LIVE EXPERIENCES OF CANCER PATIENTS

Based on the experiences from the field work, the researcher has tried to explore some facts related to tobacco related cancer patients. Their stories reveal that they are living in the very worst conditions, both financially and physically. Due to the illness they are not able to go for work and for which it becomes difficult to maintain their family financially. Every individual reacts differently to their social, economic, and physical environments and such problems of an individual are different from the problems of another.

Here, in this chapter, the researcher has tried to highlight the facts of the respondents with whom the researcher has interacted during the study. The researcher has utilized the experiences gathered from the field works. The sample size of the study is 150 and out of which detail information of five cases have been collected. The cases have been selected randomly and these cases have been interviewed at the source of data collection. The interview schedule has been prepared to know the socio-economic condition, health seeking behaviour, tobacco taking habit etc. of the patients. Here, while discussing with the cases, the researcher has maintained the principal of confidentiality. So, the names and address of the respondents are not given. The following are the cases.

Case Study 1: Head of the family

Mr. A (60yrs) is a literate, farmer by profession and married for last 38yrs. He is suffering from neck cancer, from last 8 months. He has the addictions of pan and alcohol. He has reported that he is trying to quit both of his additions but unable to leave. He has been a very active person and love to mingle with others. He has also added that he wants to become very active and wants to work and earn for his family members. His family comprises of four members, where two children are going to school and his wife is housewife. According to him that his children are very co-operative and never complain for anything but he becomes depressed as he is unable to provide them the basic needs of day to day life. His monthly income is around three thousand only. His wife is the sole caregiver and sometime she suffers from negative psychological behaviour, which affects her health and day to day family life. He has no complains against his wife and children but he is facing many problems due to poverty. Mr. A has expressed that his wife is very much supportive and always have the tendency to help. She has to work for earning money to meet the needs of the family as her husband is sick and unable to earn money for the family. Though he is poor but his family members are very much cooperative and he is having a good atmosphere at home. He considers himself fortunate enough to have a BPL card by his name. The wife of the client has become tired of responsibilities as she is always busy in providing services to him at the same time she has to do the domestic works also. As the client is financially weak, he has borrowed money from his relatives to continue the treatment. But as he is suffering from this deadly disease, he has to spend a good amount of money for his treatment and this affects his family income. He is living in his own house and does farming in his own plot of land to earn his livelihood. As per the view of Mr. A, his friends and family members are supporting him both physically and emotionally" as he has been attacked by a deadly disease. Apart from all these Mr. A is suffering from depression, insomnia as well as multiple stresses due to financial strains. The client in the beginning was not aware about the presence of cancer care services in his town, and that the family is very important in the process of decision making to seek help from formal health care. Related to medicines, the client said that he cannot take medicines regularly due to the cost. According to the client, before consulting with doctor he likes to consult with his relatives and friends to take decision. Here, it is understood that the health seeking behaviour is lagging behind.

Case Study 2: Sufferings of an aged person

Ageing itself is a risk factor for many diseases and injury, which affects person's well-being, independence, and feelings etc. Mr. C (70yrs) is a dependent person, which affects his self esteem and mood. The increased dependency on his family members has affected the normal family relationships. He is suffering from cancer of larynx. He tries to adjust with this illness by lying down or sitting through out the day. For which he is suffering from social isolation and which itself becomes a part of the problem of this chronic disease. He cannot eat properly due to this illness and as a result of which he has become too weak to go for treatment regularly. For him transportation is also a problem, because he resides very far away from the hospital. His son, who takes care of him, is a farmer and earns five thousand per month. Though they have BPL Card but it is not enough to carry the family expenses and his family consists of five members. They reside in a house received under the scheme 'Indira Awas'. He has been suffering from cancer for last two months, he has the habit of taking pan and *bidi* regularly but after diagnosis he left taking both. His son

tells that as the treatment of this disease is very costly, so it has become very difficult for him to continue the treatment, but at the same time he agrees that he will try to continue the treatment. His 60yrs old wife is the caregiver and work closely with him.

