Original Article

Understanding the Psychosocial Impact of Oral Cancer on the Family Caregivers and Their Coping up Mechanism: A Qualitative Study in Rural Wardha, Central India

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Abstract

Background: A family caregiver is the one who provides care to their near and dear one who is suffering from some debilitating disease like oral cancer. Apart from providing physical care, they also provide emotional and financial support to their close relatives. They can be the patient's spouse, children, and siblings. This study was, hence, designed to understand the psychosocial impact of caregivers of oral cancer patients. **Methodology:** This was a qualitative study using in-depth interviews of 24 purposively chosen family caregivers irrespective of age, sex, and relationship with patients, who provided deep insight into the psychosocial impact of the disease on themselves during caregiving of their loved ones and how they coped with it. Interviews were taken in Hindi, in the houses of caregivers. Care was taken to maintain utmost privacy while taking the interviews, which were either audio recorded or noted down. Informed written consent was obtained from participants before the start of the study. Themes were evolved from the interviews and content analysis was performed using ATLAS.ti. **Results:** Six themes emerged after data analysis. Those were the impact on physical health and lifestyle, emotional impact, impact on family and social relationship, impact on financial and work status, improvement of hospital services, spiritual concern, and acceptance of the disease. A concept map was made to provide a vivid explanation of how oral cancer caused these impacts on caregivers and their interrelationship. **Conclusion:** Caregiving is not an easy job. This study recommends extra care to be taken in preparing them for caregiving to the oral cancer patients with adequate knowledge of the disease process and its consequences along with counseling facilities in the hospital to address the different psychosocial needs of the patients.

Keywords: Caregiver, coping up, oral cancer, psychosocial impact, quality of life

INTRODUCTION

A person suffering from advanced oral cancer is in a debilitated state who is unable to take care of himself. There comes the role of family members who come forward to take care of their loved ones. However, this transition from a close relative to a caregiver occurs so abruptly that many a time they are not well prepared for it. While providing care for terminally ill loved one, caregivers often neglect their own needs. This neglect, over time, comes as a heavy toll on the overall well-being of a caregiver resulting in a negative psychosocial impact on them.[1] Caregivers apart from taking physical care and giving timely medication and taking the patient to hospitals on review visits are also concerened for the emotional and the financial well-being of the patients. The different jobs the caregivers get involved into are cooking meals, housekeeping, providing transportation to the cancer patients, arranging money for continuing the treatment, and providing companionship to their loved ones.[2]

It has been found that the job of continuous caregiving has a negative psychosocial impact on the lives of the caregivers. Many of these caregivers suffer from stress, anxiety, and depression and are often neglected,[3,4] There are a number of studies on the quality of life of the cancer patients, but there is lack of detailed studies on the problems faced by family

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caregivers who stay at home with the patients of advanced cancer. This qualitative study was hence planned to acquire a more comprehensive understanding of how oral cancer impacts on the psychosocial life of family caregivers; the problems they face and how did they cope with the problems.

METHODOLOGY

This was a cross-sectional study using qualitative methods. We used in-depth interviews (IDIs) of selected family caregivers of oral cancer patients. The participants were encouraged and prompted to talk in depth about the different problems they came across while taking care of their near and dear ones who were suffering from oral cancer who had completed treatment 3-6 months back. We also tried to understand how caregivers cope with the different problems they face while caregiving, though we were mostly concerned regarding the psychosocial adjustments that they had to undergo.

Study participants

The study participants included 24 family caregivers of oral cancer patients. In this study, we have considered close relatives of oral cancer patients who were with the patients since the time of diagnosis till interview was recorded and actively took part in caregiving as the "family caregivers." They can be the patient's spouse, children, and siblings, but significant others can also take on that role and function.

The participants were purposively chosen study respondents who provided rich, relevant, and diverse information pertinent to the research objectives. They were selected irrespective of age, sex, relationship with patients, occupation, educational qualification, or stage of disease their loved ones were suffering from.

