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# Care Giver's Needs in the Process of Cancer Recovery

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## Abstract

*Goals of work*: The aim of the study is to explore the psychosocial needs of persons taking care of family members suffering from cancer.

*Materials & Methods*: An Sixty care-givers participated in the cross sectional study. An interview schedule was used. The care recipients had heterogeneous cancer diagnosis and were hospitalized for at least a month.

*Main Result:* Their Financial needs were the highest followed by informational needs, family needs, personal needs, social needs, psychological needs and spiritual needs. It is in contrast to their studies from the west where psychological need was supreme.

*Conclusions:* The findings pave way for the development of comprehensive psychosocial care programs for the care-givers.

**Keywords**: Cancer-oncology, caregiver

## Introduction

By nature, man turns to his family in a crisis situation, more so in India. Hence family is the primary source of support for cancer patients whom they look upon for solace. This renders immense

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burden on the family caregiver leading to undue responsibility and expectations. During this phase, the caregiver passes through many trials and tribulations that can impede his/her normal functions of the caregiver. It would in turn affect the patients' supportive care. Therefore this paper is an attempt to understand the caregivers' psychosocial needs and it provides the scope to plan interventions to ameliorate their burden and enhance their coping strategies, social functioning and better care giving.

*Factors Contributing to Care giving*: Cancer affects not only the ill people but also family members and close friends. (Lewis, 1986; Martocchio, 1985; Northhouse, 1984; Slaby, 1988). In recent years, there is an escalating trend towards early discharge of hospital patients as a result an increased number of patients with cancer are being cared for at home by family members (Cawley et al, 1998; Conkling, 1989; Johnson et al, 1985; McCorkle, 1991). So much so, family members are being asked to provide more complex care in the patient's recovery (McCorkle. et al, 1993). Hence they are often of vital importance in meeting the patient's care needs and accomplishing treatment goals (Ganz, 1990; Mor et al, 1987).

*Interdependence of Patient and Care giver*: Cancer patients are a group in which care needs can be expected to increase over time and consequently the problems associated with care giving may change as the disease progresses (Northouse, 1984). Alterations in a patient's functional ability, bodily functions, appearance, employment status, sexual functioning, family and social role have a direct impact on the caregiver which may force them to reevaluate their future, leading to changes in life goals (Northouse, 1984). They often provide substantial amounts of emotional and logistical support and hands on personal and nursing care (valued at more than $1 billion annually) in an effort to address these needs (Hayman et al, 2001; Kotkamp-Mothes et al, 2005). During this process they experience depression, other adverse health effects and an increased risk of premature death (Schultz and Beach, 1999, Kurtz et al, 2004). Caregiver's psychological, personal and household needs increases as patient activity level decreases (Hileman et al 1992). Additional stress can be experienced by having to 'stand by' and observe the disease progress while being unable to alter or manage the illness (Stetz, 1987). Besides, the interactional environment of the family has an impact upon the cancer patient's performance of self-care practices and adaptation to illness (Lewis et al, 1985).

Impact of Cancer on the Care giver-Although numerous studies have examined home care needs of cancer patients (Houts, et al, 1986; Mor et al, 1987; Shaughnessy & Kramer, 1990; Wellisch et al, 1983), only a limited number of them have assessed the consequences of the patient's illness on the family or the needs of the family (Googe et al, 1981; Gotay, 1984; Hinds 1985; Rose, 1976; Stetz, 1987; Tringali 1986). Cancer affects the family in all spheres of life. Caregivers provide care at considerable cost to themselves, encountering difficulties in living arrangements and disruption of employment (Liebman & Axler 1991). It brings about altered role relationships and communication patterns (Wellisch et al 1983) emotional strain, physical demands of providing care, altered household roles and changes in the mental health status of the family members (Lewis et al 1985).

