

## **AGONY OF THE PALLIATIVE PATIENTS ON THE SUFFERINGS OF THE FAMILY CARE GIVERS: REFLECTIONS FROM KERALA**

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### **ABSTRACT**

Palliative care is well known for its service for the terminally ill or bedridden elderly/ patients. Since patients/elderly and their family together constitute the unit of care it is essential to realize the significance of family caregivers in executing the process of care. This study intends to identify the perceptions of the care receivers on the stress of their family caregivers and the impact of the same on their own total wellbeing. The study reveals that the care receivers are very much concerned about the strain and stress of their care givers in connection with the process of caring them.

**Keywords:** Agony, Palliative Patients, Sufferings, Family Care givers

### **1. THE RESEARCH PROBLEM**

In our society, palliative patients due to various reasons, inter alia financial constraints are cared in the family itself and not in hospitals or such other institutions as in the western societies. This method of palliative care followed in the West may be effectively carried out in economically stable families which can provide multifarious material facilities and services.

However, there is a vast segment of families in our society which cannot afford maintaining an unproductive person who at the same time requires extensive support from the family. So palliative care, in our society has been facing very deplorable situation.

In Kerala, in 1993, due to the philanthropic mentality and leadership of a medical doctor, a palliative care society was constituted to cater to the needs of the deserving persons especially belonging to the poor sections of the population. This has widened its wings and now its services are available all over Kerala. Various agencies including the state government are supporting the activities.

In Kerala Palliative Care system, the burden of caring the patients are shared by the family members and the volunteers including medical professionals, counselors and supporting good Samaritans. The two major segments experiencing reciprocal sufferings are the family care givers and the patients, forget about the burden of the Palliative Care Society.

The patients suffer from physical pain followed by mental agony. The Palliative care patients are usually victims of such diseases as cancer, heart complaints, kidney failure, paraplegia, Parkinson's disease and old age related complications. These diseases are prolonging ones and also require expensive medical care.

In this background, imagine the case of poor family which sustain on daily earnings. Further these patients have to get extreme care from their family. Even for partially satisfying the contingencies, the family members have to strenuously struggle. These struggling members are motifs of sacrifices for the palliative patients and this feeling in turn aggravate their mental stress. Naturally the physical discomfort experienced by the patients redoubles. So the sufferings of the patients become reciprocal with their family members.

According to Charles Horton Cooley, individuals develop their concept of self by observing how they are perceived by others, a concept Cooley coined the "looking – glass self". Using social interaction as a type of mirror, people use judgments they receive from others to measure their own worth, values and behavior. The patients undergo two worlds of torment. They share a major anxiety in illness equal to their own distress about death, experience of pain or loss of dignity in the midst of the suffering experienced by their family caregivers (Loscalzo and Zabora, 1998)

The engagement of this paper is the analysis of the mental agony experienced by the palliative patients on account of their empathizing with the struggle of their family members generated by they being attended to by them.

## **2. METHODOLOGY**

The major objective of the study is to find out the perceptions of the patients on the stress of their family care givers and how their concern and anxiety in turn aggravate their own well being. The population of the study is Palliative Care beneficiaries in Kerala. The three districts in Kerala (Trivandrum, Thrissur, Kozhikode) which represents the southern, central and northern zones respectively constitute the area of study. From each of the three districts 100 palliative care beneficiaries are selected for the sample and data were collected using semi-structured interview schedule.

## **3. THE AGONY OF THE PALLIATIVE PATIENTS**

The analyses of the existing literature tend to presume that the palliative care receivers who have been getting assistance from their family are agonized on the stress and strain experienced by their care givers. On the basis of this presumption this study attempted to test the validity of the perspective by analyzing the empirical data collected from the field.

### **3.1 Duration under Palliative care**

This study enquired into the duration of Palliative care of the respondents with the intention to reveal how long have been the patient undergoing the ordeal and the family facing the situation. As all of us know the longer the duration the greater will be the sufferings of the patients as well as that of the family.