General characteristics of the study participants are shown in Table 1, where we found 10 of them were male and the rest were female. The average age of the caregivers was 37 years. Most of the female caregivers were home makers whereas the males were daily laborer, servicemen, farmers, or businessmen. Few of the caregivers were illiterate while most of them had gone to school. All stages of oral cancers were included in the study, though the majority of the included patients suffered from advanced oral cancer (Stages III and IV).

Study procedure

An interview guide was prepared beforehand, which is shown in Table 2. Open questions were used to encourage study participants to express their feelings and experiences as regards the study objectives. We used probes to give the participants hint to think about the different problems felt by them. Probes were only used when the participants were unable to comment on any topic or to get in depth of the concerned topic. Before the study, a pilot interview was conducted with two family caregivers to check if the participants could understand the study question and give feedback. The pilot interview was also included in the final analysis. The study was carried out from January 2016 to September 2017.

Study settings

The study participants were the residents of both urban and rural community development block in a district in Central India. The

Table 1: General characteristics of the study group

Caregiver ID	Age of caregiver in years	Sex	Relation with patient	Occupation	Education	Stage of oral cancer of patient
C1	57	Female	Wife	Housewife	Illiterate	III
C2	35	Female	Wife	Housewife	Class 5	IV
C3	26	Male	Son	Student	Graduate	II
C4	30	Female	Wife	Housewife	Class 6	III
C5	29	Female	Wife	Daily labor	Class 5	III
C6	38	Male	Son	Daily labor	Class 8	II
C7	44	Male	Son	Farmer	Illiterate	I
C8	29	Female	Wife	Housewife	Class 10	IV
C9	22	Female	Daughter	Student	Graduate	III
C10	24	Male	Son	Student	Graduate	II
C11	55	Female	Wife	Housewife	Illiterate	III
C12	57	Male	Brother	Autodriver	Class 10	III
C13	46	Male	Son	Daily labor	Class 3	IV
C14	28	Male	Son	Business	Class 8	IV
C15	33	Female	Wife	Housewife	Class 10	II
C16	38	Female	Wife	Daily labor	Illiterate	IV
C17	37	Male	Son	Farmer	Class 5	III
C18	28	Female	Wife	Housewife	Class 8	III
C19	25	Female	Wife	Teacher	Graduate	II
C20	50	Female	Wife	Housewife	Class 6	III
C21	57	Male	Cousin	Service	Class 12	II
C22	47	Female	Wife	Housewife	Class 5	IV
C23	26	Male	Son	Shopkeeper	Class 12	IV
C24	23	Female	Daughter in law	Housewife	Class 7	III

Table 2: Interview guide

1. Did occurrence of cancer in your relative bring any change in your life?

Probe
  - Personal life
  - Family life
  - Financial life
  - Social life
  - Psychosocial life

2. Please tell me about your social and psychological support

Probe
  - Support from Family and friends – adequate or not
  - Role of spiritual/religious leaders in your life

3. Are there any thoughts that haunt you for your future? Please share those

Probe
  - Your future
  - Future of family
  - Regarding insecurity

4. What are the different challenges you face while you were accompanying your relative for his treatment among the different hospitals?

Probe
  - Timeliness of medical attendance
  - Behavior of hospital staff
  - Transportation
  - Hospital stay
  - Financial problem
  - Promptness of treatment

first author who is well trained in qualitative methods conducted all the interviews. The interviews were conducted in the houses of the participants. All the interviews were conducted in Hindi, which the study participants understood. Each of the IDIs continued for around 40–60 min. Interviews were taken till there was saturation of information and no new information came up. Many of the interviews were audio recorded, and the others were noted down, as the study participants did not give permission for using the recorder. While carrying out the interviews, concern was taken to ask the questions in private that is keeping the other family members secluded, though it was not possible all the time.

Data analysis

The audio recording of IDIs was transcribed and translated into English. Recurring ideas, words, or phrases and patterns of belief were identified and organized in codes and based on this, salient themes were defined. Following this, the investigator went through each transcribed document of IDIs and did content analysis using the themes that link people and circumstances. Efforts were made to analyze how the distribution of ideas, words or phrases under different subthemes and themes differ across the categories enumerated above. ATLAS.ti[5] was used to facilitate content analysis. A concept map was made to give a vivid explanation of how oral cancer caused these impacts on caregivers and their interrelationship.

