	<b>101</b>	<b>50.4</b>	<b>100</b>	<b>49.6</b>	<b>201</b>	<b>100</b>
<b>Duration of illness</b>						
2 years	6	3.0	7	3.4	13	6.5
More than 2 years and less than 5 years	20	10.0	23	11.4	43	21.5
More than 5 years and less than 10 years	45	22.5	48	23.9	93	46.3
More than 10 years	29	14.5	22	10.9	51	25.3
Data not available	1	0.4	0	0	1	0.4
<b>Total</b>	<b>101</b>	<b>50.4</b>	<b>100</b>	<b>49.6</b>	<b>100</b>	<b>100</b>
<b>Treatment duration</b>						
2 years	10	5.0	13	6.4	23	11.5
2–3 years	21	10.5	19	9.4	40	19.9
3–4 years	22	11.0	14	6.9	36	17.9
More than 4 years	48	23.9	54	26.8	102	50.7
<b>Total</b>	<b>101</b>	<b>50.4</b>	<b>100</b>	<b>49.6</b>	<b>201</b>	<b>100</b>

Source: Janardhana et al. (2008).

Table 2 also brings out some interesting results on marital status:

- The majority (57.3 per cent) of persons with mental illness were married;
- Among those who were single, men were almost double the number of women;
- Among the widowed, women were more in number. This could be because of the tradition of men remarrying;
- Divorce and desertion were seen among both men and women, though women seem to be affected more than men. Desertion by husbands could be the triggering factor for the onset of illness in women.

The diagnostic categories of mental illness identified were schizophrenia, affective disorders and psychosis. Nearly half of the persons with mental illness were reported to have schizophrenia (46.2 per cent), one quarter had affective disorder (27.4 per cent) and another quarter (26.4 per cent) had psychosis (NOS–Not Otherwise Specified). There appears to be a visible disparity between men and women, with more women diagnosed with affective disorder than men. The majority who were diagnosed with psychosis had schizophrenic symptoms, but did not qualify for diagnostic criteria. The affective disorders suffered more by women than men included unipolar depression and bipolar disorders.

The sample in the present study included only persons with mental illness who have been in the Community Mental Health and Development programme for two years or more. The data presented shows that a large number of them have been ill for more than five years or up to ten years or more, indicating that most of the respondents had chronic mental illness. Slightly more than one fourth of the sample has had the illness for two years, and for more than two but under five years. There is hardly any difference between men and women in this regard. Most of these people have had long years of treatment and there is not much gender disparity in this respect.

All the caregivers were from rural areas, from Ananthpur Rural Mandal in Andhra Pradesh and Doddaballapur and Pavagada taluks in Karnataka. Women caregivers were slightly more than half in number (52.7 per cent). Traditionally, within the family women are considered to

be more 'caring' than men. It is noteworthy that there were a large number of male caregivers as well. This implies the strength of relationships within the family. Nearly three-fourths of caregivers were above 36 years and only about one-fourth were below 35 years, with almost all of them above 21 years. Table 3 reveals that the majority of caregivers (40.8 per cent) were above 51 years indicating the prevalence of older caregivers. The responsibility of caregiving seems to lie more with older than younger members in the family. This may be because older family members are at home and can take over the responsibility of caregiving. Age

**Table 3.** Distribution of Caregivers According to their Age, Relationship and Duration of Care

	Number	Percentage
<b>Sex of the caregiver</b>		
Male	95	47.3
Female	106	52.7
<b>Age group</b>		
17–20 years	2	1.0
21–35 years	48	23.9
36–50 years	69	34.3
51 years and above	82	40.8
<b>Relationship with person with mental illness</b>		
Father Mother	34	16.9
Husband	47	23.4
Wife	38	18.9
Offspring	35	17.4
Brothers and sisters	19	9.5
Others (daughter-in-law and son-in-law, grandmother, sister-in-law, niece)	16	8.0
	12	5.9
<b>Duration of caring</b>		
2 years	13	6.0
More than 2 years and less than 5 years	53	26.9
More than 5 years and less than 10 years	83	41.3
More than 10 years	5	25.4
Data not available	11	0.5
<b>Total</b>	<b>201</b>	<b>100</b>

**Source:** Janardhana et al. (2008).

and experience may endow them with more patience and understanding to deal with the mentally disordered; on the other hand they may have less stamina to carry the burden.

Table 3 also indicates that a large number of mothers care for their children. Almost an equal number of fathers, husbands and wives were found to be caregivers. Almost everyone within the family served as caregivers—fathers, mothers, husbands, wives, children, siblings, daughters, sons-in-law, grandmother, sisters-in-law and nieces. It appears that whoever was available and willing was a caregiver. Thus family support comes through very clearly, which is the very basis of Community Mental Health. A majority in the sample (about 67 per cent) were taken care of for more than five years, or up to ten years or more. A large section was given care over ten years which is quite a long duration.

