

Knowledge, Attitudes and Practice of Health Care Workers towards Paediatric Palliative Care: Pilot Study for the Private Sector at M.P Shah Hospital

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Abstract

Background: Palliative care in Kenya is not funded as a national resource and is therefore offered by Hospices and Palliative care units that rely on funding from charities or non-governmental organizations (NGOs). Although access to palliative care is limited as a whole adult palliative care is more developed, with 65 centres offering this service either as stand-alone units or integrated services compared to a single centre offering paediatrics palliative care in the entire country (Garissa county referral hospital established in 2011). Assessment over a three months period in M.P Shah Hospital in Nairobi revealed that 14 children were admitted with diagnosis of life limiting illnesses. This makes an average of 4 children monthly who need palliative care services, with no dedicated service.

Objective: To integrate Paediatrics palliative care services at the M.P Shah Hospital.

Methodology: The project has started off with a cross sectional descriptive study over a two week period to assess the knowledge of healthcare professionals in the Paediatrics department. After getting ethical approval from the hospital committee, all permanent staff was invited to participate. Data was collected using a validated tool; the Palliative Care Quiz for Nurses. Good knowledge was defined as >75% score. Part two of the project is training health care providers on paediatrics palliative care and the final phase is offering the services which will include formal clinic days and ward reviews with a proper referral system.

Results: Out of 50 staff, 30 met the inclusion criteria; 4 declined consent and 5 did not return completed questionnaires thus 21 anonymously self-administered questionnaires were analyzed. 71.5% (15) of the participants were nurses; 19.04 % (4) were consultant pediatricians and 9.5% (2) senior registrars. 52.3% (11) had postgraduate qualification in either paediatrics or critical care.

85.71% (18) had no previous experience with hospice or palliative care and 90.47% had no previous training in palliative care. All of the participants had poor knowledge on palliative care scoring < 75%. 16.9% (14) Scored > 50% while 33.3% (7) < 50%. Respondents scored higher on questions related to pain and symptom management.

Conclusion: There was overall poor knowledge in palliative care attributed to lack of formal training, which is to be addressed in the next phase of the project through targeted short course trainings.

Keywords: Knowledge; Attitudes; Practice; Health Care Workers; Paediatric Palliative Care

Problem Statement

Together for Short lives (formerly ACT) in the UK have defined four broad categories of life-threatening and life-limiting conditions among children which have been adopted for different settings. These categories are as follows:

1. Life threatening conditions for which curative treatment may be feasible but can fail such as cancer, end organ failure.
2. Conditions in which premature death is inevitable such as cystic fibrosis, Duchene's Muscular Dystrophy, advanced HIV/AIDS.
3. Conditions that are progressive without curative options where treatment is strictly palliative such as Batten disease, mucopolysaccharidoses, neuromuscular or neurodegenerative disorders.
4. Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death such as severe cerebral palsy, disability following brain or spinal injury.

Goldman., *et al.* [1] suggests that dying represents technological and medical failure hence the probable cause of lack of attention to children with life limiting illnesses. They also discuss how many health care providers lack an understanding of the scope of approaches of paediatrics palliative care. They are therefore not confident to offer palliative care or communicate effectively with children and families.

Part of this project involves assessing knowledge, attitude and practice of health care workers towards palliative care. The study will influence health care providers and increase their knowledge base on palliative care for children.

Study Justification

In Sub-Saharan Africa 230,000 deaths occur each year due to HIV/AIDS in children (2012) while many children with cancers present at advanced stages when palliative care is needed [2]. Approximately 166,000 children less than 15 years of age are diagnosed with cancer annually. Of all reported cancer deaths among children, 90% of them occur in resource limited settings. In Kenya 15% of all cancer admissions are children. Survival for children with cancer is estimated at 1 out of 10 indicating that many children diagnosed with cancer eventually die out of the disease.

Some challenges encountered in offering paediatrics palliative care in Sub-Saharan Africa include, poverty, a lack of understanding of disease processes in children, limited access to affordable services and paediatrics medical formulations [3]. Harding., *et al.* [4] conducted a systematic review on provision of paediatrics palliative care in Sub-Saharan Africa and found that greater research in this matter was needed and that more attention was paid to adult palliative care. There is therefore need for more research in paediatrics palliative care in order to bridge the gap in service provision.