Literature has revealed that caregivers experience a greater lack of family support and health problems treatment uncertainty, role conflict/worry/added responsibilities, fear of being alone, coping with patient situation, guilt, lack of support, disturbed daily activity of the he/she lives with the patient and lack of information (Blank, J. J.,1989), loss of sleep by the primary care giver due to patient care requirements, unsatisfactory health of the primary care giver and expenses due to patient care (Googe, M. C. & Varricchio, C. G.1981). Their little knowledge on care tasks, surmounting cost of the treatment, care giving demands, side effects of the treatment, symptoms, the process of care giving, prolonged treatment; etc would result in a number of psychosocial needs (Nijboer. C. et al, 1999; Cawley, M. M. et al, 1988 & Mc Crockle et al 1991). According to the Institute of Medicine Report there is a lack of scientific knowledge and data on patient and family needs. Inadequate understanding of needs among diverse populations has also been identified as a major problem (Field, M., & Cassel, C., 1997).

Needs assessments are required to guide care planning, in part because many caregivers and patients do not communicate concerns to their clinicians (Suchman et al, 1997; Guadagnol, et al, 1998; Frosch, et al, 1999; Maguire, et al, 1999. When they do share needs, they often omit important psychosocial concerns (Cull, et al, 1995 & Osba, 1996). Several factors contribute to this breakdown. Many patients and caregivers believe that pain; grief, anger, and suffering are inevitable as far as cancer was concerned. Others believe that clinicians do not want to address such issues, as evidenced by the absence of clinician inquiry or concern required to develop a meaningful dialogue (Ford, S., et al, 1996; Marvel, M. K., et al, 1999; Holland, J. C., et al, 1999; Kim, M. K., et al, 1999; Sabo, D., et al, 1990 & Schulz, R., et al, 1999). As a result of inadequate understanding of patient and family needs, both healthcare costs and unnecessary suffering increases (Cegala, 1997; Northouse. L., 1998 & Northouse, P., 1987). Substantial evidence points out especially to the damaging effects of inadequately met information and support needs (Schulz et al, 1999; Peters-Golden, 1982 & Vitaliano, 1997). For instance, if clinicians are unaware that a caregiver feels unprepared to clean and treat a patient's wound, then adequate training may not be provided; infections may then develop that increase suffering and costs. The research conducted so far also fails to describe how patient and caregiver information and support needs change with key events such as learning that treatment is no longer working (Northouse, L., 1989; Ell et al, 1988; Wilson et al, 1991 & Wilkerson, 1991).

Care givers Needs: According to some of studies the care giver’s needs were information, financial, psychological or emotional support, social support, temporary escape, research for a cure, wish granting, medical advice practical assistance, transportation, household help and assistance for shopping (Walker, 2011; CLFM, 2004; Hileman et al, 1992; Northhouse, L., 1989b; Jacqueline et al,1989; Googe & Varricchio, 1981). However, the needs of the caregiver’s terminally ill cancer patients were homecare, psychological support, and financial help (Joad et al, 2011).

Health care, including cancer care, is in the midst of a revolution driven by strong forces of cost, containment and competition. Cancer care providers are expected to improve both performance and reduce costs; not as a one-time event but as a way of life. However, these improvements are unlikely to occur without a much better understanding of patient and family needs and the factors that influence them (Berwick, D., 1997). Once these needs are fully understood, interventions can be designed that will improve adherence reduce waste and rework. (Wen Kuang-Yi et al, 2004).

Most of the studies conducted on caregiver's burden and their needs at home were from the west. Family caregivers have received very little attention in published literature from India (Mehotra, 2008). Very few studies have addressed the needs of care givers during hospitalization. Thus an attempt was made to study their needs so that it could be addressed through social work interventions.

*Scope of this paper:* This study is relevant in the present scenario because of the growing incidence of cancer which has accounted for 7.6 million deaths in 2008 and is projected to account for 13.1 million deaths in 2030 (Cancer-WHO, 2012), This happens due to decreased hospitalization leading to transition of care from the hospital to the family, greater needs arising from care-giving, fewer studies and increased need of interventions.

