

Access to Palliative Care Services: A Qualitative Study of Experiences of Children and Families Attending University Teaching Hospital in Lusaka

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symptoms and psychosocial and spiritual needs requiring palliative care.

Few studies have been conducted in Zambia to assess the experiences of families' with palliative care services. However studies conducted elsewhere have revealed several gaps in palliative care services experience of families. Monterosso and others conducted a study in Australia to look at the palliative care experience of parents and guardian. reported that parents and guardians needed clear and honest information about their child's condition and prognosis throughout the trajectory of child's illness, which was not always provided. also wanted access and advice from multidisciplinary health professionals when caring for their child at home. Many families expressed were emotionally and burden of caring for their child with incurable cancer. Pain management was another aspect of care by which was of concern to the parents and guardians [10].

A study done by Ingiln et al. looking at experience parents of children with cancer revealed poor coordination and communication in providing palliative care. Families complained of lack of psychosocial and bereavement support [11].

Zambia has one of the highest HIV prevalence in the Sub-Saharan Africa with over 95,000 children being HIV infected in 2013. It also has an increasing burden of childhood malignancies many of which are referred to the hospital at a late stage when the cancer is no longer curable. In addition to promoting screening and early detection of cancer, there is a need for a systematic approach in providing comprehensive care for children and their families. Establishing quality of palliative care services and experiences of families will help in planning appropriate services for families and children. In this study, we aimed to document palliative care services and experiences of families attending the University Teaching hospital in Lusaka, Zambia.

Methodology

Study design

transcripts of interviews, validating pre-determined themes and identifying additional themes and subthemes that emerged. Two of research assistants coded the data. In order to ensure consistency in data coding we used Cohen Kappa, which is in-build into the Nvivo to check for inter-coder reliability [14]. was found to 0.76 corresponding to substantial agreement in coding by the two coders [14].

results are summarised in 5 major themes and these were

Ethical considerations

All participants were asked to provide written consent if they were able to write who could not write were asked to thumb print the consent form in the presence of an independent witness. A distress protocol was in place for participants showed signs of distress which facilitated their withdrawal from the study. study was approved by the University of Zambia Bioethics Committee (IRB number IRB00001131) and University of Cape town Ethics Committee (IRB number: IRB00001938). Permission was also obtained from management at UTH to conduct the study at the hospital.

Results

We had a total of 95 participants in FGDs. Most guardians were female (81.1%). Fathers were less than 20% (Tables 1 and 2).

age ranged from 0-16 years and the mean age was 5.3 In terms of age distribution most participating children were aged 1-5 (38/95 55.3% male and 44.7% Female).

respondents agreed that this was an important aspect of care, which

One complaint by parents with oncology patients was that when they were being referred from the local hospitals they were not informed about the possibility of long stays and were unprepared and were surprised how long it takes to investigations and complete treatment.

"Now if you stay in the hospital for many days or many months they tell you to go and buy the drug how can you buy the drug you don't have money? examine the child and then tell you to go to the social worker:...you get to the social work that I want money for drugs and they tell you they have not received any money from government..." - Male FGD, participant

Spiritual support: Families reported that spiritual support was very important but it was not routinely available. chaplaincy was more concerned with Catholics and others felt uncomfortable to seek help from a catholic priest when they were Protestants or Muslims.

church people help, but it is not that they come all the time, but they seem to come when you are feeling bad in your heart, and you have lost hope and they encourage you. Like for me, I used to lose hope because my child used to improve and again go down and this made me lose hope, but when people from church came, it made me feel better" - Male FGD participant

Psychological support: Most respondents felt that their problems needed to be discussed with someone who had experience in supporting families in situations to help them cope with their challenging situations. help of psychologist or counsellor would help the families and their sick children.

"Cancer is very big problem for the child and family. We need to receive counselling support so we can learn to live with our challenging circumstances...even children need counselling" - Female FGD participant

Recreation facilities at the hospital premises for families were very limited recreation facilities for children admitted to the hospital. Most of the parents would have loved to see their children get out of bed and do some recreation activities.

"Children have nothing to in in this place for entertainment...even when they feel better they can't play any games outside... they are bored" - Male FGD participant,

Communication

Communication of diagnosis and management to families We asked parents and guardians about their experience in communicating with health workers.

of accommodation, transport and money for upkeep. Food provided by the hospital was not only bad but also only mean for the sick children. Parents were not provided with food.

Similar

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