Ethics

The study was conducted after getting approval from the Institutional Ethics Committee. Written informed consent was taken from each of the study participants before starting the interview.

RESULTS

Cancer breaks patients not only physically but also emotionally and socially. Most of the oral cancer patients had to undergo surgical procedures that hampered their routine activities such as eating food, maintaining personal hygiene, taking medication on time, and many more. Many of the patients were put on Ryles tube or tracheostomy. In such scenario, there is an immense role of the caregivers not only to help them recover physically but also to boost them up emotionally. The caregiving activities might be of different types, including taking care of the patient, feeding, mobilization, communication and consulting the doctor at the time of illness or complications or for follow-up, doing household work, giving emotional support to the patient, administering medications timely, arranging money for continuing treatment, and many more.

Although almost all the members of the family directly or indirectly played an important role in taking care of the patient, we have considered the family member who was actively involved in taking care of the patient starting from time of diagnosis of oral cancer, carrying out the treatment and accompanying the patient to the hospital for follow-up as the primary caregiver of the patient. In our study, we found more women caregivers than men. Twenty-four such primary caregivers were identified, and their IDIs were conducted to understand how oral cancer of their near and dear ones affects them (the caregivers) psychosocially. These interviews were later analyzed, where the following themes emerged.

Impact on physical health and lifestyle

Taking care of an oral cancer patient who had advanced disease affects the physical health of the caregivers. This occurs when caregiving interferes with the usual daily activities and is associated with negative lifestyle changes. It was clear during the interviews that as the caregivers concentrate on the cancer patient's needs, their own needs generally remain unaddressed.

"Apart from taking care of my father-in-law, I have to do the regular household chores; like cooking, cleaning, sweeping, etc., in the house that makes me very tired at the end of the day," said a female caregiver. In a similar note, another caregiver said, "many a time I forget to eat my lunch on time." Quite a few of the caregivers, mostly females, had reported that they were so deeply involved in taking care of their near and dear ones that they lost the focus on self-care potentially resulting in decline of their own health and quality of life. A few of them also reported that their daily routine had changed and their lives were more restricted now. Many of the participants pointed out that they could not participate in other activities because cancer patients needed a lot of assistance.

Emotional impact

"I could never believe that my husband was suffering from cancer (oral)," a 30-year-old caregiver expressed her panic when she first heard the diagnosis, and she remained depressed for quite a long time. "I always keep thinking about the health of my father," said a 21-year-old son of a patient of stage IV buccal mucosa cancer. It was clear from the discussion with the caregivers of the oral cancer patients that they experienced distress, anxiety, fear, and uncertainty while caring for and supporting the family members who were ill. "I do not understand what to do when he (her husband) cries out in agony and pain, and I sometimes think of dying rather than standing helpless," said the wife of a bedridden patient of oral cancer. A few of the caregivers had also stated that the different procedures carried out in the hospitals that caused pain to their near and dear ones (the oral cancer patient) also made them sad and depressed.

The son of a 57-year-old patient of stage III oral cancer said, "For the last 3 months, my mother is on liquid diet only and she is losing weight;" this was a matter of concern for him. Another individual expressed her concern regarding the problems of Ryles tube feeding.

Impact on the family and social relationships

There were diverse responses as regards the impact of oral cancer on the family and social relationships of the caregiver. A female came up with a very positive response; "Our relationship (between her and her husband) has grown stronger after he was diagnosed with cancer (oral cancer)." Many of the respondents were of similar opinions. However, there were a few caregivers who complained of decreased familial bonding with the patient and also with other relatives after the treatment for cancer started. Most of the participants avoided any discussion on the impact of oral cancer on their personal life, but one of the female caregivers boldly pointed out the problems she faced in her sexual life after her husband was on the treatment for cancer.

