BARRIERS TO CONTINUITY OF PALLIATIVE CARE FOR CHILDREN WITH CANCER IN BUSOGA SUB REGION EASTERN UGANDA.

BY

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DECLARATION

I hereby declare faithfully that to the, this seminar topic is an original work developed through my personal efforts and to the best of my knowledge, has never been submitted for any award of degree at a university or academic institution.

Candidate

HIBO ABDI ADAN

Signature……………….

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Table of Contents

SUMMARY

Current evidence suggests that children and young people with cancer receiving specialist palliative care are cared for differently. However, little is understood about children's views, and research is needed to determine whether specialist input improves quality of life. The barriers as perceived by parents focus almost without exception on non-medical aspects: patient-doctor relationships; communication; decision-making, including end-of-life decision-making; and organisation. The perceived barriers indicate that care for children with a life-threatening condition focusses too much on symptoms and not enough on the human beings behind these symptoms

CHAPTER ONE

INTRODUCTION

Palliative care delivery (PCD) is offering active holistic care to individuals across all ages with serious health-related suffering due to severe illness and especially those near the end of life. (WHO, 2019). The WHO defines pediatric palliative care (PPC) as the prevention and relief of suffering in patients with life-threatening or life-limiting disease and their families *(Taylor et al., 2020).*

Palliative care (PC) is delivered by PC specialists, nurses, counselors, amongst others and its aimed at relieving pain, providing psychosocial support and identifying clear goals of care and wishes for end of life, thus enabling a good death (*Anderson, R. & Grant, L. 2017).*

According to WHO, (2012). Globally, over 20million people are estimated to require PC annually, however, only 22% get it due to challenges still facing its delivery (Bowen, et al., 2019). The Global Atlas of Palliative Care at the End of Life (GAPCEL), (2014) reported that one of the challenges that have enormously affected PCD globally, there's Limited access to opioid medication for pain control where by 80% of the world's population has either no or limited access to the drugs. As a result, 80% of global cancer patients still die with uncontrolled/poorly controlled pains, 95% of global HIV/AIDS related patients die struggling for breath without appropriate PC *(WHO, 2015).*

In Finland, although progressive, terminal and life-threatening diseases are on the rise, the PCD systems are not quite effective with the biggest challenge being the fact that the health workers are not appropriately trained in palliative care. *(Lynch, T. 2013).*

In Africa, PCD has faced challenges as hospice centers have not been fully established in many areas hence only about 22% of African patients in need of PC have access to it in a few PC settings that are run on humanitarian basis (*Reid et al., 2019).*

In east Africa, PCD for patients with cancers and AIDS remains both insufficient and of inadequate quality (*Johnston, H. 2017).*

In Uganda, According to the Uganda Health Sector Performance Review (HSPR), (2015), only about 10% of Ugandans who need PC can access it and this poor access is attributed to the many factors affecting its delivery. Only about 4.8% of the hospitals in Uganda offer PC Services indicating a large gap in PCD system of Uganda. *(UHSDP, 2015).*

At Mbarara hospice centre, there has not been any study carried out to ascertain challenges affecting PCD of health workers at Mbarara regional referral hospital. A reason for carrying out this research study. Palliative care Africa Uganda (PCAU) has supported hospitals across the country to implement the Pain Free Hospital Initiative (PFHI), this is a quality improvement initiative to integrate pain treatment into service delivery by providing education for hospital staff, raising motivation and awareness, measuring and documenting pain levels, and improving medicine supply. *(PCAU annual report 2020.)*

Despite the efforts, hospice Africa Uganda annual report (2020/2021) reported that Mbarara Hospice Centre (MHC), recorded 40% (51) of 123 deaths dying in pain, out of the 1,126 total visits that year, only 50% (572) were admitted, majority of the them were referred out for treatment, some dropped out of the treatment course and only a few were served on consultation. This report shows that there are gaps which could be due to various challenges affecting PCD hence a reason why many patients are referred out, others dropping out of care, while those under care still have painful deaths. Therefore a reason for carrying this study is to find out the challenges affecting PCD among HWs that need to be solved in order to achieve palliative care goals including terminal ill care and dignified peaceful deaths. If this study is not done, these challenges may remain uncovered hence goals of palliative care will still remain unachieved. *(PCAU annual report 2020.)*