Research Question

Does M.P Shah Hospital need to provide paediatrics palliative care as one of the specialized services?

Broad Objective

To determine the need of paediatrics palliative care services in M.P Shah Hospital and integrate the said services as part of specialized care.

Specific objectives

1. To assess the knowledge, practices and attitudes towards palliative care of nurses and doctors working in the paediatrics wing of M.P Shah Hospital.
2. To determine the gap in palliative care knowledge and skills among doctors and nurses working in M.P Shah Hospital's paediatrics wing.
3. To have training of health care professionals on paediatrics palliative care.
4. To determine which models of palliative care for children can be adopted by M.P Shah Hospital.
5. To determine the need of support groups for parents with children suffering from life- limiting illnesses.

Theoretical and conceptual framework

The World Health Organization (WHO) in 2002 defined paediatrics palliative care as the total active care of the child's body, mind and spirit and also involves giving support to the family. The care begins at the time of diagnosis of a life-limiting illness and continues regardless of whether or not a child receives treatment directed at the disease. This definition focuses on implementing approaches that address the relief of physical distressing symptoms, psychological issues, spiritual issues, social issues and alleviating the suffering of patients and their families [5].

A life threatening illness is defined as an illness that makes it possible that the person affected will die. The palliative care movement started with studies around cancer patients in the United Kingdom in the 1960s with the first hospice being established in London in 1967 by Dr. Cecily Saunders. As the care spread out to the rest of the world it has been realized that patients with other conditions can benefit from palliation as well (International Association for Hospices and Palliative Care 2016). In children, conditions needing palliation include but are not limited to cancers, Irreversible organ failure e.g. heart, kidney, liver, Cystic fibrosis, Duchenne muscular dystrophy, HIV/AIDS, Neuromuscular/neurodegenerative conditions, multiple disabilities and cerebral palsy as discussed above.

Palliative care is offered wherever the patient is. The commonest models of palliative care are home based care, facility based care, outpatient clinics, inpatient care, day care and roadside clinics (APCA 2010). This study will be looking at integration of palliative care based on two models namely outpatient clinics and inpatientcare.

Methodology

Study design

The study was a questionnaire based cross-sectional descriptive study done over two months. A validated questionnaire known as the "Palliative Care Quiz for Nursing" was selected for this study since there are no validated questionnaires specifically addressing paediatrics palliative care. There are other validated questionnaires on end of life issues but this specific questionnaire assesses basic principles and knowledge in palliative care practice. This tool was developed for a broad range of nursing personnel and has been used in various clinical settings and with other health care providers to measure palliative care knowledge and attitudes.

It is a twenty (20) question scale that includes knowledge questions using a scale "Yes", "No" or "Don't Know". Ross., *et al.* [6] scored the quiz by giving one point for a right answer and zero (0) points for a wrong or "Don't Know" responses. The maximum score is therefore 20. A high score of more than 75% indicates a better level of knowledge. The 20-scale item is divided into three conceptual categories:

1. Philosophy and principles of palliative care which measures attitudes.
2. Psychosocial and spiritual care which measures knowledge.
3. Pain and symptom management which measures skills.

Study site

The study site was M.P Shah Hospital paediatrics wing which has a bed capacity of 40 patients. Of all admitted patients about 50 need palliative care. Most children needing palliative care are seen upon admission to the wards. Palliative care is not available as a formal service in the outpatient clinic. These children are cared for by paediatricians, medical officers and nurses.

Study population

The study population included all paediatricians, medical officers and nurses working as M.P Shah Staff in the paediatrics wing.

Sampling and recruitment

A representative sample was drawn from this population in the period and the sample size calculation was obtained using the formula for finite population (Daniel, 1999). This sample size is based on a similar study done by Brazil, *et al.* [7] in Ontario, Canada to assess palliative care knowledge among nurses which had 69 participants as their sample size using the same tool.

