

Hoping Against Hope: Being the Parent of a Child with Cancer

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World-wide the most prevalent paediatric malignancies include acute lymphoblastic leukemia, acute myelogenous leukaemia, chronic myeloid leukaemia, osteosarcoma, rhabdomyosarcoma, medulloblastoma, craniopharyngioma, retinoblastoma, Wilm's tumor, Neuroblastoma to name a few apart from other less common malignancies [1]. Not only these children but their parents also suffer from physical and emotional upheaval which drastically affects their quality of life [2]. Parents bring their children suffering from various symptoms to an oncology centre after being referred by primary physicians for suspicion of cancer. Interaction with these parents on their visit generally show diverse viewpoints, some desperate to get treatment and some even questioning why they have been sent to cancer centre as their child is perfectly fine and not suffering from any kind of malignancy. When an oncologist declares the diagnosis of cancer and its prognosis after relevant investigations in a child to his/ her parents, they go to a state of utter disbelief, pain and anguish which gets clearly etched on their faces. They experience an emotional conflict within because of the inability to accept the truth. The disease dreaded for ages have now nested within their children is hard to fathom for them and invariably their first query even before start of therapy is about the stage of cancer, how long their child will live, and we are not able to give them a fixed date. Although in denial and despair at the start of their child's cancer therapy, the hope for cure, the hope for survival however exists among them. Hope of their child to live is the most effective driving force [3] which makes these parents undergo all procedures of malignancy therapy from frequent blood sample with drawls, radiological procedures, chemotherapy schedules, radiation therapy sessions and surgical procedures and their sequelae. The parents hope and wish their children get healed from the diseases, to be with them physically and not losing them. An impor-

tant observation can be inferred after interacting with the parents is their spiritual inclination and hoping for a divine intervention apart from faith on the treating oncologist. They have strong faith that God will help them to face this difficult period of their child's cancer care. However, few parents surrender the fate of their children to God and many of them even discontinue treatment hoping for a miracle. This scenario is mostly seen when children develop disease progression and dissemination needing palliative and supportive care. Few parents get mentally prepared to face the inevitable and are sincere to accept their child's destiny and only hope for a pain-free end [4].

We as an oncologist see and feel the parent's agony day in and day out when we meet them in cancer wards, in chemotherapy/ day-care centres, in radiotherapy rooms, in post-operative rooms, in palliative care centres under morphine infusions and epidural anaesthetics. They ask us why this catastrophe did happen to their child and we are not able to provide any explanation to their satisfaction. Most of the times in our daily chores of hospital work we are not able to give them more personal time and adequate listening. For us a child, like other patients is a mere patient whom we will give the best of treatment but for a parent he/she is their very own self, their world around which their lives have revolved so far. Many times, even the nursing and paramedic staff do not clarify their doubts and queries, and this adds to their distress and emotional well-being. These issues heavily impact the psych of parents already suffering from an enormous state of inner listlessness. Therefore, an effective and coordinated communication between the parents and the treating physician, oncology nurses [5] and paramedics along with provision of information relevant to them is of utmost importance

in alleviating their doubts, queries and pain. Parents need an effective, comprehensive and timely supportive care based on their perspectives which can cater for their psychological, physical, social and spiritual needs throughout the course of their child's disease. By constituting a multidisciplinary counselling and interactive committee comprising of oncologists, nurses, psychologist, parents of children earlier treated and even a spiritual teacher may help these parents in understanding the disease process, its prognosis and the expectant consequence. It also prepares them to face the ultimate truth of end of life. As an oncologist or a physician, we should show empathy for our patients and not sympathy, this has been the doctrine of medical practice. But what should be our attitude and approach for the parents, the caregivers who though not suffering physically from the disease do suffer from relentless mental trauma and stress of seeing their child being slowly engulfed by the disease. Do they need our sympathy to sustain this psychological onslaught; well it is for the oncology community to ponder on. As for the parents of a child with cancer, they must have faith on us, on God and hope for a miracle.

Conflicts of Interest

I have no conflicts of interest to declare.

Financial interest

I have no financial interest to declare.

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