

SHORT COMMUNICATION

Palliative care in Tanzania: a needs assessment study of family caregivers in urban setting

T. NGOMA

Ocean Road Cancer Institute, P.O. Box 3592 Dar es Salaam, Tanzania;

Email: ngoma@uccmail.co.tz

Tanzania, with a population of 34.5 million people is one of the highly indebted poor developing countries. About 175,000 people die from HIV/AIDS and cancer each year (WHO, 2002a; Sepulveda *et al.*, 2003). