



SOCIAL WORK INTERVENTION IN FAMILIES OF CANCER PATIENTS: THE CHANGING CRITICAL PHASES

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ABSTRACT

Cancer and other life threatening diseases have challenging psychosocial impact on the patient and their family. Most of the cancer patients and their families stay devoid of emotional and social support during the process of diagnosis and treatment of cancer. There are several critical phases of cancer through which the patients and their families have to pass. Social workers are required to identify the stressful events in the patient and their family's life and their psychosocial needs in order to provide them the maximum support throughout this challenging phase. A concerned social worker would successfully fulfill their psychosocial needs and support them in establishing equilibrium in their difficult period.

KEYWORDS : Cancer, Social worker, psychosocial needs, critical phases of cancer

INTRODUCTION:

Most of the cancer patients and their families have reported that their caregivers cannot adequately address their psychosocial health care needs. While undergoing the various stages cancer right from the initial diagnosis, treatment and post treatment observation, the patients and their families have revealed that they were not thoroughly informed about their diagnosis, prognosis, treatment modalities and the various approaches taken to manage their illness. Epstein and Street (2007) reveals that usually health care workers fail to deliver complete information in a way that is understandable by the patients. It was also stated by the patients diagnosed with cancer that most of the health care workers do not understand their psychosocial needs despite the fact that the patients consider these psychosocial needs as an integral part of their care. Usually, the health care workers themselves are unaware of the various available psychosocial health care resources and thus, often fail to realize, appropriately manage and refer the patients to the respective specialty. Such specialties include the mental health related ones such as depression, direct stress management or specialties dealing with other consequences of stress occurring because of the illness in patient and his/her family members. (President's Cancer Panel, 2004; Maly et al., 2005; IOM, 2007).

Social workers involved in counseling of cancer patients and their families should be aware of the complicated psychosocial dynamics taking place at each stage of the disease and its treatment. It is extremely difficult for the family and the patient to maintain equilibrium of mental, social and physical health during the intricate phases of the disease including remissions, relapses and terminal phase. Kaplan (1973) suggested that these "characteristic sequential phases" of the disease also involve certain tasks for the patient and the family members. Thus, social work intervention has to rely on the requirements of the patient and the family at each critical phase of the disease and encompasses use of various available resources, interpersonal interaction with the patient, therapies etc. The involvement of the patient and family in the whole process should be ensured which in turn enables the social workers to understand better the emotional and mental requirements of the patient and family.

Psychosocial Problem And Health In The Patients And Families Of Patient With Cancer:

With the technological advancements, early detection and improved treatments have become a new possibility that has

also changed our understanding of different types of cancer. It is a group of illness which could be either severely fatal in weeks or months or could be curable and treatable and for many patients even long term survival is possible. Jemal (2004) has revealed that because of the improved treatment strategies in the past two decades, the 5-year survival rate of the 15 most common types of cancers has shoot up from 43 to 64 percent in men and 57 to 64 percent in women.

Cancer disease demonstrates both - a life threatening condition and chronic illness. The treatment for cancer is very challenging for the patient and the family as it requires a consortium of surgeries, radiation therapy and chemotherapy lasting from a few months to years. Even if the patient is free of the cancer, there is lot of morbidity associated with the treatment therapy pursued for the management/treatment of cancer. The side effects of chemotherapy, radiation therapy, hormone therapy, surgeries could temporarily or permanently impair multiple organs of the body including kidney, liver, lung, heart, brain and other bodily functions. Close monitoring and continuous observation of cancer survivors needs many adjustments in life and thus, it is more of a lifestyle change.

Hewitt (2003) has reported that almost 11 percent of adults suffering from cancer or with a history of cancer (50 % of which are more than 65 years of age) are found with one or more limitations in performing routine activities required for day to day living like bathing, eating, or using the bathroom. He also revealed that 58% patients have reported functional disabilities like inability to walk for quarter of a mile or unable to stand for 2 or more hours a day. The diagnosis of the disease also leads to social changes, IOM and NRC (2006) have notified that a large number of cancer patients stop working or witness a change in employment once they are diagnosed with cancer.