This paper is the need of the hour owing for the lack of Indian literature, growing incidence of the disease, changing trends in treatment has led to the transition of care for persons with cancer onto the caregivers during the illness in the post trajectory. Often in the post phase because the residua of cancer and /or the side effects of the treatment limits their activities of daily living (bathing, eating, using the bathroom) or results in functional disabilities of their day to day activities (IOM, 2008, **Hewitt et al,** 2003). This in turn would lead to more needs that are unmet. Hence this study attempts to find out the needs of caregivers and pave the way to develop an organized care program for care givers which is totally undeveloped in Indian setting.

## Methods

The universe of the study included the caregivers of persons with cancer, who were registered at a cancer hospital in Bangalore, for six months (718 patients). Sixty caregivers were selected using purposive sampling. Only family care givers of patients hospitalized for more than a month were selected for the study.

A semi-structured interview schedule constructed through discussions with experts, focused on group discussions and the available literature was used. The following dimensions of needs were identified: informational, psychological, family, social, personal, financial and spiritual. Using these themes questions were formulated under each dimension. Informational needs had 18 items, Psychological needs had 28 items, Family needs had 10 items, social needs had 8, financial needs had 12, personal needs had 9 and spiritual needs had 4 items. Each item was ranked on a five-point scale. The points assigned to never – 0, rarely – 1, sometimes – 2, very often – 3 and always – 4 points.

Percentage and mean scores of total needs was calculated to analyze different requirements. Higher the total score, greater is the need. t-test was used to compare means between two groups, chi-square was used to find association between two categorical variables and ANOVA was used to compare the means of different groups. Analysis was done using SPSS soft ware.

## Findings

Table 1 Socio-demographic details

| Sl. No | Socio-demographic details | Categories | Percentage |
|---|---|---|---|
| 1. | Gender of care giver | Male | 48 |
| | | Female | 52 |
| 2 | Relationship with patient | Parents | 32 |
| | | Spouse | 33 |
| | | Children | 20 |
| | | Siblings | 3 |
| | | In-laws | 12 |
| 3. | Qualification of care giver | Illiterate | 17 |
| | | School Dropout | 30 |
| | | SSLC | 32 |
| | | PUC | 8 |
| | | Graduate & above | 13 |
| 4 | Work | Employed | 72 |

| | | | |
|---|---|---|---|
| | | Unemployed | 28 |
| 5 | | Nil | 28 |
| | | Daily Laborer | 17 |
| | Nature of employment | Farmer | 8 |
| | | Business | 15 |
| | | Services | 12 |
| | | Others | 20 |
| 6. | | No Children | 25 |
| | Number of children | 1 Child | 15 |
| | | 2 Children | 27 |
| | | 3 Children & above | 33 |
| 7 | | Hindu | 82 |
| | Religion | Muslim | 13 |
| | | Christian | 5 |
| 8 | Domicile | Rural | 53 |
| | | Urban | 47 |

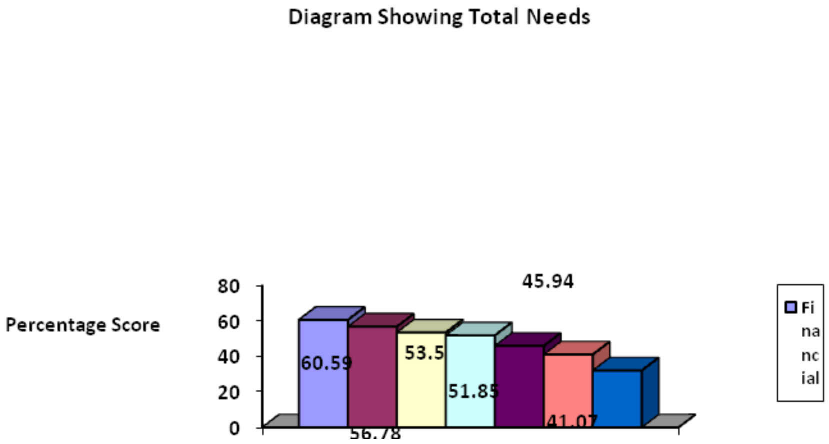
Table 2 Distribution of Caregivers based on the Socio-demographic details

| **Sl. No** | **Socio-demographic details** | **Mean** |
|---|---|---|
| 1. | Caregiver's age | 43 |
| 2. | Patient's Age | 43 |
| 3. | Monthly Income | 4733 |

## Clinical Details

The mean age of the patient was 43 years, 65% were female, 40% suffered from gastrointestinal cancers and 30 % from head and neck cancers, 80% were hospitalized for one month to six months. Each of 30 Curative and Palliative patients was considered for the study.

