Chapter 6

_Have the courage to live. Anyone can die…._Robert Cody,

Recommendations

Social science research aims to enhance theory or practice. The outcome of this research has implications for interventions at all levels including theory building. The exploratory study of lived experiences of parents of children with advanced stage of cancer identified event specific parental needs and the stress that they experienced. The findings highlighted the importance of various types and resources of support. Support offered by professional multidisciplinary team is one of the intervening conditions to select the coping strategies. As per the findings of the study, the parents of children with advanced stage of cancer experience stress because of the anticipated loss of their child. If event specific needs such as emotional, social, psychological, spiritual, financial support are not adequately and empathetically addressed then they experience stress. This stress may lead to maladaptive coping patterns that affect the way parents and children deal with the event of cancer. When parents adopt healthy coping then their response to the illness is not only effective, but also more influential in the way the family copes with their preparation for the eventuality. Therefore, the findings of the study can be used to design and provide for improved and comprehensive patient care which can be made easily available. This study recommends care in the areas of education, training, research and policy level interventions.

_Education:_ The study has emphasized the efficacy of the services and skills of professional health care providers. The existing Paediatric Palliative Care Team of Tata Memorial Hospital helps the parents and ill children to cope with the life event in healthy manner. The assistance offered by the Team in providing medical, nursing and psychological support by skilled and trained professionals help them to cope with child’s illness in a healthy manner.

After acknowledging the efficacy of this help, it is essential to understand the challenges faced by the parents and ill children. The existing service is available for eight hours a day on Out
Patients Department basis. However, the parents have access to the physician on telephone after OPD hours. When in perceived need, unavailability of personal assistance creates anxiety for parents. The role of the Home Care Team is important at this juncture. The Home Care Team provides assistance at the doorstep of the patients, helping them to save their time, energy and money. The existing service has limited geographical coverage, and as a result families staying at far distances do not avail of this help. The limited number of services available in India is inadequate to cater to the growing demand of holistic care.

The points mentioned above, denote the need for multiple centres/teams/units/departments with trained professionals. At present the training programme is conducted by Tata Memorial Hospital twice a year for medical and non-medical professionals. The findings of the research throw light on the importance of consideration of culture related aspects such as involvement of caregivers, religious and spiritual inputs and mobilizing financial resources, while imparting patient care. Such aspects can be incorporated while developing study modules to impart education to diverse professionals.

Medical professionals, paraprofessionals, counsellors and social workers need training to gain perspective and skills to provide services to people with a life limiting disease. As per the findings of this study, professionals need specialised training to address sensitive issues such as death and dying effectively and empathetically. Physical discomfort is identified as one of the stressful factors for ill people. This discomfort can be controlled by providing pain control medication by a trained physician. Training General Practitioners on palliative cancer care will be helpful, as they are the first contact for a majority of community members. This will ensure the availability of holistic services locally. Such workshops imparting skills and knowledge to health care providers will help them to recognise the needs of the ill person and provide treatment in totality. Inclusion of the concept of ‘Palliative Care’ in basic medical curriculum for graduate and post graduate educational level will ensure that all medical practitioners would have a basic understanding of imparting palliative care. Further, training existing general duty medical officers and other relevant specialists such as paediatricians, surgeons and others on palliative care would help to facilitate early access to palliative care even in primary and secondary health care settings.
**Policy:** To empower the family of ill children to access the professional help to provide care in totality is possible if there is a policy that facilitates such help seeking, especially for pain management. Hence while it is imperative for provision of palliative care for people suffering from cancer, it is worthwhile that the policy addresses other terminal illnesses too.

The data captured in the study emphasizes that currently the concept of palliative care is misunderstood by professionals as well as the general population. The policy can include the needs of the ill child and their parents from the time of diagnosis to its progression. “Every child should expect individualized, culturally and age appropriate palliative care as defined by the World Health Organisation (WHO). The specific needs of adolescents and young people shall be addressed and planned for. Palliative care for the child and family shall begin at the time of diagnosis and continue alongside any curative treatments throughout the child’s illness, during death and in bereavement. The aim of palliative care shall be to relieve suffering and promote the quality of life” (Amery, 2009: 5).

Advanced stage of cancer is associated with pain. The data captured in the study has highlighted the need of opioids for symptoms management. According to Wright et al. (2008) difficulty in accessing opioid drugs is one of the barriers in development of palliative care. The experience of stress because of the unpleasant symptoms especially severe pain is one of the results of the study. The policy changes regarding supply, storage and usage will help in the pain management which will improve the quality of life.

As per World Health Organization Collaborating Center (WHOCC) (2001), Morphine is an essential drug for cancer pain management. The fact sheet mentions that the despite India’s heavy cancer burden, it consumes far less morphine than most countries. It highlights the problems regarding accessing morphine. Institutions that use morphine have problems obtaining a continuous supply of morphine. The state licensing system for morphine is so complex that it is nearly impossible to have all the licenses valid at the same time ([http://www.medsch.wisc.edu/painpolicy](http://www.medsch.wisc.edu/painpolicy) retrieved on 17th March 2012). The government needs to
simplify these acts as easy access to narcotic drugs such as opioids will help to improve the quality of life of people with advanced stage of disease.

**Programmes:** To create awareness regarding this concept among professionals and general population, awareness programmes can be developed. Awareness among professionals and training as well as palliative care skills are inadequate to deliver service, even among general population (Mohanti et al. 2001; Sadhu et al. 2010; Karkada et al. 2011; Joseph et al. 2009). A series of awareness programmes for the general population can be planned based on the findings of the research. This can be tailor-made to suit the diverse contexts in different languages by using media such as television, radio, and print media and so on. Better awareness will help general population to empower and demand for their right for improved health.

**Research:** As per the findings of the study, professionals need to consider the cultural context while developing systems for health care provision. Majority of the work done in Western countries might not suit the Indian culture. Further research to understand context specific needs, expectations and stress inducing factors across the various ages will be useful for clear understanding and developing suitable interventions. Along with the research focusing on medical aspect of patient care, psychosocial aspects of ill people and their care givers should be studied. The research focusing on the age specific needs of children in advanced stage of life threatening diseases such as cancer, thalassemia, HIV and so on is essential. The needs and challenges experienced by various stakeholders vary from disease to disease; so disease specific research is today’s need.
Limitations of study

The study conducted at Pediatric Palliative Care Unit of Tata Memorial Hospital has included parents of ill children registered in general category. It is seen that the parents having higher economic condition prefer to take second opinion and go for alternative treatment. As a result, children from private category prefer not to continue in the Pediatric Palliative Care. The experience of parents of ill children registered other than general category is not captured in this study.

The data reveals the fact that values related to culture, religion and spirituality is one of the factors influencing overall coping. The data has included children who are Hindus, Muslims and Buddhists. Inclusion of other religions might have offered different dimensions and strategies of coping.

The children included in the study are cared for by their parents at home with the help of Pediatric Palliative Care Unit. The service is provided on an Out Patient Department basis or at home by Home Care Team. The parents of children in hospice might have different needs and coping strategies. The data reveals that those parents involved in bed side care giving cope in healthy manner and feel part of the treatment protocol. Parent who are empowered and engaged in looking after the child by using various support resources and the parents witnessing their child being cared by professionals might have different experience.

The findings of this study have emphasized the importance of role of parents in actual bed side caring and efforts to make their child happy. These efforts help them to cope in healthy manner. When the child is under institutionalized care, the parents have no access to the kitchen to cook favorite dishes to the child. They have no control over entertaining the child by taking her/him out as they need to follow the rules of the Institute. These limitations might affect their coping strategy.