

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

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Abstract

Introduction: WHO recommends provision of palliative care for all who need it according to needs and context. However, in Sub-Saharan Africa coverage of palliative care services remain low especially children. This study reports experiences of palliative care services for children and their families attending the University Teaching hospital in Lusaka, Zambia.

Methodology: This was a cross-sectional qualitative study conducted at University teaching hospital in Lusaka, Zambia.

Results: The major challenges faced by families included lack of economic/financial and bereavement support. Most families were referred to the UTH from very far places without any form of support. One major barrier identified to provision of palliative care was poor coordination of services with most patients missing out on services which were already available. While social workers were available, poor funding negatively affected this service. There were very few trained health workers in palliative care. Pain management remained poor with many clinicians still not comfortable to prescribe stronger analgesia such as morphine for severe pain.

Conclusion: The study revealed significant gaps for children's palliative care services in at the University teaching hospital in Zambia. One major barrier identified to provision of palliative care was poor coordination of services. Families reported lack of economic and bereavement support in addition to lack of information.

Keywords: Palliative care; Children; Illness

Abbreviations: UTH: University Teaching Hospital; WHO: World Health Organisation; IRB: Institution Regulation Board; FGD: Focus Group Discussion; IDI: In-depth Interview; PEPFAR: President's Emergency Plan for AIDS Relief

Introduction

Palliative Care has been described as a holistic approach to care that meets the needs of the whole person encompassing physical, social, psychological and spiritual needs [1-3].

Palliative Care for children represents a "special, albeit closely related field to adult Palliative Care", but children have different needs to adults. The World Health Organization (WHO) defines Palliative Care for children with chronic, terminal or life-threatening illness as "The active total care of the child's body, mind and spirit and also involves giving support to the family, begins when a child is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease [2].

WHO recommends that palliative care is an essential component of care for any child with chronic, starting from the point of diagnosis to the end of life [3]. This is important as chronic illnesses are often

associated with pain and other distressing symptoms, which affect patients both physically and psychological throughout the trajectory of the child's illness [3]. Families who usually care for the sick child also need to be supported in coping with the child's illness [4].

It has been established that palliative care should be accessible to all according to needs and context.

The 2014 World Health Assembly endorsed access to palliative care services as a key priority and an integral part of universal health coverage for all [5]. A recent declaration by the International Children's Palliative Care Network (ICPCN) in Mumbai, India, called upon governments around the world to improve access to quality children's palliative care services [6]. However, in Sub-Saharan Africa coverage of palliative care services remain low and there is little evidence of what services are offered for patients and whether these are appropriate in the African context and meet patients and family needs [7-9].

A recent evaluation of the status of palliative care in Sub-Saharan Africa revealed that children and their families in sub-Saharan Africa facing progressive, incurable and life-limiting disease lack access to the evidence-based and effective care that is available for adults despite the high prevalence of HIV in African children and growing cancer burden [8]. HIV has become a chronic disease with access to antiretroviral medication but patients still experience distressing

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. They 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. They also wanted access and advice from multidisciplinary health professionals when caring for their child at home. Many families expressed were emotionally and financially 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 affected 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 affected children and their families. Establishing quality of palliative care services and experiences of families will help in planning appropriate services for affected 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

The study was a descriptive qualitative study conducted at the University teaching hospital in Lusaka, Zambia between October 2013 and February 2014. A cross-sectional study focuses on a given point in time to give a snap short of the phenomenon being study [12]. We adopted qualitative approach as this approach I suitable for exploring experiences, feelings and meanings which require longer explanations and probing [12,13].

Study population

Parents, legal guardians of children attending the University teaching hospital They were eligible if they were admitted at the time of data collection and had a patient with Cancer or HIV who was under 16 years old. Participants were selected from HIV outpatient clinic or Oncology ward and two general wards.

Sampling

Focus group discussion: Participants were purposely selected to take part in the study if they met the eligibility criteria and had consented to take part in the study. A total of 9 focus group discussions were conducted as follows:

3 with parents/legal guardian/in oncology ward

3 with parents/legal guardian in HIV clinic

3 with parents/legal guardian in the general paediatrics ward

Focus Group Discussions were conducted with selected parents and legal guardians of children and 2) health workers who worked with children in the target areas: Cancer, HIV and general paediatrics. Consent was obtained from eligible participants before taking part in the FGD. Each FGD had 8-12 participants. Each FGD took about 1 hour, facilitated by principal researcher. All the discussions were recorded and later transcribed. All FGD were conducted in local language which is commonly spoken in Lusaka.

In total we have 92 participants taking part in focus group discussions with an average of 10 participants per group. All of them were parents or legal guardians and 95% were female and 5% males. No children were interviewed for this study.