## Needs of Caregivers Based on Total Scores

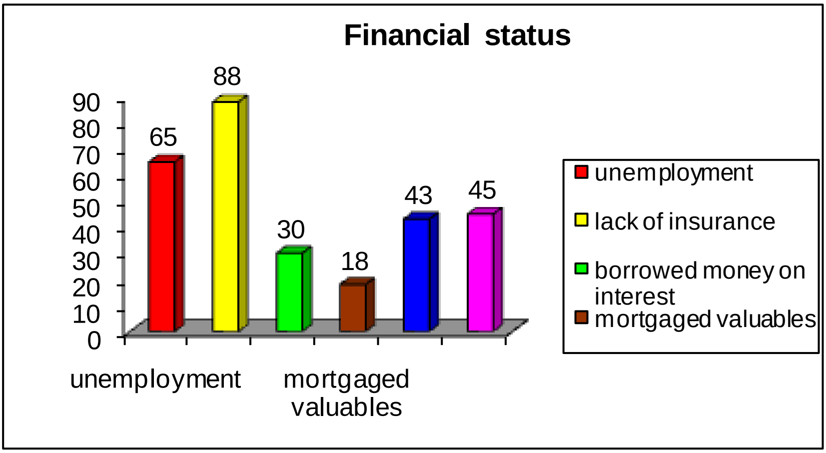


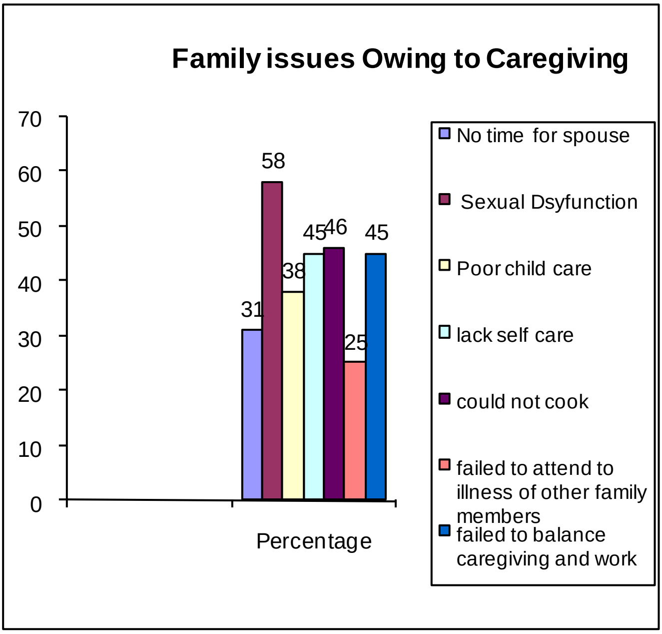
*Higher the Scores, higher the need.

## Needs of the Caregivers Based on the Total Scores

**Total Need**: Financial needs was the highest 60.59 followed by informational needs (56.78%), family needs (53.50%), Personal needs (51.85%), Social needs (45.94%), Psychological needs (41.07%) and spiritual needs (32.08%).

This study was in contrast to the study conducted by CLFM (2004) wherein informational needs (33%) was the highest followed by financial assistance (30%). Informational and psychological needs were the greatest (Hileman et al, 1992) and psychological needs was the largest need followed by household management needs and informational needs (Wingate et al 1989).


