Understanding the wounded soul of an invisible workforce: Needs and issues of family carers

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Abstract
Family caregivers have been an integral part of healthcare in India for several decades. They have been complementing the state resources, and thus, estimating the real healthcare cost becomes difficult. This paper highlights the needs of the family caregivers in an emerging change in the family structure in India – from joint families to extended families and to nuclear families. It makes a case for recognizing the efforts of the caregivers in providing healthcare, rather than just viewing them as plentiful of resources available. Their experiences and needs deserve due recognition and understanding to develop support networks and care program for the caregivers. We have made attempt in this regard to summarize the current status of research on this topic in the Indian and global context.

Keywords: Chronic illness, family caregiver, mental illness, obligation

INTRODUCTION
Although the process of caregiving is familial, caregiving is a new terminology first recorded in 1966.[1] The Merriam Webster dictionary (2010) defines a caregiver as “a person who provides direct care, as for children, elderly people, or the chronically ill.” Caregiving has a multidimensional view – for example, family caregiving and parental caregiving.

Caregivers are individuals providing unpaid support and are in high contact with the person with chronic illness (PWCI) and disabilities and those requiring assistance with their daily living task.[2] They continue to provide considerable support to the needy, despite caregivers experiencing significant burden.[3] The nature of caregivers of PWCI would be individuals who share a close bond and emotional relationship, having a close watch of PWCI, maintaining a positive attitude, providing adequate time, and creating an atmosphere favorable for PWCI. Caregiving is an obligation about the sense of responsibility or duty perceived by the caregiver to provide assistance and help PWCI. In the Asian countries, more so in India, more than 70% of individuals affected with chronic illness live with their families,[4] who are obliged in their roles to care for the person.

ROLE OF CAREGIVERS
The role of primary caregiver is unique. Understanding the role of the primary caregiver will better inform those in the counseling profession.[5,6] Caring is a fundamental issue in the treatment for PWCI. The onset of chronic illness in any family is often and understandably a time of turmoil. Most families are ill-prepared to deal with the initial onset of severe disorder in their family member.[6] Families generally have little knowledge of illness and find...
that they not only have to deal with the ups and downs of illness but also need to deal with the stigma and attitudes in the community. Caring for PWCI can be a highly stressful experience in any family, regardless of its strengths and resources available for coping with a family member with severe chronic illness. The presence of PWCI impacts family members in several ways, disrupts the family functioning, affects the occupational and social functioning, and has been reported extensively in the literature as burden of care. Chronic illnesses such as both bipolar affective disorder and schizophrenia are associated with a considerable degree of perceived burden by caregivers. The family provides considerable amount of care for their ill relatives even though they experience burden, and families view caregiving as their sole responsibility toward their offspring with illness.

Research studies in India have documented that the vast majority of PWCI live with their family members who are required to provide care and support for the extended periods of time. Most of the time, the caregiver’s efforts are neither recognized nor acknowledged but instead seen as plentiful resources freely available for caring PWCI. In India, the majority of PWCI stay with their families. Caregivers have a major role to play in the re-socialization and vocational and social skills training of the PWCI, not only because of close family ties that exist in these traditional societies but also because of lack of health and rehabilitation professionals to deliver these services in developing countries. Caregiver’s burden is exacerbated by the issues of poverty and illiteracy. Such burden manifests in reduced caregiver well-being, which admittedly depends, in part, on caregiver factors such as caregiving style. In turn, as caregivers are less able to provide support to their ill relatives, their relatives’ well-being and ability to remain in the community suffer.

**SOCIODEMOGRAPHIC PROFILE OF CAREGIVERS**

Gender differences in the obligation dimensions were reported to be higher in women when compared to men. Women provides majority of informal care to their ill family members, and daughters and daughter-in-laws provide care to their ill parents and to their parents-in-law. It is also noted from few research studies that more number of spouses (husband/wives) do provide care for their ill spouse. They provide care silently. In such cases, most of them are relatives even before marriage (consangunuity). The caregivers play many roles while caregiving: health provider, care manager, friend, companion, surrogate decision-maker, and as an advocate. Several studies have proved that the percentage of family or informal caregivers who are women ranges from 59% to 75%.