The FGDs were conducted for the different wards. Due to the large numbers of parents in each of the wards, we decided to conduct 2 FGD per ward to allow for more parents to share their experiences.

Data collection process

The research team approached all eligible participants. The voluntary nature of the study was emphasised. They were assured of confidentiality. If they agreed to take part a consent form was given to them to read in the presence of the research team. Children were given an opportunity to know about the purpose of the study and why their parents/legal guardians had been approached to take part. The age of the child was taken into consideration when providing information. Consent was FGD participation and for individual interviews. Those who could not write were asked to thumb print the consent form. Consent was done in local language. All interviews were conducted in local language and later transcribed in English.

In this study a distress protocol was developed to take care of parents/legal guardians who become distressed during data collection process. The distress protocol explained how to handle participants who became distressed during interviews. If at any point during the interview any participant was noticed to be distressed, the researcher was to stop the interview or focus group discussion. The researcher was to establish the most appropriate action whether to take a short break to allow the participant to settle back. If necessary the researcher was to help the participant to leave the interview. All research assistants were trained on how and when to apply the distress protocol.

Data analysis

Qualitative data was analyzed using NVIVO 10 where identification of themes followed conventional coding process. The results were combined and subsequently collated into relevant, larger thematic categories to improve explanatory ability of quantitative data.

Trained research assistants experienced with qualitative methods transcribed data. All transcripts were checked and validated. After data cleaning transcripts were exported to NVivo 10 for analysis. Thematic analysis was used for data analysis focusing on identifying patterned meaning across the data. The coding frame was developed initially deductively, using themes from the topic guide, combined with inductive themes, which emerged from the data. This was an iteratively progress.

Trained research assistants experienced with qualitative methods transcribed data. Two of the authors (WM and FG) reviewed

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-built into the Nvivo Software to check for inter-coder reliability [14]. This was found to 0.76, corresponding to substantial agreement in coding by the two coders [14].

Ethical considerations

All participants were asked to provide written consent if they were able to write. Those 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. The study was approved by the University of Zambia Bioethics Committee (IRB number IRB00001131) and The 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).

The 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).

The results are summarised in 5 major themes and these were further subdivided into 17 sub-themes as shown in Table 3.

Sex	Frequency	Percent	Valid Percent	Cumulative Percent
Male	18	16.5	18.9	18.9
Female	77	83.5	81.1	100
Total	95	100	100	-

Table 1: Sex distribution of guardian/parent.

Age	Males	Females	Total
< 1 year	6.0(60.0%)	4.0(40.0%)	10(100%)
1-5 years	21.0(55.3%)	17.0(44.7%)	38(100%)
6-10 years	23.0(71.9%)	9.0(28.1%)	32(100%)
11-16 years	10.0(66.7%)	5.0(33.3%)	15.0(100%)
Total	60(63.47%)	35(36.52%)	95(100%)

Table 2: Age distribution of children whose parents/legal guardians participated in the study.

Main themes	Subthemes
Knowledge about Palliative care	Components of palliative as reported by respondents
	Palliative care for children
Understanding of children's problems	Parental understanding of Reasons for admission
	Common problems affecting children
Experience with palliative care services	Support given to families and children since admission
	Satisfaction with a palliative care services received
Family experiences with Palliative care services	Bereavement support
	Physical symptom management
	Economic support for families
	Recreation facilities at the hospital premises
	Psychological support
Communication	Spiritual support
	Communication of diagnosis and management to families

Table 3: Themes and subthemes identified.

Definition and components of palliative

Parents and guardians were asked about what they understood by the term palliative care. Most of them did not know about palliative care as a term but understood it when it was explained to them. They were asked about what is involved in palliative care. Majority of the participants talked mainly about physical care. Psychological, and spiritual care were only mentioned after further probing as most

respondents did not think these should be provided by the hospital. They reported that they had seen the Roman Catholic chaplaincy service at the hospital. Those not belonging to this denomination did not think they were supported by this service. It was also reported that some church organisations occasionally came around and talked to patients and their families. In terms of importance of spiritual care, all

respondents agreed that this was an important aspect of care, which families needed, but it was not well coordinated.

“Helping those who are chronically ill so that their days are supplemented” - Male FGD respondent.

Palliative care for children

WHO differentiates palliative care for adults and children. We therefore wanted to know whether our participants were aware about the difference. Most of the participants were able to distinguish that palliative care in children is different from adults. They acknowledged that that provision of palliative care in children is more difficult and complex because of the family dynamics and that children were unable to articulate their needs compared to adults

“Children need special care compared to adults..some are very young and cant talk yet the doctors need to know what is going on” - Female FGD Respondent.