**Table 3.1: Duration under Palliative Care**

Duration	Frequency	Percentage
Less than a year	51	17%
Less than 2 years	60	20%
Less than 4 years	59	19.67%
4 years and above	130	43.33%
Total	300	100%

The analysis reveals that the largest portion of the respondents (43.33%) have been under palliative care for more than four years and almost equal portions for less than four and two years (20% and 19.67% respectively). The remaining portion (17%) comes under the category of those who have been suffering for less than one year.

The results indicate that the pain and agony undergone by largest share of the respondents are unfathomable. Several respondents stated that it is not their physical pain and discomforts that create mental agony, rather it is the sufferings that have been undergone by the care givers that matters much for them. Everyone can guess the difficulty one has to face to attend to a person who is bedridden, not for one day or one month but for more than four years. It is natural that conscious person (the patient) will feel extreme mental agony in such situation.

### **3.2 Nature of Disability**

We know that palliative Care system in Kerala provides its services to people who are suffering from a chronic disease or old age related complications. Here in this study the respondents are categorized into three different groups on the basis of the nature of their disability. They are

Diseased, Aged and Both aged and diseased. The nature of disability of palliative care patients may determine the intensity of sufferings faced by them and also their family. The type of care needed by the patients may also vary according to the type of disability they have.

**Table 3.2: Nature of Disability**

Nature o Disability	Frequency	Percentage
Diseased	261	87%
Aged	17	5.67%
Both Aged and Diseased	22	7.33%
Total	300	100%

Table 3.2 shows that the majority (87%) of the respondents have approached and availed the palliative care service due to a chronic disease. Respondents who avail the service for their old age related complications constitute a very small portion (5.67%). Another smaller portion (7.33%) among the respondents opined that they face problems related to their old age and also have a chronic illness.

On the basis of the above analysis, it is found that care for the aged may be arranged by the family itself without approaching palliative care. The major portion (87%) of the respondents is diseased at an early age and they may have multiple roles and responsibilities in their family and society. Additional roles handed over by the patients to the care givers create a chaos inside the family. The strain the caregivers put for managing the household functions and responsibilities make the patients feel distressed.

### **3.3 Marital Status of the Respondents**

Marital status and living arrangements along with changes in these in mid-life and older ages have implications for an individual's physical, psychological and social health. In particular, if a person who is disabled because of old age or a persistent disease may need special care from his/her primary care giver. Married patients living with their spouse may receive all type of care they expect when compared to the respondents in the categories of unmarried, divorced/separated and widow/widower. Also the caregivers may be comfortable with caring their intimate partner rather than caring a distant relative.

**Table 3.3: Marital Status of the Respondents**

Marital Status	Frequency	Percentage
Married	188	62.67%
Unmarried	36	12%
Separated/ Divorced	17	5.67%
Widow/Widower	59	19.67%
Total	300	100%

From Table 3.3, it is clear that 62.67% of the respondents are married and living with their spouse. 19.67% of them lost their spouse by death. While 12% of the respondents are unmarried only 5.67% of them are living separated or divorced from their spouse.

The analysis reveals that majority of the patients are cared by their spouse at their home and others are cared by family members other than their spouse. Though the pain and strain of the care givers are similar in the case of married patients and the other categories, the patients perceive the sufferings in different manners. Patients who are cared by their spouse may have a guilty feeling that they can't help their partner in fulfilling their responsibilities. At the same time the other categories of respondents feel themselves as a burden to the care givers and to the family as a whole.

### **3.4 Family Size of the Respondents**

Family system loses its stability and control over people in the modern age. Traditional joint families are even disappeared from the picture. Family structure and size is an important factor when it comes to the process of care of aged or terminally ill patients. This study identifies three categories of respondents on the basis of the number of members each family has. They are Large, Medium and Small. Large families include more than five members, medium families include three to four members and small families have maximum two members.

**Table 3.4: Family Size of the Respondents**

Family Size	Frequency	Percentage
Large	83	27.67%
Medium	139	46.33%
Small	78	26%
Total	300	100%

Table 3.4 shows that major portion (46.33%) is included in the category of respondents who are having a medium family size. The other two similar portions are having large (27.67%) and small (26%) families. Usually the medium size families have parents and their unmarried children.

