

Need for Psychosocial Support for Immediate Caregivers of Patients under Palliative Care

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Abstract: Immediate caregivers play an important role in the care of patients under palliative care, especially as a shift is observed in the pattern of care for terminally ill patients so that outpatient care is becoming more popular around the world. The caregiver burden is described as a multidimensional bio-psycho-social reaction resulting from an imbalance of care demands and caregivers' personal time, social roles, physical and emotional states, financial resources, and formal care resources along with the other multiple roles they fulfill. Although caregiver burden demands high attention, the fact is that it is not addressed in a way that it actually should. This article aims to discuss the role of psychosocial support for immediate caregivers to reduce their perceived care burden based on the results from the study titled "A Cross- Sectional Study on the Care Burden and Quality of Life of Immediate Care Givers of Patients under Palliative Care". The study was conducted as a cross-sectional exploratory study consisting of both the cross-sectional study and an in- depth interview. 62.5% of the participants in this study had a high degree of care burden according to the Zarit Burden Questionnaire. It was also found that 50% of the participants had their Quality of Life affected in terms of caring stress and the caring stress was found to have statistically significant relationship with the care burden. Duration of caring was also found to have statistically significant relation with the caring stress. The need for social support and psychological support were two important domains identified after analysing the data obtained from in depth interview. Psychosocial support is an important measure to avoid or reduce the impact of caring stress among the immediate care givers of patients under palliative care. Though stressful events are inevitable during care giving for a patient under palliative care, attempts can be made to identify those at increased risk for negative outcomes, assess the degree to which the caregiver's life and health are affected, and recommend interventions that could bring changes to the negative experiences perceived and thereby improve the quality of life.

Key Words: Palliative care, Immediate caregivers, Care burden, Caring Stress, Psychosocial support.

1. INTRODUCTION:

Palliative care is the active overall care by multi-professional team for patients with life- limiting illnesses or ailments that demand prolonged treatments.[1] According to WHO, Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening diseases by preventing and alleviate suffering by early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.[2]As per the Lancet Commission Report, Palliative Care is an essential component of comprehensive care for persons with complex chronic or acute, life-threatening, or life-limiting health conditions that is to be necessarily practiced by healthcare providers, social workers and by palliative care specialists, and can be provided in any health-care setting, including patients' own homes"[3] The definition of Palliative Care by WHO is much broader when compared with the latter, which considers the quality of life of the family members also important.

Care Giver

Eventhough the act of caregiving is very common, the term "caregiving" is relatively new, with the first recorded use of the word in 1966.[4] A **caregiver** or informal caregiver is a paid or unpaid person with or without formal training (in related treatment) who helps the patient with activities of daily living. They may have to assist the patient in a wide range of activities like bathing, dressing, and taking medications to tube feeding and ventilator care. The duration of caregiving varies in each case, ranging from a short period as in post-acute care, especially after a hospitalization, to more than 40 years of ongoing care for a person with chronic care needs.[5]

Caregiver can be any relative, partner, friend, or neighbour who shares a personal relationship with the patient assisting them in carrying out a broad range of activities. These individuals may live with or separately from the person receiving care. Individuals who provide care and not included in this definition are those who are employed by or volunteer with a formal service system.[6]

Caring for someone in a palliative stage is more or less considered as a moral duty and in almost all the cases, family members are the privileged group for this purpose. In many of the countries a shift in the pattern of caring for the terminally ill patients can be observed that outpatient care is getting more popular and family members are central in providing care for such patients.^[7]

Care Burden:

Though the norms of obligation are strong, caregiver's ability to care may fail to meet the needs of the patient which eventually interfere with routines and hence be perceived as burdensome, causing a negative evaluation of the relationship.^[8]

Caregiver burden is described as a multidimensional bio-psycho-social reaction resulting from an imbalance of care demands and caregivers' personal time, social roles, physical and emotional states, financial resources, and formal care resources along with the other multiple roles they fulfil.^[6] Compared to non-caregivers, caregivers are more prone to psychological, behavioural, and physiological effects that can result in impaired immune system function and coronary heart disease, and early death.^[9]

Caring Stress:

Based on caregiver's appraisal of the experience, there is relative risk of developing various psychological problems and most commonly presenting symptoms include anxiety, depression, worries and loneliness. It is observed that those who report more benefit and deriving more meaning from the experience feel less stress and report better quality of life.^[10]

This article aims to discuss the role of psychosocial support to immediate caregivers in reducing their perceived care burden based on the results of the study titled "A Cross- Sectional Study on the Care Burden and Quality of Life of Immediate Care Givers of Patients under Palliative Care"

2. STUDY DETAILS:

Design:

Telephonic cross sectional Study and in-depth interview.

3. MATERIALS AND METHODS:

A telephonic cross-sectional survey was conducted among 80 immediate caregivers and in-depth interview among 7 immediate caregivers of patients registered in Kaniv Pain and Palliative Society. The inclusion criteria were that the participants should be registered male/female immediate care givers, taking care of the patient for at least 6 months. Care givers with known psychiatric illnesses were excluded from the study. Audio consent were collected from the patients and are saved.

Questionnaires used:

- Zarit burden interview questionnaire:

It is a 22 item questionnaire to assess the care burden in which each question is given with five options as Never, Rarely, Sometimes, Quite frequently and Nearly always which respectively score from 0-4. The burden level is assessed as absent to mild burden (0-20 points), mild to moderate burden (21-40 points), moderate to severe burden (41-60 points), and severe burden (61-88 points).^[11]

- Adult carer quality of life questionnaire:

It is a 40 item questionnaire in which each question is given with four options such as 'Never', 'Some of the time', 'All the time' and 'Always'. The entire number of questions are given under 8 domains; that is five questions in each domain.