The average caregiver is a female aged 46 years, married, and working outside the home. Although men also provide assistance, female caregivers may spend as much as 50% more time providing care than male caregivers. It is often observed that for any consultations or caregivers gathering/meeting, more number of women represent or escort their family member with illness. Men do provide care for their ill female family member with the help of the extended families, but the same is not shared or spoken to others and they do not participate in the caregivers’ meeting. The representation from the male caregivers is less, mainly because of their engagement in the livelihood activities, but men do share the responsibility of providing care for their female ill family member. Even though men do not participate and vocalize about the care they provide, they do spend more time for their loved one’s having chronic illness. The trend of increasing care providers from male family members has been observed in the studies even though most caregivers are women who handle time-consuming and difficult tasks such as personal care. However, at least 40% of caregivers are men, growing trend demonstrated by 50% increase in male caregivers between 1984 and 1994. However, family members irrespective of gender usually wish to be involved in the care of their loved ones and would appreciate an opportunity.

Studies indicate that PWCI would require the same amount of care during symptomatic phase and load of caring gets reduced in the remission for all people with different types of severe illness. Very few studies have been conducted to look at the experiences of the caregivers, and many studies have looked more in terms of burden of caregiving people with different forms of severe disorders.

**TYPES OF CAREGIVING**

The types of care required also vary; physical care and medical care are required more during acute-phase/symptomatic phase; psychological care is continuous, followed by social care even after the person recovers from the illness. Caregivers have to spend more support when their family member is symptomatic as they need to care for their personal hygiene, calm down during emotional outburst, and take the brunt of abuse and assaults from their ill family members. Caregivers’ involvement in direct and indirect care changes over time, in response to...
the stage of illness and treatment, and caregivers must be able to adapt to changes in the amount, level, and intensity of care demands. Caregivers often take the support of other family members during acute phase to deal with the stressful situation of caring in symptomatic phase. Szmukler et al. in their study found that there were significant changes over time for the carers while their family members with illness are on in-patient treatment; however, the most striking was a reduction in the severity of caring difficulties posttreatment phase. Caregivers of PWCI face different challenges and are affected by cultural and social attitudes to the illness and these have important effects on the level of burden experienced.

Caregivers do have stress while caring for their ill family members; their stress and burdens need to be addressed in the interest of PWCI. Caregiving for chronically ill family members disrupts the normal functions of families, and it almost always causes stress in the family. Examining caregiving within the context of stress theory, the authors have distinguished between primary stressors, caused by performing the physical care role for the sick family members, and secondary stressors, problems that arise in social roles and relationships as a result of caregiving. This distinction highlights the fact that caregiving work is stressful not only because it requires the performance of difficult physical care and medical care, such as administering medicines, follow-ups, involvement in productive work, and encouraging, but also because of secondary stressors, such as marital discord, social isolation, economic strains, and family dysfunction.

Caregiving roles and experiences are similar. There is a significant relationship between the acute phase of the illness and caregivers’ burden of providing physical care, medical care, and psychological care. The social care starts once the person with illness is moving toward the remission phase. Modern medical interventions and technologies have extended the lives of chronically ill persons, which have increased the responsibility of families for caring for the sick. Many chronic illnesses that once signaled, institutionalization can now be managed at home with medical interventions. Moreover, the escalating costs of healthcare in most countries has led to restrictions of institutionalization and encouraging community care and family care as it fosters the rehabilitation process. Thus, it is necessary to adequately acknowledge and recognize the contribution of caregivers in the recovery process and to be seen as resource. There exists a need for developing specific interventions to empower the caregivers.

**OBLIGATIONS AND MOTIVATIONS OF THE CAREGIVERS**

Particularly in a country like India, the caregiving is considered to be a part of their social responsibility which is mandatory toward one another. In the Asian countries, the family members are obliged to take care of each other, and in particular, the elders of the family. Among families having relatives affected with chronic illness, it ultimately becomes the obligation of the caregivers to provide care, due to high cultural values and norms. The obligation has been viewed in five dimensions such as duties of caregivers to maintain regular contacts, providing assistance to the ill relative, the caregivers efficiency to avoid conflicts with the ill relative, the caregivers personal sharing, and self-sufficiency.

The obligations of the caregivers are divided into two types:

a. Filial responsibility: The responsibility concerns the sense of duty and obligation expected from that of a young adult by recognizing their social roles toward elders

b. Filial piety: It is the primary duty of a young adult to show their respect, obedience, and their care for parents and elderly family members as a duty. It is an intense form of filial responsibility.

There lays a great emphasis on families and primary caregivers in India on how one carries a proper attitude and an appropriate behavior, for those obligations, duties, or roles prescribed to them. The obligations in the United States among the Asians and Asian Indians have been viewed as an expectation according to their culture and also as an obligation, love, and the caregiver’s attitude toward the elderly persons for whom the caring is rendered.

Studies come up with a view that for caregiving aspects, it becomes obligatory for the caregivers to be in contact with the mentally ill relative. Caregivers, particularly in India, perceive it to be obligatory as family member or the primary caregiver is culturally bound to care for the ill relative, and tradition plays a prominent role where the family members make decisions with regard to the ill relative’s treatment. The study which focuses on “cure vs. care” brings out the view that this concept has been encapsulated by the natural preferences of the families, to care for the kin who is mentally ill. This, in turn, makes the primary caregiver to examine them as to whether they have adequately provided care for the ill kin or will there be anything more that they need to do.

Since most of the Asian families take up the caring process as an obligation, because of the ethnicity. The primary
c. A “perceived obligation” about caring when another family member is unable to care for themselves

d. The internal motivation shows the activity of caring to be judged as valuable by the caregiver which is called the “identified regulation,” and the already identified activity of caring is in harmony with the other structures of the self, called the “integrated regulation.”

The external obligations of the caregivers depicting the social pressure are as follows:

a. Caring as an obligation as it is “expected” from other family members

b. Obligation to care as the caregiver feels that they are being “forced to care” for the family members, by their own family and friends

c. Caring of their own family members as an obligation, because, if the caregiver takes the ill kin to a nursing home, it would “not be approved by the other family members”

d. The external motivation is perceived as the external regulation where the caregiving happens to satisfy the pressure from the society or to satisfy the external demands.

A study on understanding the macro-theory of human motivation suggests that the caregivers perceive good mental health because of their internal obligation. Motives of caregivers were useful to understand the multidimensional construct and to identify the risk the caregivers are involved in during the process of caring. The caregivers scored higher on their extrinsic motives than the intrinsic, showing the particular risk that the caregiver can have for negative outcomes in caregiving.

In India, obligation is viewed as an act of reciprocity. The young adults during their life time are obligated to give back their sense of responsibility physically, emotionally, and socially to their parents or any other family members. The act of reciprocity is being edified in the young adults as children in both manners, i.e., implicitly and explicitly. There are the two other concepts in connection to reciprocity such as “being there” and “unconditional regard.” Reciprocity has played a predominant role in the act of caring for an ill kin, because studies shows that when there is a paucity in the reciprocity of care, it would automatically fence set a gap between the caregivers’ and the patient’s relationship. Few caregivers perceived it to be a commitment emerging in on-going relationships. However, the other caregivers felt that it is not necessarily an obligation to take care of a family member affected with chronic illness but instead an enormous satisfaction...
with the amount of contact with them and found personal sharing to be more helpful.\textsuperscript{[54]}

**CULTURAL INFLUENCE IN CAREGIVING**

In most of the Asian countries, the act of caregiving is influenced eminently by the cultural norms and values. The following are the areas influenced by the same.

a. The caregiver's perception about the role particularly about caring as to whether the act of caring is an expected or unexpected part of their lives
b. The cultural aspect of caregiving has an impact as to whether the caregiving was a choice or an obligation
c. The classification of caregiving as to who is expected to provide care for the ill kin in the family
d. The mandatory values of the family traditions and the filial piety about the responsibilities of caregiving and therefore which averts caregivers from curbing their responsibility to care.

**BURDEN OF CAREGIVING**

Caregiver syndrome is the condition that can be broken down into two categories called “caregiver burden” and “caregiver stress.”\textsuperscript{[55]} “Caregiver burden” is defined as the actual management involved in the tasks, while “caregiver stress” is the strain or emotional toll caregiving has on an individual. The term caregiver stress includes caregiver burden and stress. The main symptom of caregiver stress is depression. Other symptoms include fatigue, insomnia, and anger.

The nature of the relationship between caregiver and the ill person, interpersonal relation within the family, preexisting emotional resources of the caregiver, type of the family, coping ability of the caregiver, availability of economic and social support, personality of the caregiver, and caregiving beliefs and values have been found to be significant related to the caregiving.\textsuperscript{[14,36-59]} The structure of the family as well as their life stage as a family, e.g., elderly parents caring for an adult with chronic illness, or a former family breadwinner incapacitated by illness, will have its effect on the caring. This can also present challenges to caregivers.

