

Abstract for tropEd website

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Year of submission: 2014

Title: Evaluation of a children's palliative care outreach programme for Burkitt Lymphoma patients in a rural area in the Northwest Region of Cameroon: Does it meet their needs?

Key words: children's palliative care, home visits, sub-Saharan Africa, Burkitt Lymphoma, health related quality of life

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Abstract

Background Endemic Burkitt Lymphoma (BL) is the most common childhood cancer in tropical Africa. Survival rates in sub-Saharan Africa (SSA) are below 40% due to a lack of resources. Palliative care (PC) is the appropriate treatment for patients with life-limiting, non-curable diseases. By addressing physical, psychological, social and spiritual needs of patients, PC improves the health related quality of life (HRQoL) during the last period of life. PC is a relatively new concept in SSA. Its provision is rare, while a lack of curative treatment options creates a great demand for PC. Research like this study that evaluates an existing children's PC outreach programme for BL patients in a rural area in Cameroon is needed to create an evidence base confirming the importance of appropriate PC services in SSA.

Objectives To gain a better understanding of the needs of patients and families visited by the PC nurse and to identify aspects that can be improved to better meet these needs and thereby improve the recipients' HRQoL.

Methodology A qualitative study design with semi-structured interviews was used. Tape-recorded interviews were transcribed and thematically analysed.

Results Financial aid, general improvement of the disease and prayers were the directly expressed needs of the recipients. Open communication about the current clinical status of treatment failure, more detailed counselling, more distraction for patients and relief of carers were identified underlying needs. The belief in God was comforting, helped to accept the situation and connected families socially. The free PC service was welcomed by the families and perceived as a major help. Specialised training in children's PC and a better counselling of the patients were the main needs expressed by the nurses.

Discussion Despite its small sample size, this study adds valuable information to the sparse literature on evaluation of children's PC services in SSA. The need for medical support as the major concern of the families was met adequately and the PC home visits were received with delight. The programme and this study consider cultural aspects, which is important for the acceptance, value and evaluation of a newly implemented service.

Conclusion This study shows that an effective service that meets the most urgent needs of recipients is possible in a rural setting in SSA. Recommendations include improved counselling, more specialised education for the staff, expansion of local supportive networks and more frequent home visits to better relieve families. More studies that evaluate existing services in SSA are needed to help children with life-limiting diseases not to suffer an inhumane death.