A few of them also reported that as they (the caregivers) remained busy in caretaking, they seldom could take out time to attend any social event. They also added that, after the illness of their family members, the neighbors were not visiting their homes like before. While there was a group of participants with the opposite view, where, one of them stated, "our neighbors now regularly come to my home and ask about the condition of his health and if we need any help."

Impact on financial and work status

The treatment of oral cancer like any other cancer is costly and the majority of the cost has to be borne by the family. "My husband was the only bread earner in our family, and since he is having the disease (oral cancer), he cannot go to work, and our financial problems have increased," said the wife of a 40-year-old oral cancer patient. To find an alternative, most of the spouses (mostly wives) of the patients started going for work, and it affected their family life and care of the children, especially for those who had small kids to take care of.

Son of a 72-year-old oral cancer patient said, "After passing higher secondary, I got the chance to study BSc (Bachelors of Science degree) honors, for which I had to go away from my village but because of the need of taking care of my father, I did not join the course and stayed in my village; I joined BA (Bachelor of Arts Degree)."

A number of important family activities had to be postponed or canceled to manage the cost of treatment. "My sister's marriage was fixed but had to be postponed as a result of my father's disease (oral cancer)," said the son of a male oral cancer patient. There were many such similar incidences where important family activities had to be given lesser importance. "I had to shift the schooling of my children from English medium to the Marathi medium government school, as it was not possible on my part to meet the expenses of that private school," said the mother of two children who was also the caregiver of a 34 years old postsurgery and post radiotherapy oral cancer patient.

Apart from these, there have been reports where the family had to sell the livestock like cattle, goats to arrange money for continuing treatment. However, there was a good chunk of the caregivers who stated that their relatives and friends were of enormous help; a few expressed that it was difficult to meet the challenge without help from relatives and friends.

Necessity of improving the services provided in the health facilities

A few of the caregivers were concerned regarding the long waiting hours in the hospitals. "I have to spend the whole day in the hospital for his (father's) follow-up. Moreover, we have to go from one place to other for check-ups and investigations," said the son of an elderly oral cancer patient.

Another study participant opined, "Long waiting hours in the hospital, make me think more into the disease condition of my brother," that increases the emotional stress as a result of the disease.

Another important issue came out in the interviews with the caregivers which was regarding the need for training them for caregiving a cancer patient. "My husband had tracheostomy done and it often get blocked, that need to be cleared almost every alternate day. As I am not an expert in doing that, I lack confidence in cleaning the tube," said the wife of an advanced oral cancer patient on palliative therapy. Most of the caregivers had stated the importance of a small training session for caregivers to be conducted at the hospital before discharge of the patient.

"For minor illnesses, such as cough and cold, fever or loose stool, many a time the PHC doctor avoids treating my father and advises me to take him to the cancer hospital," said the daughter of a 62-year old man suffering from tongue cancer. A few of the caregivers also had similar opinion that as the patient was a diagnosed case of cancer, doctors most of the time referred them to higher centers for their treatment that added on to the problems.

Spiritual concern

Like many of cancer patients, family members also expressed that they became more spiritual after their loved ones were diagnosed with cancer. “Its God’s wish that he (her husband) had the disease, then what can we do?” was the explanation given by the wife of an oral cancer patient regarding causation of the disease. After a prolonged discussion on the issue, it was found that many of the caregivers gained confidence and could fight away from their emotional stress as a result of their spiritualism. This was clear when one of them very positively said, “He (her husband) is taking the treatment and by God’s grace he is getting cured gradually.”

Acceptance of disease

Quite a good number of the caregivers were very positive regarding the future of their patients; one of them said “We have taken him (the patient) to the best hospitals and he is undergoing the best treatment available. We are confident that he will get cured.” Another individual said, “Cancer is now a very common disease, and in our neighborhood itself there were three cancer cases, and all of them are healthy now.”

The findings of the qualitative study on caregivers of oral cancer patients are further illustrated in the concept map [Figure 1] on the psychosocial impact of oral cancer on the caregivers.