Caring a person with long lasting disease is considered as a cumbersome task if there would be no enough caregivers in a family. While large families conveniently manage the care giving and other household activities, medium and small families may struggle to maintain the balance of different activities and responsibilities. Also the quality of care received by the patients may have influenced by the size of family he/she has been included. Palliative care patients share their concern about the absence of caregivers due to their multiple responsibilities.

### **3.5 Monthly Income of the Family**

Monthly income of a family determines the standard of life a particular family has been maintaining. Unexpected and huge expenses in association with an intrinsic disease of a family member may mess up the family budget. Maintaining the economic stability of the family becomes impossible for those who are depending on daily earnings. Here the researcher categorized the respondents' families into three as Low, Middle and High income families on the basis of the total income of the family in a month. Low income families have no regular monthly income, Middle income families have members working on daily wages and high income families have a regular monthly income.

**Table 3.5: Monthly Income of the Family**

Monthly Income	Frequency	Percentage
Low	241	80.33%
Middle	46	15.33%
High	13	4.33%
Total	300	100%

It is evident from table 5 that the majority (80.33%) of the respondents is from low income family. Only 4.33% of them have a regular monthly income and another 15.33% is having members with daily wages.

The economic instability faced by the majority may create multiplicative sufferings for the families associated with caring a disadvantaged family member. Increased cost of living and extensive treatment charges push the patients and their families into a deep moat and a recovery may not be easily attainable.

#### **4. PERCEPTIONS OF THE PATIENTS ON THE STRAIN OF THE FAMILY CARE GIVERS**

A palliative patient can never enjoy autonomy. They could do with their friends, family and especially the medical professionals to help them crossing through illness. Despite the need and dependence on medical expertise in disease progression, many care receivers consider as though they should steer treatment options and decisions with their family members. If the care receivers experience an open awareness of their illness trail, it is noted that there is a budge from concern over medical issues to a need to express some control over the burdens related with the later stages of life and how the strain of their family members could be minimized through preparations (Yurk et al., 2002).

Here, the patients' perceptions on the physical and mental strain of the family caregivers are tried to be revealed through the data collected from the respondents.

##### **4.1 Physical Strain of the Care givers**

There is no doubt that the physical labor of the caregivers may vary depending on the stage of illness. In the later stages of illness, this physical strain of the caregivers can dominate and disturb the activities and schedule of a household. In a survey by the National Family Caregivers Association (2000), more than half of the family caregivers provided help with activities of daily living and 85 percent of the care receivers were fully reliant on their caregiver for this help.

**Table 4.1: Physical Strain of the Care givers**

Physical Strain	Frequency	Percentage
Very much	38	12.66%
Somewhat	207	69%
No Strain	20	6.67%
No opinion	35	11.67%
Total	300	100%

Table shows that 69% of the respondents identify the physical strain of their caregivers because of their disadvantaged condition. 12.66% of them opined that the physical strain of their caregiver is too much to be measured and they feel very sad about the peculiar situation of their family. Only 6.67% of them have the opinion that no physical strain is experienced by the care givers and 11.67% has no specific opinion about the strain of the care givers.

The bedridden condition of a diseased or elderly person affects the total balance of the household activities especially that of the primary caretaker in the family. Thus in spite of the activities of daily living, medications, changing dresses, bathing and clothing a patient, the caregivers spend a considerable amount of time and energy transporting the patient and keeping the household functioning (Hauser and Kramer,2004). The patients expressed severe mental agony due to the large amount of physical strain faced by their care givers.

#### **4.2 Mental Strain of the Care givers**

The major part of the burden for family caregivers is created by the changing roles they must perform in a family structure as a consequence of a partner's, parent's, sibling's or child's terminal illness. The pressure caused by such condition creates feelings of high anxiety,



confusion, anger, frustration and loss. Though the majority of caregivers are considering such situations as worthy, the patients or the care receivers are in fact very much concerned with their caregiver's stress, the pain they are taking for caring them.