The calculation was as follows:

$$n' = \frac{NZ^2P(1-P)}{d^2(N-1) + Z^2P(1-P)}$$

Where:

n' = Sample size with finite population correction,

N = Size of the target population = 30

Z = Z statistic for 95% level of confidence = 1.96,

P = Estimated proportion of knowledge, attitudes and practice = 75%

d = margin of error = 5%

$$= \frac{75 \times 1.96^2 \times 0.5 \times 0.5}{0.05^2 (75-1) + 1.96^2 \times 0.5 \times 0.5}$$

$$= 30 \text{ healthcare workers within 5\% level of precision.}$$

The target population was estimated at 30 members of staff working in the paediatrics wing. They were recruited over a period of one week by consecutive sampling every afternoon with an average of 5 members of staff approached daily.

The study population was recruited by the principal investigators. Nurses and doctors working in the paediatrics department were informed about the study and invited to participate in it. 8 doctors were approached to participate in the study and a double number of nurses (16) were approached. This was because there were more nurses in the department and the sample size needed to be representative of all health care workers.

30 members of staff fulfilled the inclusion criteria and were requested to sign a written informed consent in order to be recruited into the study. Those who do not meet the inclusion criteria will not be admitted into the study. 4 declined consent thus 26(86.67 % of total screened) were recruited (Figure 1).