Financial status
90
80
70
60
50
40
30
20
10
0
65
88
30
18
43
45
unemployment
mortgaged valuables
unemployment
lack of insurance
borrowed money on interest
mortgaged valuables


Family issues Owing to Caregiving
70
60
50
40
30
20
10
0
31
58
38
45
46
25
45
Percentage
No time for spouse
Sexual Dsyfunction
Poor child care
lack self care
could not cook
failed to attend to illness of other family members
failed to balance caregiving and work

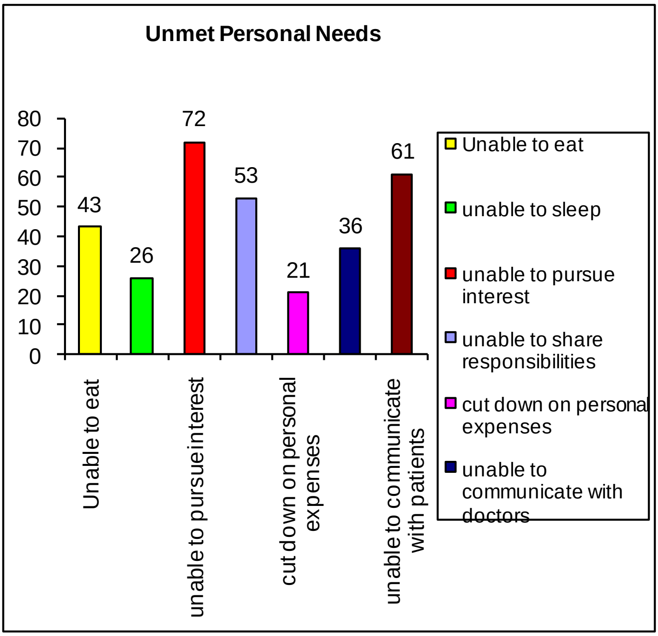


Diagram Showing Financial status, family issues and personal need

# Discussions

## Financial Need

The study reveals that finance was the highest need. It is owing to the soaring cost of treatment, loss of employment after the onset of treatment because of care giving (65%) or the person with cancer might be the bread winner, lack of insurance (88%) and prolonged treatment which means absence from work were the other causes. There were respondents who did not receive any financial support from family (45%) and mortgaging and borrowing were also common (30% & 18%). These findings are similar to the study conducted by Children's Leukemia Foundation of Michigian (2004) which revealed that 70% of respondents said that the patient's illness had changed their employment status and financial need was the highest probably because of significant illness related expenses – costs that are not medical, still essential due to patients illness.

It was observed that irrespective of getting benefits from organizations, they had financial constraints because of expenditure on transportation, lodging, food and special food or supplements for patients in addition to loss of income/work.

## Informational Needs

Informational need ranked the second. The respondents required information about period of stay (83.33%), palliative care (78%), diet (70%), treatment (65%), railway-concessions (61%) and about funds (58%). It is similar to the study conducted by Children's Leukemia Foundation of Michigian (2004) in which the illness related topics of interest of caregivers were causes of the disease, side effects, financial assistance and facts about diagnosis.

The respondents were unfamiliar with the terminology, disease, symptoms, protocols, the kind of diet to be given, availability of resources, professionals to contact, different treatment modalities, costs and procedures on which they required information in order to cope with the changed roles, adapt to the environment and plan their activities. According to Northouse (1984) care giving enforces the care-givers to reevaluate their future and make changes in life goals which can be done only by acquiring information.

## Family Need

Family need is the third category. The study revealed the strength in Indian families as emotional support (70%), absence of sexual relationship (58%), the inability to cook (46%), the inability of not being able to balance care giving and work (45%), lack of time for self (45%), children (38%) and spouse (31%) and 25% not being able to attend to the illness of other family members. Findings reveal that an adult's cancer can upset the whole family system, affects quality of children's life and increases burden on the partner of the cancer patient. It can result in increased stress and decrease quality of relationship (Kataja et al 2006).