DISCUSSION

Family caregivers are vulnerable to suffer from emotional stress which occurs as a result of a variety of reasons such as increased physical exertion, change in the daily routine, and negative thoughts about the future of their loved ones. Given *et al*.[6] expressed similar views regarding the family caregivers, who according to the authors need to devote more time in caregiving their patient and often suffers from the strain of caregiving. McMillan[7] found that continuous caregiving results in reducing their physical health, emotional health, and overall quality of life. Blanchard[8] studied the psychosocial impact of cancer on family caregivers where they found families are important in providing the environment for adjustment for the cancer patient, and it was not the patient alone, the family members were also directly confronted with the impact of cancer. As the number of cancer patients and survivors of all age groups are increasing, the role of caregivers is growing as well.

In this study, many of the participants stated that they were the victims of poor social and familial relationship as a result of the disease process of their relatives. They have no one to share their feelings and that increased their mental stress. Clark *et al*.[9] stated that the burden of caregiving leads to constrained social activities, deterioration of health, and increased mental illness like that of anxiety and depression.

We had included patients of all stages in our study but did not study the difference in the quality of life of caregivers of the patients who receive palliative treatment versus curative therapy. Weitzner *et al*.[10] did a comparative study between

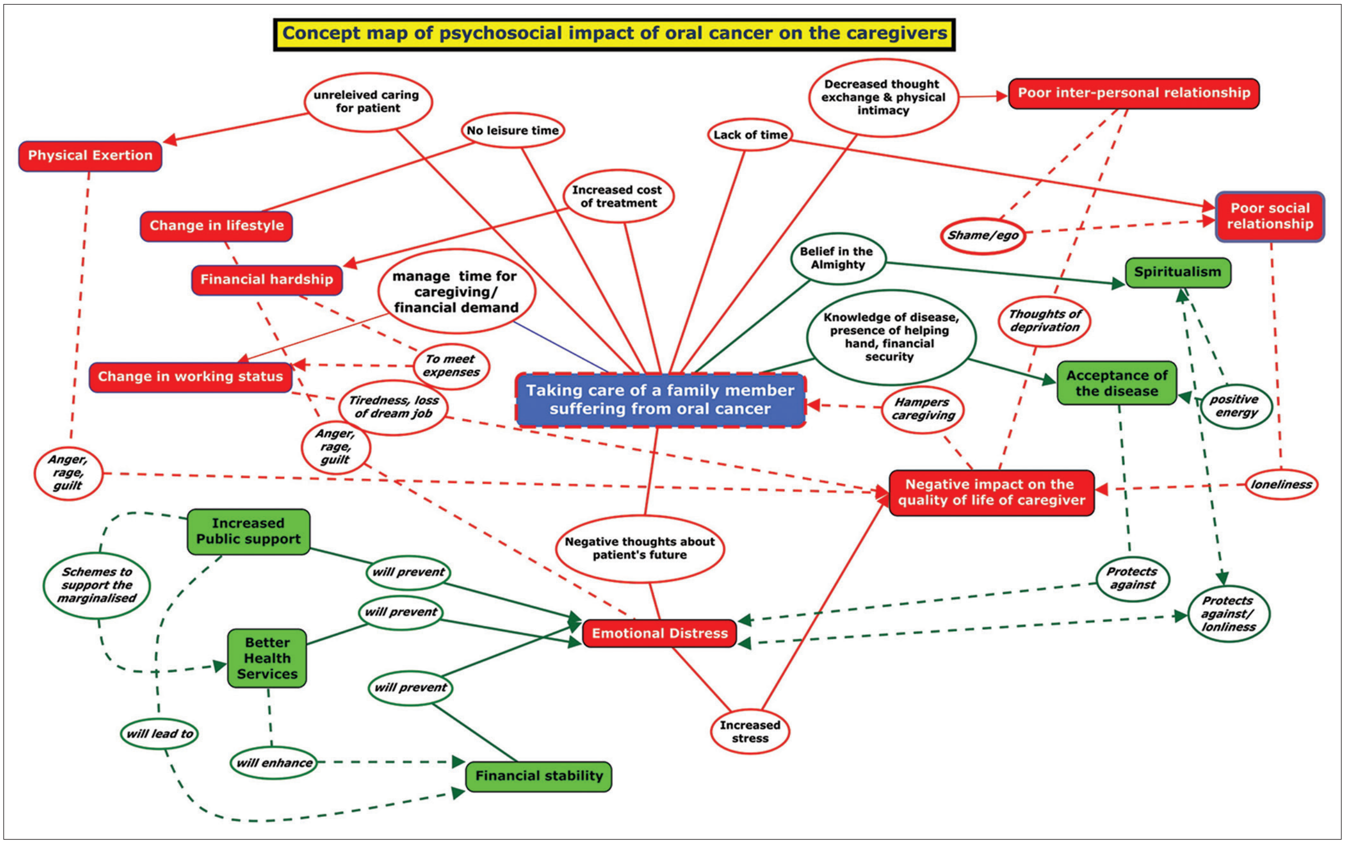

Figure 1: Concept map showing psychosocial impact of oral cancer on caregivers. Color code - Red (box and arrow): Negative theme, Green (box and arrow): Positive theme, bold arrow: Direct association, broken arrow: Indirect association

these two groups and found that caregivers of patients in palliative therapy generally reported greater psychosocial impact than those responsible for patients in the curative phase.

We had more of female participants than males in our study, and we found that the female caregivers were more affected emotionally because of the disease process and seemed to be more concerned regarding future of their loved ones. Grov *et al*. used Hospital Anxiety and Depression Scale score to estimate[11] the quality of life of caregivers of cancer patients and found that though depression was common in both the sexes, but female caregivers had a higher prevalence of depression which was in conjunction with this study.

Financial stress was the other reason for increased mental stress among the caregivers as they are the ones who were responsible for arranging money to carry out the treatment of their relative and also to run their families smoothly. Sharp and Timmons[12] found in their study that the cost of cancer treatment was huge. Wissinger *et al*.[13] did a systematic review on the economic burden of head and neck cancer to evaluate the evidence existing on the association of resource use and cost of the diagnosis and treatment of the head-and-neck cancer. They have included 77 studies in their systematic review, where Wissinger *et al*.[13] found that treatment costs for the head-and-neck cancers are generally high for cancers with advanced stages.