It was also established that cancer patients not only suffer from physical illness but also from mental health problems like depression and anxiety disorders (Spiegel and Giese-Davis, 2003; Carlsen et al., 2005; Hegel et al., 2006). Patients suffering from cancer and with existing chronic illnesses typically face a number of problems that could negatively influence their health and recovery. The associated problems can be wide based including but not limited to lack of knowledge about their illness, poor communication, lack of transportation/conveyance facilities to visit for regular appointments and last but not the least - financial issues. (Wdowik et al., 1997; Eakin and Strycker, 2001; Riegel and

Carlson, 2002; Bayliss et al., 2003; Boberg et al., 2003; Skalla et al., 2004; Jerant et al., 2005; Mallinger et al., 2005).

Usually the family members of the cancer patients provide or try to provide substantial amount of support and care both emotionally and financially. The family members also actively contribute to personal and nursing care of the patient. (Hayman et al., 2001; Kotkamp-Mothes et al., 2005) It however, does not come without a cost which is not just financial and the loved ones themselves could experience depression, stress, lack of self care, adverse health and consequently, increased risk of premature death (Schultz and Beach, 1999; Kurtz et al., 2004). Schultz and Beach (1999) have viewed that the spouses supporting and taking care of cancer patients are 63 percent more likely to die 4 years earlier than others of their age.

Therefore, it is quite evident that the patients diagnosed with cancer and their families do not face only physical health related challenges but also a deteriorating psychosocial health. The present medical system largely focuses on addressing the physical morbidity part but psychosocial needs are completely or broadly ignored. Thus, it is required of the social work intervention teams/volunteers/professionals to work towards the psychosocial stability of the patient and the family.

Delivery Of Psychosocial Health Services:

As mentioned in earlier sections, it is apparently not sufficient for cancer patients to be just provided with effective physical health services, strong steps should be taken to identify the patient's psychosocial needs and provide connect them with appropriate social services. It is fortunate that some health care providers in oncology understand the importance of fulfilling psychological needs and work towards addressing these problems. Below hereby is presented a model which dictates the implementation strategy for delivering psychosocial health services (see Figure 1).

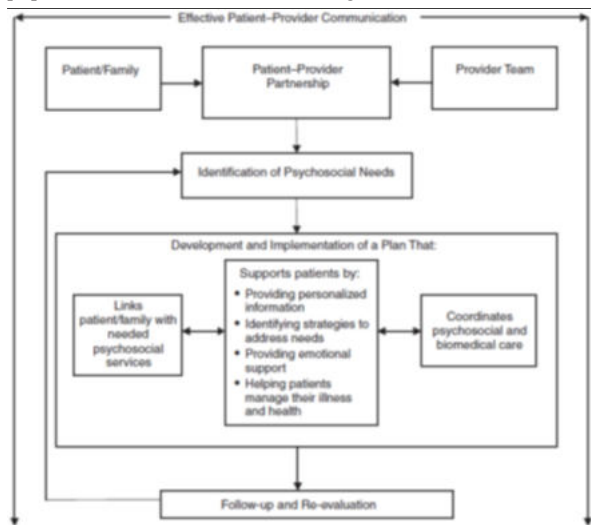


Figure 1: The Figure Presents A Model Of Strategy For Delivering Psychosocial Health Services

Social Work Intervention With Patient And Families Of Patient With Cancer:

In close association with medical services, the social workers can positively intervene in enhancing and ensuring the social, psychosocial, emotional and mental wellbeing of the patient and the family. The intervention might involve counseling, assistance and emotional support to the patient and the family as they may be facing problems during the hospital stay or may not be getting complete or proper information or may not be getting required attention of the medical staff etc. The key target of social worker in such situations is to provide psychosocial support to the patient and the family and to

assess the importance of emotional and subjective aspects of the human experience in the overall disease management process. Taplin (2016) had stated that a social worker has to a) recognize b) be aware of the improving medical strategies/procedures/treatment flow for the disease and c) meet the psychosocial and support needs of those who are living with, undergoing treatment, treated and cancer free or are in terminal stages of the disease cancer.