It is indeed a challenge for the caregivers to spend most of the time in the hospital along with the patient. The patient always requires a bystander owing to the probable side effect of the treatment, to procure medicines, supportive supplements like platelets, blood, food to meet other requirements or to attend to other needs of the patients as they may be bed bound completely or partially. Even if the patient is independent, the caregivers might tend to be in the hospital because of other constraints like transportation, funds, time, maintaining schedules, tedious journey, their health, unfamiliar bus routes etc. As a result the family suffers in the long run and they are unable to balance care-giving and work.

**Personal Needs**

Personal needs are affected fourth in the order of challenges. The caregivers are burdened with meeting the needs of the patients and eventually their patterns of daily living are altered. This study revealed that care givers are unable to: pursue their interests (71.7%), communicate with patients (61%), share responsibilities (53%), always have timely food (43%), communicate with doctors (36 %), sleep (26%) and cut down on personal expenses (21%) which substantiates the statement that family and friends frequently provided patient care at considerable cost to themselves, encountering difficulties in living arrangements and disruption of employment (Liebman et al 1991).

Communication is poor with the patient as they try to instill hope in them and sustain it. In India, the caregivers of families are the decision makers and they feel that there is no need for the patient to be aware of what would happen to them. They also forbid the doctors from disclosing the disease to patients. It is also poor with patients as they feel that they are incompetent to comprehend what the doctors discuss or they fear that they would ask a wrong question. The care-givers are anxious about or tend to panic at the unknown that keeps them at bay from exploring it.

Symptoms especially pain, prolonged treatment, side effects of treatment modalities, meeting the needs among others takes a toll on the caregivers demanding their constant attention and as a result they would be unable to meet their daily living activities like eating, sleeping, meeting responsibilities, etc.

The decrease in personal expenses owing to the patient's illness is 21% in contrast to the study conducted by CLFM (2004) in which the reduction in personal expenses was 79% in 2004 and 66% in 1998. It implies that the caregivers are trying to meet the patient's needs as far as possible unlike in the West. It could also be one of the reasons for increased financial need and the increased percentage of procuring loans. The decrease in cut back could also be due to sponsoring the treatment by other organizations (43%).

### Social Needs

Social needs are the fifth need of the caregiver. It brings out the fact that after the onset of illness, the caregiver's social interaction had decreased. It was found that 57% of respondents failed to interact with friends, 40% did not interact with neighbors, 33% could not attend functions, 36% never celebrated festivals, 28% felt guilty to leave the patient and go out. The decreased social interactions could be due to meeting high demands of the patient, lack of time, prolonged hospitalization, stigma (24%), guilt to leave the patient alone (28%), difficult to answer queries, side effects on the patient, financial constraints, patient's dependence, over involvement, fear of uncertainty or fear that something would happen in their absence, others would blame them if anything happens in their absence, inability to maintain patient's needs because of going out, does not like to share responsibilities with others or feels others are incompetent, etc.

### Psychological Needs

The studies from the West shows Psychological needs are the highest but in this study it takes the sixth position. Perhaps the care givers were unaware of their psychological needs as in other countries and hence not paid heed to it. Or it might be owing to strong family ties of our culture from where they draw more emotional support.

The analysis shows that caregivers are emotionally connected with family (70%) and friends (26%). This could be one of the reasons for the decreased felt need despite feeling sad (70%), intolerance to see patient suffering (60%), tension (55%), insecurity (45%), impatience in dealing with disease (45%), helplessness (36%), outburst of tears (26%) and fear of relapse (23%). While the CLFM (2004) study revealed that 85% of respondents felt they needed emotional support. Yet 45% said that they never or rarely asked for it when needed. They felt that psychological support was the most personally important need for coping with the diagnosis. They also said the patient's illness made them feel overwhelmed, they felt the need to escape, and their lives revolved around the patient's illness. It was found that 47% of caregivers felt they were depressed.

