Chapter 7

Summary & Conclusion

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INTRODUCTION

“In this vast wide world”, says the philosopher, all are groping in darkness, but hope and hope, alone, sustains them. The investigator has been inspired into this venture or adventure by the scriptural exhortation: “Seek and you shall find”. The present research work was undertaken with the objective of studying the basic socio-demographic details of the terminally ill cancer patients, to assess their family burden, their social support, the coping patterns adopted and also for assessing the depression dimension in them. It was also aimed at understanding the relationship of depression to family burden, social support and coping pattern and depression to various variables in the socio demographic profile namely age, sex, family size, duration of illness, marital status, education, family history, type of cancer, the family burden, social support and coping strategies.

MAJOR FINDINGS OF THE STUDY

- Majority of the affected patients, 56% are in their terminal stage during their middle age. (Age group of 40-59).

- The average age of the patients is 49 years. For males 51 years and females 47 years.
Most of the men and women who are terminally ill are had an educational qualification of less than SSLC (76%).

A higher percentage of patients are from the low-income group (54%).

53% patients were members of nuclear family.

A high percentage of the males are affected with lung cancer (14%) and females with breast cancer (14.5%).

Only 17% of the patients had a family member affected with cancer.

52.5% of the patients have been found to have incurable cancer at the time of diagnosis itself.

Irrespective of the type of cancer, patients experience moderate to severe depression.

97% of the patients experience moderate (54%) to severe (43%) family burden.

74% of the patients suffered from pain and 65% from loss of sleep which had an indirect effect on their total wellbeing.

45% of the patients adhered to active cognitive coping strategy.

62% adhered to religious practices. In spite of their adherence to religious practices they did not find any relief or improvement in their condition.
• No uniformity was noticed in their adherence to coping strategies.
• Tendency to use avoidance strategies more was a major observation. A large number of patients at times experienced pessimistic obsessions and resort to suppression of feeling as a means of coping with terminal illness.
• In spite of the social support received the patients experienced depression.
• 37% of males and 24% of female patients used good coping strategies.
• 62.5% of the terminally ill cancer patients experienced severe depression.
• Irrespective of the demographic profile of the respondent, terminally ill cancer patients experience severe depression.
• The concept of spirituality was foreign in patients.
• Patients who adopted good coping strategies felt less depressed and were in a better position to face reality and develop positive self concept.
• It is not the type of cancer but the constant changes in the mood that bring about depressive thoughts in a patient. The commonly experienced feelings are oppressive sadness, hopelessness, frustration, worthlessness, self-criticism, dislike for being alive in that state, irritation,
incapacity to take decisions, dissatisfaction with life all which lead to depression.

- Higher percentage of patients did not use ventilation as a coping strategy.

**RECOMMENDATIONS OF THE STUDY**

This quantitative cum qualitative study with the terminally ill cancer patients has thrown light into the following areas of social work intervention.

In social work practice, relationship has traditionally been a prime focus of attention. Terminally ill are vulnerable groups in need of a safe, supportive environment to which they feel securely connected. Gor-felton and Spiegel (1999) describes the sense of isolation experienced by patients. Cancer patients consistently report that friends disappear and family members don’t know what to do. This dynamics is often compounded by an escalated sense of isolation when faced with increased symptoms and the process of dying.

Social work intervention can help in diminishing the isolation many cancer patients face, and encourage the sharing of painful feelings and fears. This treatment approach tends to be less analytical and more geared towards helping patients develop effective coping strategies. Non-traditional methods such as meditation, visualization, play therapy, music therapy, prayer therapy, yoga etc can be introduced to build up positive self concept in a patient. Various psychological interventions have
paved the way resulting in increasing longevity of terminally ill cancer patients.

**THE SPECIFIC SOCIAL WORK ROLES BASED ON CASE STUDIES**

The qualitative study has made the researcher arrive at a conclusion as to the specific areas of intervention for medical social workers.

- Emphasis has to be given in the area of social interaction mainly with the patient and his close relatives and family members.
- Locating human experiences in the context of the conscious, intentional and social nature of an individual’s activity.
- Including the significant others in the patients life for being instruments of peace so that the patient die peacefully’ as well as live until they dies.
- Encouraging the patient to be optimistic in situation which requires facing pain and accepting despair.
- Helping him use appropriate coping strategies.
- Building up strong religious faith in the patient. Faith for accepting God’s will or strong faith that God will definitely shower his healing touch on the patient. It is believed that, this positive coping strategy in turn according to the mind body model, will develop strong positive self concept where
by develop healthy cells to fight with the diseased cell-ultimately bringing fast recovery.