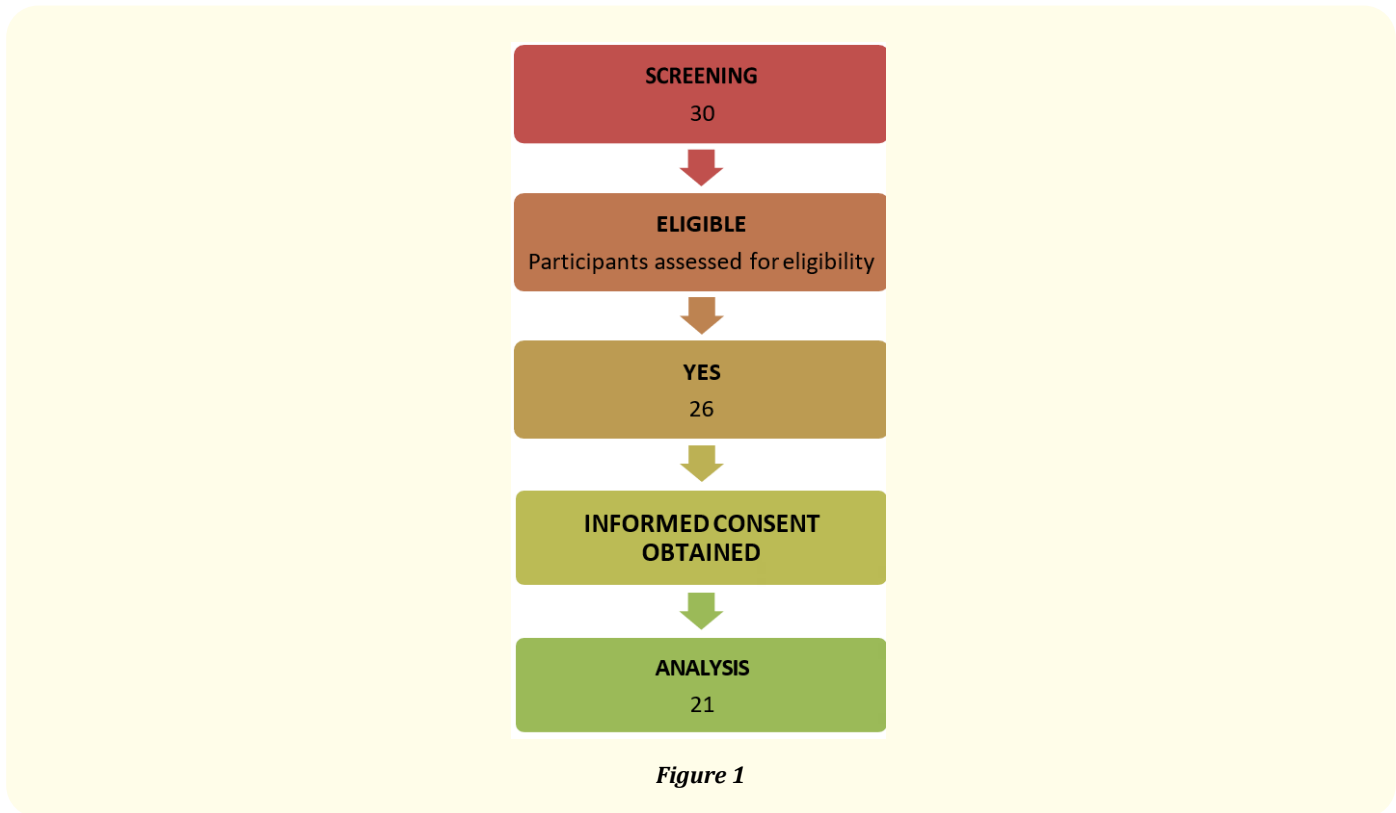


Figure 1

Participant selection

Members of staff selected had to meet specific inclusion criteria. This is demonstrated in table 1.

| Inclusion Criteria |
|--|
| 1. Have a Diploma or Bachelors’ degree in Nursing; or a Bachelor of Medicine and Bachelor of Surgery Degree. |
| 2. Have postgraduate training in Nursing or Medicine. |
| 3. Be registered by the relevant body regulating practice in Kenya. |
| 4. Be employed on permanent basis by M.P Shah Hospital and working in the paediatrics wing. |
| 5. Sign informed consent to participate in the study. |

Table 1

Exclusion criteria are demonstrated in table 2.

| Exclusion Criteria |
|--|
| 1. Participants working in M.P Shah on part-time or locum basis. |
| 2. Those who do not wish to participate in the study. |

Table 2

Ethical considerations

This study was conducted after getting approval from the Ethics and Research committee of M.P Shah Hospital. An informed consent form was given to study participants and those eligible subjects who agreed to participate signed the form.

The principal investigators ensured confidentiality in the whole process. Any private information obtained from participants was not disclosed to any other party without the participant's consent. All data obtained in this study will be used to meet the objectives of this study stated above. On completion of the study, all data collected will be submitted to the Medical Director and the head of the Paediatrics Wing, M.P Shah Hospital for possible follow up studies. Information from the study will also be shared with the Kenya Hospices and Palliative Care Association (KEHPCA) [8] as well as the International Children's Palliative Care Network (ICPCN).

Within three months of finalizing this study, data will be disseminated to healthcare working in M.P Shah Hospital during a CME session with the aim of determining the gaps in knowledge and practice of palliative care identified by the study. The same study will also be presented at the 3rd. International Children's Palliative Care Network conference in May 2018 with an aim of getting feedback on improving the practice of paediatrics palliative care in M.P Shah Hospital.

Study procedures

After approval from the Ethical and Research Committee, M.P Shah Hospital, the principal investigators prepared a list of those who were willing to participate in the study.

The details were explained to them. Every afternoon, 5 members of staff were given the questionnaire to fill. This was repeated until all recruited members of staff participated in the study.

Results and Discussion

Data management and analysis methods

This study aimed to investigate the extent of knowledge, attitudes and practices among healthcare providers working in the paediatrics wing using a validated questionnaire. Data was collected using a validated tool for assessing knowledge, attitudes and practices of healthcare workers towards palliative care.

Data was analyzed using SPSS version 21.0. The results are discussed below.

Demographic information and epidemiological characteristics of the respondents

There were 95.2% (20/21) female respondents. The mean age of respondents was 28 years. 71.5% (15) of the participants were nurses while 19.04 % were consultant paediatricians (4) and 9.5% (2) senior registrars. 57.14% (12) of the participants had been working with children for an average of 4 years. 52.3% (11) of the participants had postgraduate qualification in either paediatrics or critical care. 85.71% (18) had no previous experience with hospice or palliative care and 90.47% (19) had no previous training in palliative care. This is illustrated in table 3.