The domains are:

Support of caring, Caring choice, Caring stress, Money matters, Personal growth, Sense of value, Ability to care and Carer satisfaction.

The third domain Caring stress of ACQOL questionnaire assesses the psychological wellbeing of the caregiver during care delivery.^[12]

3. ANALYSIS:

The chi square test of analysis was performed to determine the association of care burden with different determinants. The data collected through in-depth interview were analysed and arranged under different domains.

4. FINDINGS:

In this study, 62.5% of the participants were having high degree of care burden as per Zarit Burden Questionnaire. It was also found that 50% of the participants were having their Quality of Life affected in terms of caring stress and the caring stress was found to have statistically significant relation with the care burden.

Table 1: Chi square association and cross tabulation of caring stress and care burden

Cross-Tabulation					Chi Square Test		
Quality of Life		Care Burden			Total	Chi Square Value	P Value
		Absent-Mild	Mild-Moderate	Moderate-Severe			
Low Quality of Life	Count	0	4	6	10	52.013	.000
	Expected Count	3.8	5.3	1.0	10.0		
Medium Quality of Life	Count	4	24	1	29		
	Expected Count	10.9	15.2	2.9	29.0		
High Quality of Life	Count	26	14	1	41		
	Expected Count	15.4	21.5	4.1	41.0		
Total	Count	30	42	8	80		
	Expected Count	30.0	42.0	8.0	80.0		

As the calculated test statistics 52.013 is greater than the table value of chi square at the degree of freedom 2 and p value is less than 0.05 the association is statistically significant. Hence it is clear that caring stress is positively associated with care burden.

Duration of caregiving was found to have statistically significant relationship with the caring stress in this study with chi square value 8.040 and p value 0.018.

The average duration of caregiving among the participants in this study was 24 months and the chance to develop caring stress was found to more in those participants who have been caring the patient for more than 24 months.

Need for social support and psychological support were two important domains identified after analysing the data obtained from in depth interview. 71.4% of the participants were unsatisfied about the social support obtaining. They were not getting help in care giving from others and this situation added to their burden.

- 55 years old female spouse of 62 years old patient: “I don’t get much support from any of my family members or relatives except that they give some money during Ramadan fasting days. Also, I’m afraid to ask for help as the society’s view about wives of bedridden patients is different”
- 73 years old male spouse of a 68 years old female patient: “I and wife are left alone at home mostly. I don’t get any help from neighbours and I don’t expect that. We cannot demand others to show concern in our things. Also I am getting aged and have diffused body pains. And it’s natural to have a disturbed mind when your spouse is ill and bedridden. I accept all these and never complaints”
- 56 years old mother of a 34 years old female patient: “I always feel sadness. But I can’t do anything about that. I have to take care of my daughter.”

5. DISCUSSION:

Caregivers are often referred to as “secondary patients,” who need protection and guidance.^[7] The findings of this study regarding caring stress is in line with the findings from previous studies that the chance for psychological distress is high in immediate caregivers of patients under palliative care. Different research findings indicate that caring stress can lead to psychological and sleep disturbances in caregivers which eventually affect physical health, immune function, and financial well-being.^[13] Studies even report that the degree of anxiety like symptoms during the first stage of home care has impact on the psychological distress experienced by the caregivers following the death of the patient.^[14] Psychosocial support is an important measure to avoid or reduce the impact of caring stress among the immediate care givers of patients under palliative care. The term ‘psychosocial’ indicates a dynamic relationship between the psychological and social aspects. The *psychological* dimension consists of the internal, emotional and thought processes, and reactions, while the *social* dimension includes family and community network and relationships, social values and cultural practices. ‘Psychosocial support’ refers to the measures that address both psychological and social needs of individuals, families and communities.^[15]

Recognizing the psychological, behavioral, and physiological impacts of caring for a patient under palliative care is an opportunity for primary prevention. Screening questionnaires like *Self-Assessment Questionnaire (CASQ)* developed by American Medical Association to assess the caring stress which was validated as a self-report screening measure for depression in caregivers of patients with dementia.^[16]

As caring stress and duration of illness of patients are associated, as seen in this study, attempts are to be made to identify caregivers with an increased risk of developing caring stress and managed. Studies suggest that a good support from family members, friends and relatives and professionals lessen caregiving burden of immediate caregivers considerably.^[17] A proper psychosocial support can be ensured by preparing standardized guidelines for caregiver assessment, education, and resources; identification of “caregiver champions” in practice settings; provision of referrals to established support organizations for caregivers (eg, Cancer Support Community, Cancer Care); and collaboration among caregiving, professional, and palliative care units and other NGOs for policy implementation and thereby bringing positive changes in the lives of caregivers.^[7] Screening is to be done among the caregivers by either the palliative care units or NGOs to find out those at increased risk of caring stress and the problems are to be addressed. A network of caregivers can be made and meetings to be arranged frequently where they are allowed to share their problems openly which can help in lessen the caring stress. Various relaxation techniques like breathing exercises and yoga can be taught to them during these gatherings.

6. CONCLUSION:

Immediate caregivers are irreplaceable in palliative care system and hence it is very important to modify palliative policy to incorporate care for immediate caregivers and address the care burden. Though stressful events are inevitable during care giving for a patient under palliative care, attempts can be made to identify those at increased risk for negative outcomes, assess the degree to which the caregiver's life and health are affected and recommend interventions that could bring changes to the negative experiences perceived and thereby improve the quality of life.

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