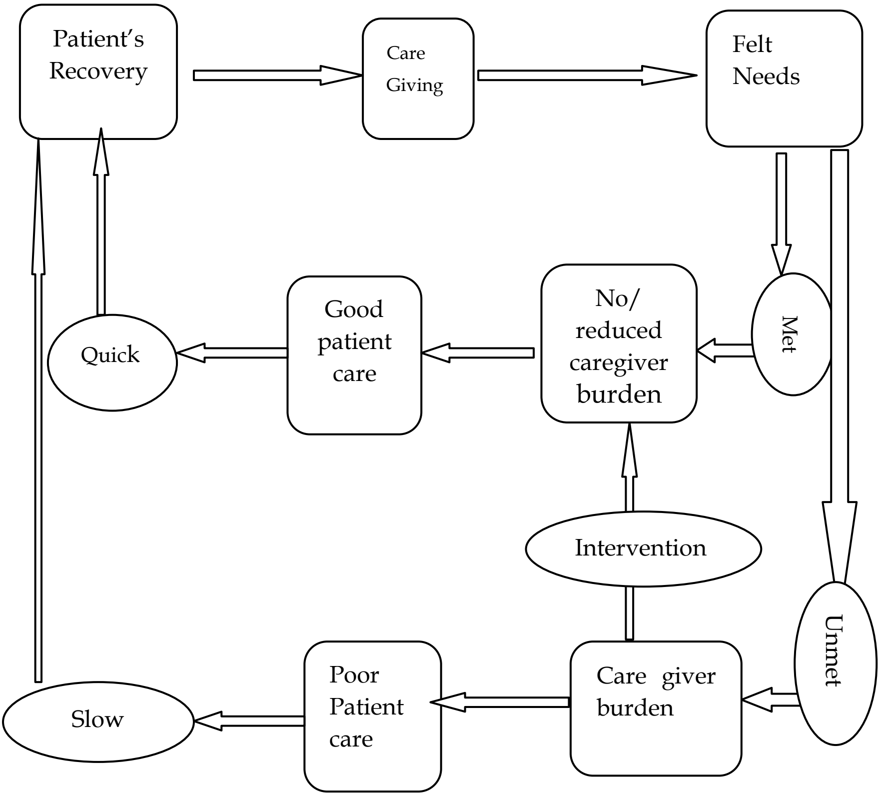
The study revealed that caregivers do not pay attention to their needs as their central focus was the patient which is obvious from the attention paid to their personal needs.

### Spiritual Needs

Spiritual needs are the last domain. It could be probably that this concept is new to hospital settings, unlike in the West, where they are exposed to pastoral care. Unfortunately even the caregivers of palliative have expressed requirement of spiritual need as sometimes.

## Implications for Psychosocial Care

This paper depicts that during the process of care-giving the caregiver struggles to strike a balance between internal and external self to meet the patient's need, paying a price in all spheres of life namely physical (health), financial, psychological, familial, social and spiritual. The lacunae or lag in these dimensions surfaces as problems which are actually the felt needs or unmet needs. If these felt needs are unattended to, in the long run, it would become a caregiver's burden and deplete all their internal and external resources. Consequently it would affect the quality of care giving and in turn the patient's response to the treatment (recovery) and result in illness of caregiver. As a result, the caregiver might throw up their frustrations on the patient like failing to show compliance with the treatment, purchase medicines, demotivated to get the necessary investigations done, to continue further treatment or to continue the follow up until grave situations arise. The sandwiching between patient care and the care giver's family, friends, health, work and spirit would inevitably or unconsciously result in poor care giving. Thus if these needs are taken care of through comprehensive psychosocial care giving program, the care giving burden can decrease and quality of patient care could increase. This would pave the way for positive response towards the treatment. Thus the authors have raised the importance of care giving through the schematic representation as given:



Schematic representation of importance of care giving.

## Conclusion

All the caregivers have financial, informational, family, social, personal, psychological and spiritual needs at different levels based on the socioeconomic characteristics and patient's profile. This needs to be assessed and addressed through interventions. If met it would reduce care giving burden and enhance patient care and in turn lead to quick recovery and enhanced quality of life for patients as well as care givers.

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