| Variable | Frequency % (n/N) N = 21 |
|---|-----------------------------|
| Gender | |
| Male | 4.8 % (1) |
| Female | 95.2% (20) |
| Age | |
| 20-25 yrs. | 4.8% (1) |
| 26-30 yrs. | 28.5% (6) |
| 31-35 yrs. | 38.09% (8) |
| 36-40 yrs. | 19.04% (4) |
| Over 40 yrs. | 14.2% (3) |
| Designation | |
| Consultants | 19.04% (4) |
| Senior registrars | 9.5% (2) |
| Nursing Officers | 71.4% (15) |
| Highest qualification | |
| Master of Medicine in Paediatrics | 28.5% (6) |
| Higher Diploma in Paediatrics Nursing | 14.2% (3) |
| Higher Diploma in Critical Care Nursing | 9.5 % (2) |
| Bachelor of Science in Nursing | 14.2% (3) |
| Diploma in Nursing | 38.09% (8) |
| Years of working experience | |
| 0 - 2 yrs. | 9.5% (2) |
| 2 - 4 yrs. | 23.8% (5) |
| 4 - 6 yrs. | 33.3% (7) |
| 6 - 8 yrs. | 9.5% (2) |
| 8 - 10 yrs. | 9.5% (2) |
| Over 10 yrs. | 19.04% (4) |
| Professional or personal experience with hospice/palliative care | |
| Yes | 19.04% (4) |
| No | 85.71% (18) |
| Previous palliative care training | |
| Yes | 9.5% (2) |
| No | 90.47% (19) |

Table 3: Demographics and characteristics of respondents.

Palliative care quiz scores

Respondents answered single response questions, scoring 1 for a correct answer and 0 for an incorrect answer or a “don’t know” response. The questions had three categories namely:

1. Philosophy and principles of palliative care (questions 1,9,12 and 17)
2. Psychosocial and spiritual care (questions 5, 11 and 19)
3. Pain and symptom management (questions 2 - 4, 6 - 8, 10, 13 - 16, 18 and 20).

A score of more than 75% was considered good knowledge [6]. None of the participants in this study had good knowledge on palliative care. 13 (16.9%) of the respondents scored more than 50% while 7 (33.3%) scored scoring less than 50%. The overall mean score was 30%.

The scores are illustrated in table 4-6 respectively.

| Scores | N = 21 |
|------------------------|-----------|
| Knowledge Score | |
| Good knowledge | 0 (0%) |
| Poor knowledge | 21 (100%) |

Table 4: Distribution of respondents by scores.

| Conceptual Categories of PCQN | Mean Score |
|--|------------------------|
| Philosophy and Principles of Palliative care | 1.9 out of 4 questions |
| Psychosocial and spiritual care | 1.3 out 3 questions |
| Pain and symptom management | 9 out of 13 questions |

Table 5: Mean score per category.

| Question | True % (n/N) | False % (n/N) | Don't Know % (n/N) |
|--|---------------|----------------|--------------------|
| Palliative care is appropriate only in situations where there is evidence of a downhill trajectory or deterioration. | 33.3% (7/21) | 61.9% (13/21) | 4.76% (1/21) |
| The provision of palliative care requires emotional detachment | 23.8% (5/21) | 76.2 % (16/21) | 0% (0/21) |
| The philosophy of palliative care is compatible with that of aggressive treatment. | 33.3% (7/21) | 42.85% (9/21) | 23.8% (5/21) |
| The accumulation of losses renders burn-out inevitable for those who seek work in palliative care. | 61.9% (13/21) | 14.28 % (3/21) | 23.8% (5/21) |

Table 6.1: Philosophy and principles of palliative care.

| Question | True % (n/N) | False % (n/N) | Don't know % (n/N) |
|--|----------------|---------------|--------------------|
| It is crucial for family members to remain at the bedside until death occurs. | 52.3 % (11/21) | 47.6% (10/21) | 0% (0/21) |
| Men generally reconcile their grief more quickly than women. | 23.8% (5/21) | 52.3% (11/21) | 23.8% (5/21) |
| The loss of a distant or contentious relationship is easier to resolve than the loss of one that is close or intimate. | 57.14% (12/21) | 38.09% (8/21) | 4.76% (1/21) |