- Expression of accurate empathy.
- Respecting the worth and dignity of the patient.
- Counselling respond to the emotional impact of serious illness. So providing facilities for supportive therapy.
- Fulfilment of needs of the patient mainly –emotional, spiritual, practical needs. The social worker can respond to all these as they manifest in the individual and family.
- The core social work tasks are one of assessment and intervention. So periodically assessing changes in the patient and intervening in times of need for the patient’s betterment.
- The social worker should give information, provide resources, facilitate communication; help family make adjustments to new social roles, help people set realistic goals and also offer bereavement counseling.
- Social work methods like case work and group work can be made use. The methods to expedite these tasks might include one to one meetings, family work, and group work, a focus on children in the family, sharing information and listening.
- A multi disciplinary approach –reminding the other team members the need to keep the ‘whole person’ in mind as they plan their particular intervention.
• Training, staff support, development of community network contributing to educational programmes.
• To set up effective running of these networks.
• It is crucial to develop and organize support volunteers.
• Emphasizing on care management which results in the prioritization of physical and practical needs at the expense of listening and counseling.
• A psycho-social approach is reflected in the service to the terminally ill.
• End goal is ‘Total care of the patient’

The findings give clue to the areas of intervention for the terminally ill patients. Right for information is a human right and it should not be denied for the patient at any cost. Improved communication can reduce levels of distress for terminally ill cancer patients. The following suggestions may help to promote coping and communication in couples and families in the light of this study.

Talking about cancer and problems is advisable for those who would like for it. There is a wrong notion prevalent among us that partners and families often worry that talking about cancer and associated problems will make things worse and upset their partner or loved one. In fact the opposite is generally true. Talking about problems usually relives stress, puts things out in the open where they can be dealt with directly, and lightens the load of persons with cancer. Although it may be upsetting, talking and crying about
feelings or concerns it is a way of sharing the burden and the journey, understanding each other better, clearing the air, and relieving tension. It shows that you care and are concerned about your partner’s well-being. Putting feeling and fears into words helps make them tangible so they can then be dealt with. Hiding feeling may be more distressful. Silence about feelings is open to a variety of interpretations, many of which may be negative.

Being realistic is a good practice which has to be internalized into the system. While the study proves that being positive and optimistic can be helpful, it is more important to be realistic. An excessive focus on being positive and avoidance of anything negative (fear, anger, sadness) can create tyranny of positive thinking where people are afraid to discuss feelings. This stifles communication instead of promoting it, makes coping harder and may create new problems. Regarding expressions of fear, anger, and sadness should be considered as normal and healthy rather than a sign of negative, pessimism or “giving up”. When negative feelings are expressed and attended to they can generally be resolved or accepted. When they are avoided or suppressed, they are more likely to persist and deepen. Ventilation is the best method of coping with stressful situations. It helps the patient and his family members to lighten their heart and take meaningful steps ahead.
The patient has to be trained in dealing with one's own stress. Men often think that being stoic, tough and unemotional is an effective way to cope and showing emotion is a sign of weakness. Unfortunately, this way of coping is not always effective. It puts the patient in increased levels of stress. Worse still, this pressure and distress may cause them to react with anger, use of alcohol or drugs or follow other maladaptive ways of coping.

The feeling that you are wanted creates a positive stroke to go forward. When someone you love is diagnosed with cancer, your primary concern is for the patient and it has a collateral impact on everyone close to the patient. This is always not acknowledged. The oncology health professional has to have an empathetic approach towards the patient as well as the caretaker since both are in total confusion as to how to go ahead when it is dark on the other side. They are psychologically weak. Only a sincere and empathetic approach can bring about a total change in the patient and his family members.

The spouse will have to take on new roles, manage multiple responsibilities and cope with his distress. This is hard work and needs to be recognized and support provided where possible. Cancer affects everyone and it has huge collateral impact.

Usually, cancer patient's cope by fixing problems. And if not by thinking that there is nothing much to do to help.
Thinking this way only creates powerlessness rather than helping the patient to feel useful and needed. The simplest thing often makes the biggest difference. It’s not about fixing the problem... listening and “being there” help’s. Never underestimate the value of listening or just being there. Asking the patient what they finds most comfortable and helpful and encouraging them to do those things.