Role Of Social Worker In Identifying The Stage Of Grief:

It is very essential for a social worker to accurately identify the stage of grief that the patient and family are undergoing. As per Kubler-Ross Grief Cycle (Elizabeth Kubler-Ross, 1969) the various stages of grief are as follows: Denial, Anger, Bargaining, Depression and acceptance. At every stage, the patient and family may have specific emotional/ mental/ social/ psychosocial needs and thus, the social worker in order to be of suitable assistance should be adept at identifying the stage of grief.

The Changing Critical Phases: Role Of Social Worker In Fulfilling The Psychosocial Needs:

There are certain critical phases of the cancer which have varying emotional and psychological impact on the patient and the family. The critical stages are explained as follows: (a) pre-diagnosis; (b) the diagnostic period; (c) remission; (d) relapse; and (e) death and mourning-before and after.

Pre-diagnosis: Every family who has a cancer patient diagnosed apparently has a "before the diagnosis" phase when their life is normal. It is highly expected that the behavior of the family and the patient in the middle of the crisis would be entirely different from their normal one. As a social worker, the intention should be to identify closely the way patient and its family were before the diagnosis so that the psychosocial influence of the illness on the patient and the family can be determined.

Social work interventions are solely based on the customized needs of the family and the emotional impact generating because of the illness of their dear one. It is crucial to understand the functioning of the family before the diagnosis and at the time of illness. It can be assessed by collecting the information regarding family relationships, coping strategies, extended family details and community support or community deficit. The crucial component here is to focus on the marital status, parental and sibling relationship. Understanding the ground reality of patient from a collectivist system point of view is advisable, as it might affect decision making, leading opinion, family mood etc. Sometimes, major decisions such as financial expenses, choice of place of treatment, breaking the news, signing relevant medical declarations (involving decision making) are dealt by the financial head of the family only and they may even not inform the patient completely about the diagnosis. This can lead to difficulty in the treatment because the information asymmetry originating from such veil is a clear obstacle in an effective doctor patient relationship. A social worker is expected in such cases to identify the opinion leader, financial head of the family and make them understand the best practices and help to clarify any myths and stigma associated with the illness.

The Diagnostic Period:

In some circumstances there could be a long pre diagnostic phase when the investigations are being made, prognosis is being ruled out and at this stage the impairment in psychological status is inevitable. When the diagnosis of cancer is made it is expected to be a shock to the patient and the family resulting in fear and disbelief which, may or may not be relieving for some who have been dealing with an unknown morbidity or symptoms from a long time. Even if the patient and the family feel initial relief it is very hard for them to accept the news of cancer breaking out and is accompanied

with sudden burst of mourning. Actually this kind of mourning at that stage is helpful in some ways as it demonstrates that patient and the family has accepted the reality and is coming to terms with it. However, at this stage the social worker should examine the effect of diagnosis on the family members in good details to avoid any chances of a sudden shock related action/break down. In the initial phase after the diagnosis, most of the patients and their family members oscillate between calmness and hysteria and usually do not feel comfortable or ready to discuss the description and/or treatment protocols with the health practitioners. The social worker at this stage with his/her experience and available resources could help orienting the family members and the patients. In few of the cases the patient or family resort to inappropriate behavior with the medical staff which can at times be even aggressive. In these cases social worker should interpret their reactions and create a bridge to help them understand that they have to rely on those who are taking care of the patient.

If the family of cancer patient undergoes extended mourning then the job of the social worker is to make them think positively for the patient. The family members should be empathized and should be assisted to realize that the patient is still alive and needs love, support and care. The social worker should carefully work on making them understand that the patient is seriously ill and is in need of a lot of care. The motive of the social worker is to make sure that the care should be continued and any psychological, social queries that the patient or the family have should be addressed satisfactorily.

Remission:

In the diagnostic phase, the family mostly dealt with mourning which sometimes leads to health negligence in the remission phase. In this stage, the patient might be doing well and might have little or no functional problems or might have almost no signs of the disease.

It might be possible that the patient and the family might have forgotten (knowingly or due to ignorance) about the disease. In such cases, usually the clinical visits are ignored and most of the patients and the family complain about the side effects of the cancer treatment modalities.

If the remission period is very extensive then most of the patients are advised to leave and take medications as part of treatment protocols. At this stage the patient or the family might think the drug to be a part of active treatment and the patient may feel unprotected without them. The patient and the family might have questions about the relapse without the medication.

The role of social worker is to reiterate the risk of continuing the medications or risk of the long term chemotherapy. The family members need to support the patient at that time and the patients needs to be closely watched.

Relapse:

Relapse from a medical point of view brings the patient closer to the death although the cancer patient may survive for years after the first relapse. Relapse after the long remission phase could be shattering for those hopes which went strong for survival. The feelings of the patients at the time of diagnosis might revert back at this stage more strongly and with much larger shock. Once again the family members have to face the fear of losing their loved one as the probability of death has increased. At this time it is more important to fulfill the wishes of the patient and make the patient feel happy.

Futterman and Hoffman (1973) stated that Relapse stage usually taxes the "ability of parents to maintain equilibrium" and the family might be even more stressful than the period of the diagnosis. Most families basically those who have

explored their knowledge about the illness and who have come across the patient suffering from the same disease that died during the course of treatment, accept the reality. Futterman (1972) depicted that the experience of other patients might bring a sense of reality and a kind of emotional rehearsal in them about what may occur in future to the patient too.

The social workers' help at this point is essential if in case the family responds by withdrawing their care towards the patient in this stage. These family members should be encouraged to rekindle hope and shower more love and affection on the patient. It should be explained to the family that at this stage the patient might need a new treatment which might need a lot of adjustment and it just might not be easy for patient to adapt to them. If the patient feels emotionally detached then it could be a serious problem because it not only de-spirits the patient but also makes them negligent and morose in this crucial time. The social worker should identify the behavior as early as possible and should make necessary amends by motivating, interacting, engaging and share experiences, to balance the patient and family so that the care continues and thus, the treatment.

Death And Mourning: Before And After

a. Before: Most of the literature explains the emotional and psychosocial support needed by the family at the time of the patient's death. But the ignored part is the terminal period before the patient dies. When the patient is advised to no longer take the medications and final verdict of terminal illness is delivered, the family has to decide on continuing with some investigational drugs or stop the treatment at all and wait for death to arrive. This decision depends on multiple factors including the explanation of the success rate by the staff. Most of the family members or the patient chooses to end the medications thinking that the patient deserves some time free of these aggressive treatments as the death is inevitable. At this time frequent questioning for the family members could be disconcerting as they might misunderstand even the most casual thing stated to them.

This is the terminal phase which is very crucial for the patient and the family but is very difficult on them too. Friedman, chodoff, Mason and Hamburg (1973) depicted that the family members might have mixed emotions like grief, fear, disbelief, despair and stress all at the same time. The family members might have their questions and might be fearful for their own reactions regarding how the death will happen. At this stage, the social worker should be able to discuss the difficulties which the patient and the family members are facing and can get actively involved in their preparation. The health providers and the social workers should be honest, firm and clear and yet gentle to the family which will make them able to deal with the death.

b. After: The death of a family member is a very difficult time that the family needs to face. Initial weeks do not look very difficult as the closed ones stay supportive and stay close to the family but after almost 6 months post death it becomes very painful and difficult because the relatives/close members get busy with their own lives. The parents especially the mother/spouse/child who has stayed very close and involved in the daily chores of the patient would feel as there is nothing more to do. It is a very difficult phase when the family needs to learn to live without the person that they have lost. The social worker who has been actively involved during the above mentioned stages with the family is qualified to ease out the pain and the grief the family might be facing. Aftercare of the family of the dead patient is an important element of the social work intervention.

CONCLUSION:

Cancer patients and their families go through a lot of

emotional, financial and psychosocial challenges while under the process of the management. The social worker is required to assess the need of the patient and the family to provide what could ease them and relieve them during the process. The psychosocial needs might keep on changing with the changing stages of the illness which should be examined. All possible social work intervention should be taken to help the family and the patient coping with the ongoing stress and fear of death. The active role of the social worker is targeted towards ensuring the continuation of medical treatment, emotional care during and post the treatment/death and possible wellbeing of the patient during the process and the family.

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