Few studies show that caregivers while caring for the others, particularly the ailing individuals, experience significant distress both physically and mentally, although the impact of both varies. There is also momentous deterioration in their mental health (Johnson et al., 1990).\textsuperscript{[68]} Research have proved that secondary to caregiving, the well-being of the caregivers was affected by either worrying or being depressed to an extent where the caregivers are depicted having impaired health behaviors. These impairments are in the form of neglecting their own health/doctor appointments, inadequate diet maintenance, as well as deterioration in their activities of basic living, such as bathing and toileting.\textsuperscript{[61]}

Studies on the resilience of caregivers depict that the resilient factors among caregivers do have a differential impact on caregiving. It is concluded that there is tremendous decrease in the levels of caregiver burden as the resilience of the caregivers increases.\textsuperscript{[62]} Subsequently, another parallel study depicts that since the caregivers are mostly young adults, the increase of resilience within them for caring their elderly persons does have a good impact on their positive health.

Caregiver stress can lead to a number of different ailments, afflictions, and health issues for the caregivers. Several studies have shown that caregivers can suffer from exhaustion, poor immune systems, depression, and high blood pressure.\textsuperscript{[64]} More serious conditions may also arise, such as heart disease, stroke, and increased mortality – particularly for those providing care for a disabled spouse.\textsuperscript{[53]} In addition to the physical and mental stress placed on caregivers, there is also the financial stress placed on those providing care. Lack of or reallocation of finances to pay for caregiving has resulted in lost wages.\textsuperscript{[65]} This can have a multiplicative impact. Some of this stress is potentially relieved, but not eliminated, through reasonable accommodation of the caregiver.\textsuperscript{[55]}

**COMMUNITY-BASED REHABILITATION AND CAREGIVING**

It is well researched and proved that community-based interventions fasten the rehabilitation of PWCI (BNI, 2006).\textsuperscript{[66]} same led developing and developed countries to invest more on community health program rather than institutional care.\textsuperscript{[37,67,68,80]}

The emergence of community-based methods of care and the decrease in economic resources have led to a shift in the responsibility for the care of the ill individual from the institution to the family.\textsuperscript{[69,70]} The paucity of healthcare has resulted families to shoulder more responsibilities of caring their ill family member. Whether it was by choice or our cultural influence or due to the lack of facilities, it is difficult to conclude. Although there is some evidence to support that family involvement in care was and continues to be a preference of families,\textsuperscript{[71,72]} it is unfortunate that the experiences of the families with different types of severe chronic illness have not been adequately studied and their strengths not being optimally utilized in the recovery of person with mental illness. Yet, there is limited holistic
understanding of both the difficult roles they play and the circumstances under which relatives look after PWCI, as also the emotional and practical challenges they face through the different phases of the illness.

The recent trends in the community-based intervention have raised many expectations from the family, as they are viewed as primary caregiver of their ill family member. Families are now seen as a principal source of support and an important partner in the rehabilitation of the chronically ill. The responsibilities most often assumed by the immediate family member, disturbs the family routine and contributes to family burden (Jaganathan et al., 2011b).[18,19,38,73-76] Caregivers who are highly burdened and distressed may have diminished coping resources and exercise less resilience in dealing with crises or exacerbations of the patient's illness.[89,77] The caregivers should be acknowledged and looked as resource in any health program. The caregivers should be included and consulted and their voices should be recorded while we work on implementing health policy for the country. The national health program should incorporate caregivers as resources and initiate program for enhancing the well-being of unheard caregivers.

The caregivers have variety of psychosocial needs (understanding illness, managing the ill family member, dealing with stigma, involving them in to community activities, etc.) that should be understood and addressed.[9,78] There is a need for developing psychosocial interventions for caregivers to address their mental health and their needs. Caregivers needs of caring and concerns of caring should be supported to enhance the quality of care and to reduce the burden of caring. There is a need to understand the expectations of families of chronically ill family members and the impact of family level interventions at the community level on those families, as the psychosocial problems of families are related to their high level of expectations (from the PWCI) and of their emotional (over) involvement.[74] Other problems from the perspective of both caregivers and patients lay in the question of patients’ marriages and general rehabilitation into society. The needs should be understood and met to enhance the functioning of the family to provide care and thereby reduce emotional problems of the family members.[75]

Caregiving of the families and their role in the recovery of their ill family member needs to be understood. Their contributions to the recovery never gets emphasized or acknowledged. There is a need for measuring and understanding caregivers' roles in the recovery of the person, which is at the hidden cost, not getting reflected in the cost arrived at treating people with chronic illness in their homes and in communities. For example, in India, 0.83% of the total health budget is spent for mental health services,[88] does this includes the hidden cost of caregiving, a question to be reflected and answered.

Financial support and sponsorship
Nil.

Conflicts of interest
There are no conflicts of interest.

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