Talking about fear of death or making practical arrangements is something practical even though talking about death in any society is morbid and negative. When someone has cancer, we normally worry that talking about fear of death means that we are expecting the worst to happen. We may also fear that talking about it will somehow make it a reality. It is natural to fear that the person you love may die. Fearing this does not mean you want it to happen or expect it to. Talking about it is not morbid, negative or “giving in” and will not make it more likely to happen. Discussing it helps open up communication about difficult issues which can help people to adjust and improve family functioning. Expressing concern is something what the patients expect from his relatives. Lack of showing concern will totally wreck the patient and go into depression and develop in him that life is meaningless, burdensome and its better off dead. Similarly the reality is that the spouse and caretaker too need support to cope emotionally and to deal with information relating to
the disease. The emotional needs of the caretaker are overlooked.

Practical arrangements like will, power of attonomy, getting financial affairs in order are sensible things which should do and once done can be forgotten.

Psycho-social interventions are aimed at supporting patients not only at times of acute crisis but during long period of chronic illness as well. In their clinical role, medical social workers provide a broad range of practical and financial assistance service. Counselling patients and families and helping them with the complex plan and decisions that often must be made during times of extra ordinary stress. Preparing the patient for death is a major task. Social support and coping are the two pillars on which terminally ill cancer patients live. It is often believed that it is not appropriate to talk about the fact that one is going to die. However for those who wish to discuss death, open discussion, ideally from early diagnosis, can help the dying person feel, their concern are heard, their wishes are followed and that they are not all alone.

**MERITS OF THE STUDY**

The advantage of the study on the depression dimension of terminally ill cancer patient throws light into the various areas of social work intervention essential to help patient at their end stage of life.
The conventional medical establishment, with its focus on curative treatment, has not been able to address the problem faced by these patients. It is obvious that those who realize that their days have been numbered, experience problems quite different from other patients. The total care concept has to be delivered at their door step because due to this fatal and chronic illness their mobility decrease, their moods keep on changing within seconds.

Thus the suffering of a terminally ill cancer patient is complex. This particular research study aims at studying the psycho-social problems faced by patients in living with cancer which is chronic, fatal and end-stage illness. Thus study has gone deep into the depression dimension of these patients and has also suggested appropriate intervention in the specific areas which will be relief giving to the terminally ill cancer patients. Addressing the problems of these patients and making life peaceful and easier for them is the ultimate aim of this research work.

LIMITATIONS OF THE STUDY

A serious limitations of this study are that parameters cannot be measured it can only be experienced. Mood changes occur in every cancer patients in accordance with their physical well-being, so there may be slight variations in values of the collected samples. The quantitative values are only approximately correct because the unit of study is a terminally ill cancer patient who is worried and in pain psychologically and
physically. Qualitative data cannot be measured and the results obtained by using standardized tools only peripheral. Terminally ill cancer patients are physically well today but down the very next day. Similarly emotions cannot be quantified because for each person the intensity is different. Standardized instruments specifically for the interest groups should be developed.

**SUGGESTIONS FOR FUTURE RESEARCH**

**At the service level**

Much is left to be done at the service level, training level and research level. At the service level, each terminally ill cancer patient has to be attended personally. Apart from their basic needs being met, more importance has to be given to their felt needs and psychological needs. Individual counselling aiming at catering to the personal problems of the patients which will help them come out of their crisis situation, which is definitely relief giving.

At both the hospitals, where this particular study was conducted oncology social workers were not employed for serving the patient. The consequence observed was, there was no one to clarify the doubts of the patients, which made the patients anxious and confused. This has had an indirect effect on the patient in the long run.

Employing medical social worker in dealing with patient’s problem will be of help for the patient to receive the maximum benefit and enhance the effectiveness of medical care rendered to
the patient. The medical social worker can act as a liaison officer between the doctor and the patient, doctor and the relative, patient and the nursing staff, relatives and the hospital staff, and hospital and community. Insight about their illness was what the patients were lacking and it can be provided through the professional competence of an oncological social worker.

At the group level, group therapy sessions can be administered. Sharing of negative feelings of the patient with other patient in the group in the safety of a professional social worker is going to be of healing touch to the patient. In group sessions the principle of individualization and universalisation is used, and the patient gets a sort of psychological satisfaction and relief.

Formation of relatives group would help the relatives to know about the difficulties other care takers face and how to take care of the patients and handle the problems experienced by patients. Group therapy sessions help the relatives to have an empathetic understanding toward the patients who is altogether living in an entirely different island confused and perplexed. When the problem is universalized the care takers will finds it easier to dedicate themselves to the service of the patient.