CHAPTER TWO

LITERATURE REVIEW

Each year, almost 16,000 children in the United States are diagnosed with cancer; 1 in 5 die of the disease. Studies suggest that many children with cancer experience gaps in care, such as poor management of physical and psychosocial symptoms, failures in communication,3 inadequate support for family members, and inconsistent bereavement follow-up. These gaps may result in the provision of cancer care that is not consistent with the goals and preferences of children and their families. Many of these gaps in care could be mitigated through the widespread provision of comprehensive and effective palliative care; studies have demonstrated numerous benefits of pediatric palliative care (PPC) for children with cancer, including improved pain and symptom management, more robust psychosocial support, increased care coordination, fewer deaths in the intensive care unit, and increased overall patient and family quality of life. The World Health Organization (WHO) defines palliative care as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness by preventing and relieving suffering through the early identification and assessment and treatment of pain and other problems, including physical, psychosocial, and spiritual problems. Although often conflated with hospice care, palliative care is broader in scope; whereas hospice care is intended exclusively for those with a prognosis of 6 months or less, palliative care is not limited to the end of life (EOL). Core principles of palliative care for adults and children include symptom management, quality of life, communication, goal-driven decision making, and interdisciplinary care for a patient and his or her family. PPC is unique because it includes factors like the appropriate involvement of children in medical decision making and ethical and legal considerations when children who are seriously ill become legal adults, among other considerations. Despite the proven benefits of PPC, many children with cancer do not receive palliative care services. Early integration of services is even more uncommon, preventing families from fully benefiting from the range of physical, psychosocial, and spiritual services included in palliative care.This gap between the evidence and actual use patterns has increasingly garnered the attention of researchers and policy makers, with organizations like the WHO, the Institute of Medicine (IOM), and the American Academy of Pediatrics (AAP) calling for further integration of PPC earlier in the cancer trajectory Although PPC has become a priority, multiple barriers continue to prevent its adoption and implementation. Evidence of these challenges is dispersed in the literature, particularly evidence specific to pediatric oncology, thus inhibiting a full understanding of the varied barriers to care occurring at multiple levels (eg, policy level, organizational level, individual level). This review consolidates existing literature on the multifaceted barriers to accessing PPC encountered by children with cancer and their families and strategies that have been proposed to address these barriers. This synthesis of current knowledge is a critical step toward addressing the underuse of services and optimizing the care received by children with cancer and their families. In a nationwide qualitative study conducted in in the Netherlands, parents identified six categories of difficulties that create barriers in the care for children with a life- threatening condition. First, parents wished for more empathetic and open communication about the illness and prognosis. Second, organisational barriers create bureaucratic obstacles and a lack of continuity of care. Third, parents wished for more involvement in decision- making. Fourth, parents wished they had more support from the healthcare team on end- of- life decision- making. Fifth, parents experienced a lack of attention for the family during the illness and after the death of their child. Sixth, parents experienced an overemphasis on symptom-treatment and lack of attention for their child as a person *(Brouwer et al., 2020).*

Working conditions

Research study it was revealed that health workers offering palliative care in Ndola District, Zambia reported undesirable working conditions and unreliable transport network for linking patients from palliative care centers and their homes for effective holistic care to even other family members**.** Facilitating favorable working conditions for caregivers is essential in fostering the provision of quality palliative care and poor working conditions demotivates palliative care workers who deliver the services.*(Musonda et al., (2021).*

Resource inadequacies

According to research study by Musonda et al., (2021), findings revealed that there was lack of supporting resources both human and material to effectively offer palliative care. lack of Inadequate resources in patient care such as lack of food supplements may culminate into nutritional deficits leading to body wasting, anemia, diminished energy and organ failure were also reported by as challenges affecting palliative care delivery *(Khadka, 2019).*

Availability of basic drugs and inadequate staffing

Shortage of skilled manpower and medication in health institutions has made it difficult to manage patients with chronic conditions leaving the burden to the voluntary sector, friends and relatives in a home environment (*MacPherson et al., 2020).*

