ABSTRACT

The proposed study tries to contextualize the parental experiences and coping while dealing with the advanced stage of cancer of their child. The aim of the study is to build a field based grounded theory. The in-depth analysis has explored the role of various resources of support and parenting style in coping. The findings of the study can be used to develop the training programmes for multi professional health care providers. The findings can prove useful for policy development to ease the access to holistic care for ill people.

To understand the parental experience and coping, Folkman and Lazarus’s (Folkman and Lazarus, 1980, 1988: Folkman, 1984: Lazarus and Folkman 1984: Lazarus 2006) stress and coping theory is used as the conceptual framework. The research design is exploratory in nature.

The research is based on Grounded Theory approach, the theoretical sampling method (Glaser and Strauss, 1967) is used for data collection. Twenty nine parents (both or either parents) of twenty ill children were interviewed to understand experience, needs, expectations, sources of support enhancing positive coping, parenting style and overall coping process. In-depth interviews were conducted by using interview guide. The interviews were conducted at Out Patient Department of Pediatric Palliative Care Unit-Tata Memorial Hospital or in the ward by following ethical consideration.

The interview transcripts were read line-by-line and paragraph-by-paragraph. Then it was coded to identify similarity. Identified codes were clubbed to form subcategories and categories. The categories are composed of various subcategories called “properties” that represent multiple perspectives about the categories (Cresswell, 2007). Each category was saturated through constant comparative method to see that no new information or perspective can be added to the category to provide further insight. Then the axial coding was done to establish the relationship between categories and subcategories to form the story line.

The lived experience of parents of children registered in Pediatric Palliative Care Unit of Tata Memorial Hospital is described using the paradigm of grounded theory by Strauss and Corbin (1990), a) causal conditions that underline the stress experience by parents while witnessing the
worsening of physical symptoms of child and the efforts by parents to cope with anticipated death of child and coping strategies appointed by parents; b) the phenomenon that arises from the causal conditions; c) context that pertains to the phenomenon and influences strategy development; d) intervening conditions that influences coping strategy development, and flexibility of parents to change/modify them by seeking various sources and types of support. e) actual coping strategies and f) consequences of those strategies.

The emerging theory is discussed in details and recommendations are described subsequently.