Religion plays an important role and if religious leaders of all caste could make available their service for the patients it would be of great relief. Ventilation of feelings and timely feedbacks will show drastic change in the patient’s outlook since services are rendered at a personal level.
Pleasing music and talks by eminent personalities on positive thinking and how to handle crisis will be of great help. Similarly video cassettes delivering messages of healed patients will be useful because it depict the live story of the patient themselves. Internalization of positive self concept helps coping. This in turn develops healthy cells in our human body capable of fighting, with carcenogenous cells, resulting faster recovery from illness, and prolonging life.

At the hospital level, the authorities should give priority to patients care. All sorts of comfort facilities have to be arranged for patients’ welfare. Poor patients has to be given concessions for treatment and free food .There should be a cell working for mobilizing resource from welfare agencies in order to help the needy and poor terminally ill cancer patients.

High risk strategy, population strategy and screening are the ways which are helpful in detecting cancer patients in our community and providing treatment at the initial stage, there by avoiding fatality. The high incidence of breast cancer is emerging as a health problem in the state and therefore facilities for offering mammography as a routine screening procedure for the early detection of breast cancer should be promoted at community level.

At training level

Medical professionals in the field of patient’s care has to be given scientific training in relating themselves with patients
so that these patients get maximum benefit of medical care, which enables faster recovery.

Doctors, medical social workers, nurses and all who are involve with patients has to be given compulsory training as to how to deal with patient during crisis situations.

Practical training has to be made compulsory and a part of the professional course. It is just practice and training that makes a man perfect in any field. Proper supervision and monitoring has to be given to the trainee by experts in the field.

**At research level**

Importance should be given to intervention studies, which are beneficial to the patients.

Action oriented research should be encouraged among individuals as well as groups working in the medical field.

External resource should be arranged for funding organizations and individuals indulging in action projects aiming at patients well being.

Importance should be stressed on the psycho-spiritual well being since it is observed in the findings that spirituality holds an important place in patient’s life, especially those nearing death bed.

Instead of small sample studies, studies on a larger population as well as studies on samples belonging to different culture should be conducted.
Other areas of research work should be with patients affected with slow killing illness like diabetics, heart disease, hypertension, renal failure, rheumatic heart disease etc.

Measures at the N.G.O and government level has to be taken in areas of detection and prevention at individual, family, society, community, national and international levels.

In the year 2007 a new governmental policy has been introduced aiming at the welfare of the very poor cancer patients introducing a monthly pension of rupees twenty on producing a certificate from the consulting oncologist and a certificate from the village office stating they are a resident. This news was broadcasted by the Kairali channel in a programme named “Mukthi” for cancer patients. Even patients and their co-traveller can avail railway concession.

Controlled research assessing the effect of spiritual based intervention is needed to establish what method of help can engender a sense of peace and meaning. A whole person approach, as advocated by a growing number of health care professionals would not only help to treat the emotional and social aspects of living with cancer, but also provide considerable long term cost saving and avoid over burdening health care system. The time has arrived to promote a compassionate model for treating patient’s physical and emotional needs as a vital part of our health care systems.
It was also remarked by the survivors that medicine along with positive self concept can bring about fast recovery and even cure cancer. 50% body as well as 50% mind plays an important role in curing cancer. Apart from all these for the total management of the patients, every oncology centre should promote total psycho-social care, emotional wellbeing and spiritual wellbeing by fulfilling the basic needs as well as psycho-social needs of the patient.

Few other suggestions are setting up medicine bank, bed sponsorship programme, raising charitable funds, forming helping forums, arranging facilities for individual and group sponsorship programme. Practice of tele-medicine by practitioners aiming at best service to the patient has to be kept in mind. This will definitely bring about fast recovery even if the patient is in his end stage of life.

**CONCLUSION**

Prevention is better than cure but this is more easily said than done. The present life situation, reckoned globally, is so complex that in many cases things have reached a stage of no return or reversal. Practical wisdom counsels for an acceptance of reality. As in the case of any major crisis the cancer situation also calls for a thorough study, which will enable us to see gravity in all its dimensions and to adopt appropriate remedial action. The blind cannot lead the blind to safety. Hence the
search in this research for a thorough insight into the diverse ramifications of the problem to be solved.

Traumatic experience causes stress, which is beyond the coping capacity of an individual. In such a situation, body and mind react by measures of 'fight' or 'flight'. These reactions manifest in the form of changes in behaviour, bodily experience and emotional reactions. Anything that exceeds one's personal ability to cope with a stressful event becomes a crisis. Crisis affects everyone and every individual react to a crisis differently. The success lies in the hands of each individual how he or she manages through a crisis and remains positive, making the best out of the situation by adopting effective coping techniques to master the situation. Having relatives and friends who could help through a crisis is also a way of effective coping.