Understanding of children’s problems

Reasons for admission: We asked parents and guardians if they knew the reason why their child was admitted to the hospital. Most of the reasons given by parents were none specific. Most did not know what was wrong with their child and talked about symptoms. Parents with children with haematological problems and HIV were much more aware about the reasons for admission or visiting the hospital. This was less so for oncology patients and general wards. One respondent said:

“He started feeling pain in the hands and the legs and also started feeling week, we then brought him here at the hospital and they gave us an appointment, the appointment was quiet long and in the process of waiting the child’s legs started swelling” - Male FGD respondent.

Common problems affecting children at the time of interview: Parents were asked about the common problems affecting their sick children. Most common problems in order of significance were loss of appetite, pain, loss of weight and a drop in the body cells among others especially for oncology patients on chemotherapy. For parents with HIV positive children the major problem was that their children often missed school to come for treatment and investigations. These were not done over the weekend for stable patients.

“My child is having less blood in the body he needs blood transfusion. He is now complaining of a headache and stomach ache” - Female FGD respondent.

“The problems our children are experiencing are bad, my child now has no appetite, and has diarrhea” - Female FGD respondent.

Family experiences with health care services

Support given to families and children since admission: We asked parents and guardians what help their children received since they came to hospital. Majority had received treatment targeting the main problem for example cancer but no other symptoms which they felt were also very important. Some of the respondents said that they were still waiting for the diagnosis and had not received any help. For those whose children were on chemotherapy, the biggest nightmare was when the body cells dropped following chemotherapy. Most associated this with poor prognosis and worried that their child would die. This is a well-known and expected side effect of chemotherapy but this was not well communicated to the parents.

“Ok since we came doctors are working well, our children are improving. When they are given chemotherapy the disease improves, if it does not improves they change the drug, they give a different protocol. They try it and if it’s not that they will refer us to Lab so that they test to know the disease is improving” - Male FGD respondent.

Satisfaction with a palliative care services received: Most respondents were happy with medical management of the patients but were not happy with the support given to families looking after the children. The services were said to be less family centered. This was even more difficult for men who had no shelter yet they were expected to be present for extended period of time. They also were not satisfied with the information which was given to them concerning the illness of the child.

They also complained that they had to pay for certain medical tests and sometimes the results took too long to come out, making families to travel several times between home and hospital which was costly to the families. They also did not like the tendency to be seen by medical students who were just asking questions and not providing any tangible help.

“I think the doctors are good at giving chemotherapy....but we have many issues for example, there are is no accommodation and no food for parents. It is very difficult for most of the parents as most of them have travelled from very far and they don’t have family support” - Male FGD participant.

Bereavement support: Bereavement support was among the most important unmet needs. According to our respondents, most bereaved families lacked support and were left on their own. Although none of respondents had personally lost a child at UTH they had observed what had happen to some of the families who lost children while admitted at UTH. It was reported that most families had travelled from far away and did not have money to return and the hospital did not provide any bereavement support. Well-wishers from nearby churches sometimes helped families if they were asked or when they accidentally passed-by the ward on their routine hospital outreach. Sometimes the social workers helped with transport costs but due to poor funding they could not guarantee such support to the bereaved families.

“If you lose a child in this hospital you are on your own. There is no support given to families who have lost children on this ward. Most of them don’t have even transport to go back and later on take the body back for burial” - Female FGD participant

Physical symptom management: Majority of participants in FGDs complained that their children were in pain but pain killers were only given if requested. They usually were given paracetamol even when the child was in severe pain. Parents wanted their children to receive regular and stronger pain-killers. This was noted especially in the haematology ward where children had sickle cell disease and the oncology unit.

“Our children are in severe pain but they are always given Paracetamol, even when you complain nothing is done” - Female FGD participant

Economic support for families: Most families were from distant places and were referred to the UTH where they had no family support or any source of income. This disrupted family life. They faced many financial challenges ranging from transport and accommodation to food.

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 often surprised how long it takes to finalise 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? They 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. The chaplaincy office was more concerned with Catholics and others felt uncomfortable to seek help from a catholic priest when they were Protestants or Muslims.

"The 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 difficult situations to help them cope with their challenging situations. The 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: There 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.

Most respondents in the oncology and general ward reported that they were not informed about what was wrong with their children and what the prognosis was. They usually learnt when they over heard the doctors discussing in English about the patient. Most parents expressed frustration with discussing their child's illness with health workers. They were left in the dark and didn't know what to expect. This is reflected in the following quotations:

"...as for me, they mentioned or talked about it, but they are not sure, they are still going to tell us, so we are still waiting for one more test from another hospital and that is when we will know how the problem came about and the solution to the problem" Female - FGD participant.

"I have not yet received assistance because they steal don't know the problem that is causing the child to have pain in the stomach, the child does not even go to the toilet..." - Female FGD respondent.

"...they [doctor] speak in English among themselves. You find that they come as a group and begin to speak among themselves in English.....They don't even explain anything to us, you find that they just start the treatment without explaining anything to you" - Male FGD participant.