**Table 4.2: Mental Strain of the Care givers**

Mental Strain	Frequency	Percentage
Very much	97	32.33%
Somewhat	183	61%
No strain	20	6.67%
Total	300	100%

While 61% of the respondents realize that their care givers have mental strain due to the terminally ill condition of their family member, 32.33% of them opine that their care givers have a high amount of mental strain only because of the bedridden condition of the respondents.

Care-givers usually have other roles and duties within their own context. They may also need to restrict their own social activities or even to take leave from work, which imposed additional financial hardships. Care receivers realized the extra stress of caregivers who also have to assert with issues like childcare and work assignments. This realization makes them feel guilty and depressed.

### **4.3 Adverse Impact on the Children of the Family**

Family members in general suffer greatly from the consequences of a complicated illness of one among them. Children in these families may lack care when compared to children in normal families. Children in different ages face different adverse impacts due to the precarious situation in their family. No proper attention could be provided to the children by that particular family and it negatively affects children's health, education and socialization.

**Table 4.3: Adverse Impact on the Children of the Family**

Adverse Impact	Frequency	Percentage
Very much	98	32.67%
Somewhat	143	47.67%
No Impact	59	19.66
Total	300	100%

The data reveal that 47.67% of the respondents observe the adverse impact of their condition on the children in their family. Only 19.66% are having the opinion that their diseased condition does not affect the children in any manner. A significant portion (32.67%) has the opinion that the family can't give enough attention to the matters concerned with their children.

The hectic responsibilities of family care givers cause significant anxiety among the patients and they are very much concerned about the future of the children in their family.

## **5. CONCLUSION**

Being the informal caregivers, family members are important in maintaining the well being of the care receiver at home. A family member therefore is a caregiver and a care receiver. They have multiple roles which are conflicting and to be handled carefully. They can be helpful or obstacle during the process of care (Doris, 2007). Family caregivers and their efforts decide the ability of a bedridden/chronically ill person to be cared for and to die at home.

The study uncovered the extent of dependence by the care receivers and psychological support they are seeking from their family caregivers. They have evident mental distress associated with their bedridden condition or chronic illness. Socio-economic conditions of the family in connection with the disease and caring cause worry and anxiety among the respondents and the pain and strain of their family caregivers in turn negatively influence the total well being of the care receivers.

It is obvious from the above given tables and descriptions, the care receivers are depending on their caregivers for fulfilling their physical, psychological and socio-economic needs. It is also found that the care receivers are worried and anxious about the physical strain, peace of mind and the future of their caregivers who are concerned about caring the bedridden or chronically ill family member.

Guilt and worry at the hardships experienced by others are frequently addressed. Depression and mourning arise from the losses as a result of not being able to contribute in the lives of their loved ones, or fulfill meaningful roles and expectations. Care receivers also express frustration and anger that they cannot do more to help themselves and others. Such condition negatively affects their self-worth and lead to feeling of uselessness.

Thus the caregivers' stress negatively influences the physical, psychological and social symptoms of the care receivers. The care receivers are not willing to access quality medical care, even to express their physical pain properly because of the increasing burden on their family caregivers. Hence the active total care proposed by the Palliative Care agency to the bedridden or chronically ill person and the family becomes impossible and the total wellbeing of the beneficiaries could not be maintained.

Fulfillment of the wish of many bedridden/ chronically ill persons to remain at home towards the end of life is heavily dependent on the care giving efforts of family members. Palliative care giving entails considerable health risks for the family caregiver. Provision of appropriate support for family caregivers can ameliorate these risks and enhance family members' quality of life (Stajduhar, 2013). Population is ageing fast and life expectancy is increasing with complex morbidity conditions. Hence providing the best support for family caregivers should have high priority in the field of health. Palliative care agency has such an integrated approach to offer care for the terminally ill/bedridden and their caregivers. But the implementation of such provisions is to be modified to make their theoretical concepts into practical.

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