In spite of all these negative impacts of caregiving for longer times, most of the caregivers generally cope up with the problems. Acceptance of the disease was found to be the most important measure that helped in adjusting with the deteriorating health conditions of their relatives. Spiritualism too in some extent helped them in adjusting to the mental agony. Barrett found that more than half of the caregivers cope with the difficulties of caregiving through prayer or seeking support from a partner. He has also added, female caregivers were relationship-oriented and often shared things with friends, siblings, children, and medical professionals for support. Unlike other parts of the world, the good thing about rural India is, joint family system is still prevalent here, that helped primary family caregivers to have task sharing and task shifting in many episodes that was found to be protective to the negative impacts of oral cancer. Few of the participants showed a positive attitude regarding caregiving. There are few studies[1,3] with similar findings. According to these studies, the positive attitude of the caregivers might be either seen both during the early and late stage of the disease. According to Sculz *et al*.,[1] caregivers feel good about themselves as they feel their importance that gave meaning to their lives, helps them learn new skills and strengthened their bonding with their near and dear ones who were suffering from the deadly disease.

CONCLUSION

In India, though work is going on palliative care of cancer patients that has been boosted up by the National Program For Prevention and Control of Cancer, Diabetes, Cardiovascular Disease, and Stroke program,[14] yet management of cancer has not fully incorporated the family care for cancer patients at home. Hence, it is the informal caregivers or family caregivers who are at the prime role of caring for their beloved ones who are suffering from cancer. Strategies need to be adopted for giving basic training on caretaking to the primary caregivers of cancer patients including oral cancer. Training should also include rendering health education regarding the cancer process and the identification of the side effect of cancer treatment. Last but not the least, the long waiting hours in hospitals may be utilized for counseling the caregivers to address their different psychosocial needs which will, in turn, help in improving the quality of life of family caregivers.

Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form the patients have given their consent for their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

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Conflicts of interest

There are no conflicts of interest.

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