There is a significant difference in the care that men and woman require during their symptomatic phase. Men required more physical and medical care compared to women. Men did not pay attention to hygiene and needed to be reminded and persuaded to take medicines. Therefore, families had to take on greater responsibilities to meet their personal and medical needs. It was different with women with mental illness. When reminded and forced to take care of personal hygiene, they were able to do so. Outbursts of anger were much less among women when compared to men. Men would often abuse and assault their family members; this was not seen in women. The intensity of anger was also much less among women.

A close observation of the differences in the mean score of types and dimensions of caregiving showed that:

- During the symptomatic phase, both in physical and medical care, there was a significant difference in the care given to men and women with mental illness. Families favoured men more than women during the symptomatic phase, bringing them earlier for help to the doctors, whereas in the stabilised phase there was no difference in terms of physical and medical care provided. This implies gender bias in access to medical care.
- In terms of psychological care, men and women received the same amount and quality of care in both phases of illness.
- In terms of social care, in the symptomatic phase there was no difference in the care provided to men and women, whereas in the

stabilised phase there is some difference in the care provided, with families favouring men more than women.

In short, there is a gender bias in physical and medical care during the symptomatic phase. Psychological care is deeply tied to physical and medical care. Hence gender bias would necessarily be reflected in psychological care as well. Non-reflection of bias in psychological care may be due to the limitation of the tool used.

## Discussion

The socio-demographic profiles of persons with mental illness and caregivers are consistent with earlier studies conducted in community settings (Murthy, 2001, 2007). All caregivers were mainly close family members (parents, spouses, siblings or children) and were generally older persons staying at home. In India cultural factors such as strong family ties and family systems have reduced the state's burden and responsibility. In India a person with mental illness is always accompanied by a family member as compared to other countries where caregivers are not necessarily family members (Leff, 1994; Thara et al., 1998).

Women provide most of the informal care that their children, spouses, parents or parents-in-law with mental illness need. They play many roles while caregiving: as health provider, care manager, friend, companion, surrogate decision maker and advocate. Many studies have looked at the role of women in family caregiving. Although not all have addressed gender issues in caregiving specifically, women have been found to be the main caregivers. According to several studies, the percentage of women caregivers ranges from 59 to 75 per cent. The average caregiver is a female aged 46, married and working outside the home.<sup>6</sup> Although men also provide assistance, women caregivers may spend as much as 50 per cent more time providing care than men (Alliance for Caregivers and AARP, 1999; Family Caregiver Alliance, 2001; Kreisman and Joy, 1974).

Types of care vary, with more physical and medical care being required during the acute or symptomatic phase. Psychological care is ongoing, followed by social care even after the person recovers from the



illness. Caregivers do feel stressed. Their stress and burdens need to be addressed in the interest of the person with mental illness. Caring for family members with chronic mental illness disrupts the normal functioning of families, and it almost always causes stress in the family. Examining caregiving within the context of the stress theory Aneshensel, Pearlin and Schuler (1993) make a distinction between primary stressors caused by performing the work required to care for sick family members, and secondary stressors, which are problems that emerge in social roles and relationships as a result of caregiving. This distinction highlights the fact that caregiving is not only stressful because it requires the performance of difficult physical and medical care like administering medicines, follow-ups, engaging persons with mental illness in productive work and encouraging them, but also because of secondary stressors like marital discord, social isolation, economic strains and family dysfunction.

It has been observed that caring for men and women with mental illness has crucial differences. Men require more physical and medical care as they are more symptomatic and violent when compared to women. Second, stereotypical cultural practices exist, whereby men avail of services rendered by a woman family member like the serving of food, cooking, bathing and personal care, dressing after a bath and so on. During the training of Mental Health Coordinators, one of the women coordinators said that as a wife even in the normal course of daily life she provides all the physical care her husband needs, as culturally it is expected that a wife should so care for her husband. Third, men have always been viewed as earning members, while a woman's contributions are not viewed from the economic angle as they do not get paid for the services or tasks they perform in the household. This in turn leads to diminished care and attention when they are mentally ill. Thus, gender does determine the level of caring received from family members. Women with mental illness are comparatively neglected. It is the expected norm that men with mental illness who have stabilised (recovered enough to function) will work and contribute to the family income; 'stabilised' women are expected to continue to work at unpaid household chores, animal husbandry and agricultural tasks. Men are seen as contributors to family income; whereas women's role is limited to productive but unremunerated activity that leads to a lower status in family and community.