Table 6.2: Psychosocial and spiritual care.

| Question | True % (n/N) | False % (n/N) | Don't know % (n/N) |
|--|----------------|----------------|--------------------|
| Morphine is the standard used to compare the analgesic effect of other opioids. | 66.66% (14/21) | 19% (4/21) | 14.2% (3/21) |
| The extent of the disease determines the method of pain treatment | 71.42% (15/21) | 28.57% (6/21) | 0% (0/21) |
| Adjuvant therapies are important in managing pain. | 80.95% (17/21) | 4.76% (1/21) | 14.28% (3/21) |
| During the last days of life, the drowsiness associated with electrolyte imbalance may decrease the need for sedation. | 57.14% (12/21) | 28.5% (6/21) | 14.28% (3/21) |
| Drug addiction is a major problem when morphine is used on a long-term basis for the management of pain. | 66.66% (14/21) | 23.80% (5/21) | 9.52% (2/21) |
| Individuals who are taking opioids should also follow a bowel regime. | 85.71% (18/21) | 9.52% (2/21) | 4.76% (1/21) |
| During the terminal stages of an illness, drugs that can cause respiratory depression are appropriate for the treatment for severe dyspnoea. | 9.5% (2/21) | 80.9% (17/21) | 9.5% (2/21) |
| The use of placebos is appropriate in the treatment of some types of pain. | 61.9% (13/21) | 23.8% (5/21) | 9.5% (2/21) |
| In high doses, codeine causes more nausea and vomiting than morphine. | 42.8% (9/21) | 14.2% (3/21) | 42.8% (9/21) |
| Suffering and physical pain are synonymous. | 38.09% (8/21) | 57.14% (12/21) | 4.76% (1/21) |
| Demerol is not an effective analgesic in the control of chronic pain. | 23.8% (5/21) | 23.8% (5/21) | 52.8% (11/21) |
| Manifestations of chronic pain are different from those of acute pain. | 66.66% (14/21) | 23.8% (5/21) | 9.5% (2/21) |
| The pain threshold is lowered by anxiety or fatigue. | 47.6% (10/21) | 42.8% (9/21) | 4.76% (1/21) |

Table 6.3: Pain and symptom management.

61.9% (13) of the participants agreed that palliative care was not only appropriate when the patient had deteriorated. 76.2% (16) thought that provision of palliative care needed detachment and 61.9% (13) also thought accumulation of losses caused burnout for staff working in palliative care. Their overall knowledge on palliative care principles was a mean of 1.9 out of 4 (47.5%) which is considered poor.

52.3% (11) thought that family members needed to remain at the bedside until death occurs. This view could be influenced by the practice we see in our hospital and the cultures practiced in our country. 57.14% (12) thought that it was easier to resolve grief over a distant relationship. The overall performance in this section was a mean of 1.3 out of 3 (43.3%) which represents poor knowledge.

71.42% (15) thought that the extent of disease determines the method of pain management. There was poor knowledge on morphine addiction with 66.66% (14) thinking that the major problem with long term morphine use was addiction. 61.9% (13) also thought that placebos can be used in pain management. 80.9% (17) thought that drugs causing sedation are not relevant for treatment of dyspnoea at the end of life yet benzodiazepines are used for this symptom. In this section, the mean score was 9 out of 13 (69.2%) still demonstrating poor knowledge on symptom management. This section scored better than the other two sections.

Conclusion

There was overall poor knowledge on palliative care with an average score of 30%. Ross., *et al.* [6] got a mean score of 61%. Brajtman., *et al.* [9] also got a mean score of 61% when the same questionnaire was used among Canadian nursing students. The poor score in this quiz is thought to be due to lack of basic training in palliative care in nursing and medical school curricula [7].

From the findings of this study we recommend that M.P Shah Hospital organizes a short training course of about three days on the key concepts of palliative care for interested staff working in the paediatrics department. Later on, other trainings on different aspects of palliative care such as pain management, breaking bad news or symptom management can be organized based on feedback that will be received from the trained staff. Initial training can be for trainers to ensure sustainability of the project [10].

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