Case Study 3: Illness suffered by a woman

Mrs. B (30yrs) is married and diagnosed with breast cancer. She is mother of a girl child, her age is 7 years. She has developed a recurrence in the root of her neck, which causes pressure on the nerves of left arm and which creates progressive pain, altered sensation, and reduced function in the left arm. She is being treated with chemotherapy but still she is suffering from pain. The client's version is that, women, who are diagnosed the disease or suffering from this disease, face many problems everyday. She has expressed that it is very difficult to accept this deadly disease. She is illiterate but wants her daughter to go to school. And her daughter is in class- 2, in a near by school. Her weak health does not permit to perform the household responsibilities in a proper way. Her husband is a daily labourer and earns approximately three thousand per month. He finds problem to meet daily expenses with his income and at the same time he has to give a big amount for his wife's treatment. Mrs. B tells that they are not having BPL Card and for which her husband is trying for a long time. Her family consists of nine members, which is very difficult for her husband to manage. Her husband says that it is very difficult to perform household works by male members without the help of wife, because he has to go out for earning. But still her husband is happy with his family and admits to continue her treatment as per doctor's advice and if required he is ready to borrow money from relatives or friends for her treatment. Her husband at last has accepted this challenge of life. Lastly the client told that it has become very problematic for her to carry on the household or domestic works, like cooking, washing, rearing of her child etc.

Case Study 4: Problems faced during treatment

Mrs. C (52 yrs) is married from 30 years having a daughter and a son, suffering from cancer of stomach. Before diagnosis she has faced various stomach problems like pain, weakness etc. and she has become very weak as the food has not been taken by her properly due to these stomach problems and her entire family function gets disturbed. She is illiterate but she always want to make her children literate, because she knows the importance of education and as a result of which her children are going to school. She is facing many problems related to treatment. Financial problem is main

problem though they are having APL Card, but it is not meeting the needs properly. Her family's monthly income is ten thousand, with which family's all expenses cannot be fulfilled. As her wards are going to school, for which she has to spend money for many reasons like traveling expenses, books, school fees etc. For her treatment a good amount of money is being spent from the monthly income. Apart from financial problems, physical and emotional problems are also being faced by her. She is not able to perform the household works due to the physical problems like fatigue ness, pain etc. Another most important problem is the side effects of treatment, as she has undergone the surgery treatment. She also complains of the inadequate treatment facilities, lack of staff in hospital etc.

Case Study 5: Ill still working

Mr. D is 50yrs old businessman and diagnosed with cancer of larynx which has spread to his esophagus. He is the only earning member of his family and his family comprises of five members. He has told that it has become very difficult for him to carry on the livelihood. He is under the treatment of surgery and for which he has become very weak but still working to earn his family's livelihood. He is working even with many sufferings as because he has to maintain the cost of his treatment along with the needs of his family. He wants to keep himself busy for helping him to forget the deadly disease he has. He shares that after diagnosis of cancer, he has stopped going to temple as he is angry with the God because his life has become miserable for him due to this illness. But, the positive part of Mr. D is that when he talks to other people, he realizes that he is not the only person suffering from cancer. He understands that he can find pleasure by helping or advising others who are suffering from cancer. At the end he determines not to make himself weak and depressed by lying down on bed. He also claims that he wants to keep himself busy through out the day and continue the work until and unless he falls down on bed.

Conclusion

This chapter deals with the experiences gathered during field work, where it has been noticed that women are over burdened with many works like looking after a child, household or domestic works etc. and sometimes they have to go out for earning their livelihood. But still they are not concerned about their health. The socio-economic condition is also responsible for low health status, which does not allow an individual to think about his/her health or the financial condition restricts them to go for check up. Apart from socio-economic and financial problems, they suffer from physical problems which don't allow them to visit a doctor for check up.

As cancer is a life threatening illness and there is a belief that cancer ends lives. It is out of the experiences that caregivers face multiple problems like stress, anxiety, depression, tension etc. which creates problems in providing care to the cancer patients. Apart from providing services, the caregivers have to perform other various activities in a family. The limited money or income of respondents becomes most vital problems and challenges and these are being faced by both care giver and patients.

It is seen that many caregivers like doctors, nurses, friends, relatives etc. provide specific services for specific duration as they have to perform other various duties related to them and their families. The main caregivers are the family members of the cancer patients. The level of burden upon the caregivers of tobacco related cancer patients is very high and full of tensions in comparison to the caregivers of other diseases.

The respondents feel hopeless and become ineffective due to this illness and they are also having the high risk of developing negative emotions which may further carry on many complicated and physical problems. All respondents irrespective of age, such as adults, teenagers and children suffer from this chronic illness and experiences significant emotional distress both in acute phase and in long term follow up. Above all it is experienced by the researcher that the caregivers also need someone to talk to or to share with as well as to get the chance to take rest.