The situation was better for parents with HIV positive children who were well informed about the diagnosis and treatment of their children. The major challenge in this group was that some of the parents had not discussed the diagnosis and prognosis with the own affected children even when they were encouraged to so. Nonetheless, majority of the parents had disclosed this to their children.

Feelings experienced by parents when they learnt about the child's illness.

We asked parents and guardian how they felt when they first learnt about the diagnosis of their children. The reaction of most parents after learning about the child's illness were generally similar and could be summarised as: confusion, isolation, abandonment, shock, unexpected and stressful. The information about the child's illness brought a lot of panic and suffering, as parents did not know what to expect and nobody was explaining to them the expected outcomes. Following are some experiences from some of the respondents:

"My child's disease has made me move up and down a lot, since she was 7 years, it has been like that, others even say is it witchcraft, I even went to traditional doctors and was cheated and I came back, I then stopped and started going for prayers, then I just decided to place everything in the hands of God and stated bringing this child to the hospital" - Female FGD respondent.

"when my child was sick, they gave me a referral letter, I did not even know what to do with that referral paper because I didn't even have transport money to come here,no one even told me if there is any transport or ambulance to bring me to the hospitalI really suffered I just kept on crying for two days" - Female FGD respondent.

Discussion

The study revealed major gaps in palliative services offered to families who's children suffer from chronic illness at the University teaching hospital in Lusaka.

Families narrated lack of both financial and bereavement support. In addition, limited information was given to families to explain the disease entity and expected prognosis. Pain management remained sub-optimal for children with pain both acute and chronic pain.

It was clear that most families were referred to the UTH from very far places without any form of support. Most families expressed need for financial support, which could not be provided by the hospital. The fact that many were required to stay for longer period of time to complete investigations and treatment, meant loss of wages and family support. While on paper the social worker is supposed to meet the need for economic and financial support, in practice the office of the social worker was inadequately financed so could not meet the demands from parents and children.

The centralization of treatment center in Lusaka was a huge burden for families. They were referred without assurance for support in terms

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 findings have been reported in other low-income settings where families experience lack of support while being admitted with sick children [15,16].

Lack of bereavement support was another major gap in palliative care services. Families who lost their child were left to mourn on their own and arrange transport to take the funeral to wherever they were referred from. There was no bereavement support team at the hospital to support bereaved families. This was of concern to most parents who worried that if their child died then they would have to go through this process without support.

The study also showed the desperation that parents with life limiting go through in Zambia. When a diagnosis of life limiting illness is made for one of the children in the family, there was huge anxiety and disruption to family life. Most families felt unsupported emotionally and recommended that having a counselor or psychologist would help them to cope in such circumstances. Similar findings have been reported in high income countries where families need psychological support to cope with caring for a sick child [10]. Unfortunately, this service was not routinely available at UTH.

There was generally a very high need for information for families which health workers did not adequately provide according to the respondents. This was true for diagnosis, prognosis and expectations. The problem was worse in the oncology and general paediatric wards. Parents with HIV positive children seemed to receive better information with respect to management and prognosis. This could be attributed to the fact that, there were more trained health workers in HIV counselling and that the service is running as separate service with good funding support from partners such as PEPAFR. This was in sharp contrast to other wards which dependent on government support.

While some elements of palliative care were offered, the services were inconsistent and lacked coordination. For example some form of spiritual support existed but not well publicized or utilised. Families expressed desire to receive spiritual and psychological support, but how and when to access this service remained unclear for most parents. Harding et al, 2014 has reported the general lack of coordination of paediatric palliative care services in Sub-Saharan Africa and our finding is therefore in line with this observation [16].

The emphasis of care seemed to be on physical symptoms where clinicians and nurses were focusing on giving medical treatment directed at the disease with less focus on symptom management, which was of concern to parents. Most parents were worried about nausea, weight loss and pain but these were not given priority. Poor communication did not help in this matter, as families were not able to share their needs with clinicians who seemed to be overwhelmed with work and only talking among themselves in English, which most parents did not understand well.

Conclusion

The study revealed significant gaps in children's palliative care services at the University teaching hospital in Zambia. Family experiences point to high-unmet palliative care needs for children and their families with poorly coordinated services.

There was lack of economical and bereavement support for families in addition to lack of information.

Author Contribution

WM: Designed the study, collected the data, analysed and drafted the manuscript

FG: Critical reviewed the manuscript and reviewed the final version of the manuscript

LG: Participated in study design and data analysis. Critically reviewed the manuscript and the reviewed the final version.

Data Availability

This data is part of larger dataset that is being used for other purposes so it cannot be shared publicly. However, authors can be contact for specific information that can be shared to individual who are interested.

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