Caregivers' needs should be understood and addressed; they perform a variety of psychosocial functions: understanding the illness, managing the family member who is ill, dealing with stigma and integrating the recovering patient in community activities (Jagannathan, Thirthalli, Hamza, Hariprasad, Nagendra and Gangadhar, 2010; Janardhana and Naidu, 2006, Shetty et al., 1996). There is a need for developing psychosocial interventions for caregivers in order to address their own mental health and other needs. A study carried out in India to understand the needs of families with a mentally ill member and the impact of family interventions revealed that the psychosocial problems of families were related to the high level of expectations of the person with mental illness and the family's emotional involvement with the patient's future (Suman et al., 1980, pp. 97–102). Families expect that after regaining premorbid levels of functioning, the person who had been ill would return to normal life, earn a living and contribute to family income, marry, have children, etc. In other words, concern for the rehabilitation of the recovering or recovered person into society caused great anxiety in the family. The study concluded that family members have multiple needs when living with a person with chronic schizophrenia. Their needs should be understood and met to enhance the functioning of the family in order to provide care and thereby reduce the emotional problems of family members (*Ibid.*).

Despite the apparently direct cause-and-effect relationship between patient illness/disability and the psychological distress felt by the caregiver, there also exists considerable variability in caregiver outcomes. The nature of the relationship between the caregiver and the person with mental illness, interpersonal relations in the family, pre-existing emotional resources of the caregiver, coping abilities of the caregiver family type, availability of economic and social support and factors such as gender, personality, caregiving beliefs and values have been found to be significantly related to caregiving (Adler, 2001; Magliano, Fiorillo, Marasco, Malangone, Guarneri and Maj, 2002; Songwathana, 2001; Yates, Tennstedt and Chang, 1999). The structure of the family as well as their life stage as a family—whether it is elderly parents caring for an adult with severe mental illness, or a former family breadwinner incapacitated by mental illness—will have an effect on caring, presenting challenges to caregivers (Pot, Deeg and Knipscheer, 2001; Tarrier, 1991).

## **Conclusion**

Modern medical interventions and technologies that have extended the lives of persons with chronic mental illness have increased the caregiving responsibilities of families. Many chronic illnesses that once signalled early death (for example, kidney failure) or institutionalisation (for the mentally ill) can now be managed by medical interventions and by keeping the patient at home. Moreover, the escalating costs of health care in most countries have led to restrictions in institutionalisation, thereby encouraging community care and family care as they foster the rehabilitation process.

The present study was conducted in order to understand caregiving in families, the role of caregivers in the recovery of the family member with mental illness, their contribution never emphasised or receiving acknowledgement. There is a need for measuring and understanding caregivers' roles in the recovery of the mentally ill person, which is a hidden cost not getting reflected in the cost arrived at for treating people in homes and communities. In India, 0.83 per cent of the total health budget is spent on mental health services (WHO, 2001a, 2001b). Does this include the hidden cost of caregiving? a question to be reflected upon and answered. It is therefore necessary to understand the role of caregivers, adequately acknowledge and recognise them, remind them of their contribution so that they recognise their roles themselves. There exists a need to develop a specific intervention package to empower caregivers, a need to see them as resource people and not merely as mental health service providers.

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## **Notes**

1. Basic Needs India (BNI), a Trust working as a resource group in Mental Health and Development, capacitates NGOs and CBOs to include mental health programmes in their existing community development activity. BNI operates in parts of eight states in partnership with 50 NGOs in South India, Orissa, Maharashtra, Bihar and Jharkhand.

2. Community Based Rehabilitation (CBR) programmes aim at empowering people with disabilities (PWD) in their own communities so that their rights are respected and safeguarded. As per the PWD Act, mental illness is also considered as disability and BNI is capacitating NGOs/CBOs to include mental health in their existing development programmes.
3. Social Action for Child Rehabilitation, Emancipation and Development (SACRED) is an NGO implementing CBR for people with disability in Ananthpur Rural Mandal and Papuly Rural Mandal in Ananthpur and Kurnool districts. The community mental health programme has been included in their CBR programme.
4. Grameena Abyudaya Seva Samsthe (GASS) is an NGO implementing CBR for people with disability in Doddaballapur taluk, Banaglore Rural District. The community mental health programme has been included in their CBR programme.
5. Narendra Foundation is an NGO implementing CBR for people with disability in Pavagada taluk, Tumkur District. The community mental health programme has been included in their CBR programme.
6. All the women caregivers did not work when the ill family member had acute episodes of mental illness. After the symptoms subsided, they resumed working, mainly agricultural or coolie work, either on their own or neighbouring farms.

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