Researches with biological unit’s cells have proved that prolonged continuation of biological response following stress and depression may lead to an inappropriate paring of traumatic situation which results in multiplication of malignant cells. This results in taking the patient towards his deathbed at a faster phase. Where as in patients who accept positive coping patterns namely religious means, ventilation, accepting and living in reality, always being optimistic, hopeful and seeing positive side of life was found to survive more than patients who go in for negative coping strategies.

In most cancer patients the disease causing organism gradually gets immunized and eventually become resistant to
standard Chemotherapy. To state an example, Mr. A, who had liver cancer, was diagnosed only during his end stage of life by his medical practitioner. He was advised to undergo surgery and take Chemotherapy. Even though he continued treatment, the doctor had assured him only 3 months ahead. He was a person who believed in his strengths. On learning the seriousness of his illness he started regularly attending mass and spending hours in prayers. He was courageous as well as had a positive approach towards life. He attended yoga classes regularly and practiced the Art of Living. In few months, he was able to experience some healing from within. He also found a priest whom he went for regular counselling. To everybody's surprise he lived another two and a half years peacefully with no much complication. This particular study proves the fact that positive coping works miracle in a patient’s life.

Regular medications as advised by the physician along with social work intervention and promotion of spirituality would definitely help in re-gaining vitality and developing a positive self concept in the terminally ill. This in turn would enable them to accept reality and face life situation as it comes. Family initiative is very much essential for building up reassurance in patient and ensuring positive outlook and hope for future. Religious belief or belief in a higher power greater than human beings is an integral part of one self. It can provide great relief and support during difficult times. It is important to practice
whatever spiritual belief one has as it has tremendous power to heal.

Spending some time to relax every day is a way in which one can built up a strong mind and a healthy body. It is equally important to have sufficient rest, spare time for recreational activities like reading, listening to music, singing devotional songs and reading scriptures, watching video cassettes of people who have been cured by their positive approach and spiritual ways.

The need for a holistic approach is inevitable for dealing with the multifaceted problems the patients face. India is a country with rich social heritage. Kerala is a state which claims to have high literacy. It's a state which gives great importance to values, culture, tradition, heritage etc. Patients are deprived of the most essential psychological want. The patients’ long for tender love and care. It was observed during the study that patients were isolated from the main stream. They were left alone to live a life of their own.

Society is a web of social relationship. Family is the basic unit of society where the bonds of love are strong. It was noted that in the case of a chronically ill patient the attitude of his relatives considerably changes. Society becomes the worst place to live for the patient. It is our civic responsibility to take care of the weaker section of the community by upholding all the democratic values of liberty, fraternity, equality and social justice to all.
The bible reminds us of the teachings of Jesus Christ. His life is an example for all of us. Care is an expression of love. Love is patient and kind; love is not jealous or conceited or proud; love is not ill-mannered or selfish or irritable; love does not keep record of wrongs; love is not happy with evil but it’s happy with truth. Love is eternal. It gives confidence and hope to individuals. If that is the case how much ever will the patients long for it especially when they are in the evening of their life. The policy makers should come forward for providing total care of the patient and see to it that every cancer is treated in a human manner.

Indulging stressors and effective training programmers and counselling services to the patients and families on effective coping strategies are indispensable to cope with the complexity of the patient’s precarious predicament. Human resource department which has become part and parcel of every modern organizational structure, should take upon itself the primary responsibility for chalking out feasible and effective action programmes to meet the challenge posed by the rapid spread of a disease like cancer, which has the evil potential to exterminate the human race from the surface of the earth, portending a universal holocaust. All the available expertise in the various aspects of palliative care and distress management should be included in the curriculum of every staff induction programme. Provision for securing the services of a sufficient number of oncology specialists should receive top priority in evolving a
defensive mechanism against this dreadful menace. Considering the multifarious dimension of the problem the fight against cancer will be a prolonged and protracted one and the stupendous task that lays a head, should be taken up by the community as a sacred duty to be shared in its collective interest instead of leaving it to be tackled on an individual or family basis. The increasing interest shown by philanthropist and charitable societies in the problems faced by the patients and their immediate relatives augurs well and the investigator is confident that in the foreseeable future a day will dawn to proclaim with trumpet beat that cancer has tamed to the indomitable will and undaunted courage of man. If this effort of the researcher, however feeble be, will prove just one link in the concerted action against the formidable foe, there is ample reason for the investigator to feel gratified and satisfied.