According to research studied in Nigeria, findings revealed that 68.3% of palliative care centers were inadequately staffed hence health care givers cared for many patients which made them to be exhausted and desiring to just leave the patients alone and take a rest. *Oyegbile and Brysiewicz (2017).*

Properly coordinated

Coordinated working is very important in achieving the objectives of a team for successful palliative care, failure to have good coordination between family and caregivers, as well as between care centre and national administration units' leads to poor quality palliative care *(Zhang et al., 2018).*

According to research study by Bowen et al., (2019), it was also found out that palliative care coordination was among strength that contributed to palliative care success in Canada. *Zhang et al., 2018).*

Inadequate training

Research study by it was revealed that health workers offering palliative care in Ndola District, Zambia reported lack of training as a challenge that affected their ability to offer palliative care to patients. Also, Poor training at workplaces is associated with dissatisfaction, low confidence and high likelihood of accidents including mistakes at work Musonda et al., (2021),

Anxiety

found that although palliative care givers in Malawi often handled dying patients under their care, 56.7% had anxiety regarding handling dying patent hence it was one of their moments full of discomfort and lack of ease. However, Ahlam et al., (2019) did not find anxiety related to handling dying patients among Moroccan palliative care givers. (*Mkwinda & Lekalakala-Mokgele 2016)*

Transmission of infections

Research study revealed palliative care givers with knowledge gaps in how to protect themselves from contracting diseases from patents under their care since some like HIV could be transmitted. Bates et al., (2013) also found disease transmission threat in palliative care givers as 54.7% were not formally trained on infection prevention hence lack knowledge on self-protection where as 65.8% of palliative care centers dealing with HIV/AIDS lack enough PPEs for caregivers' personal protection. (*Mkandawire et al., (2015).*

Knowledge Deficit

Research studied that have assesses prospects of palliative care in Africa, it has been revealed that health workers are often challenged and they become angry and exhausted because of lack of knowledge on what to do and what to expect while caring for the terminally ill patients (*Makhele & Mulaudzi 2012)*

Emotional support

A study revealed that more than 33.6% of health care givers offering palliative care experience need for emotional supports hence they undergo syndrome termed as "struggle to give emotional supports while themselves need emotional support". Reid et al., (2018) also found emotional needs among health care givers offering palliative care to life-limiting illnesses in Ethiopia.*(Streid et al., (2014)*

Long working hours

According to findings revealed that 81.1% of health care givers of patients under palliative care were supposed to work for long hours hence they experience burnout while caring for these patients as result of lacking in between breaks. *(Musonda et al., (2021).*

CHAPTER TREE

CONCLUSION, RECOMMENDATION AND REFERRENCES

CONCLUSION

Although integrating PPC can benefit providers, patients, and their families, the barriers described in this review have limited the widespread adoption of PPC for children with cancer. With nearly 16,000 children in the United States being diagnosed with cancer each year and 1 in 5 dying of the disease, understanding the barriers and exploring ways to overcome them are critical.

PPC experts can help all stakeholders manage the challenging topics associated with high-risk cancers in children and provide integral support to the care team. However, addressing the underuse of PPC services for children with cancer will depend on simultaneously overcoming barriers at each level of the socioecological framework. The current review summarizes recommendations from across the literature, but ongoing sharing of lessons from providers experienced in PPC and health systems and pediatric oncology programs with established PPC models may best enable broader adoption.

RECOMMENDATION

Redefining what PPC means and changing perceptions will rely on changes in practices and the framing of PPC within the context of cancer care.

In the WHO definition of palliative care and the AAP policy statement, as noted above, the introduction of PPC should begin at the time of diagnosis as part of an overall cancer treatment plan for the patient.

Others have also recommended integrating palliative care specialists into the child's care team early in the care-planning process.

This can support the perception that PPC is part of the overall treatment plan rather than a last resort for children with cancer.

Furthermore, integrating the PPC team as part of the child's multidisciplinary care team reframes PPC in a positive light. PPC providers become additional supports for the child and family throughout the continuum of cancer treatment.

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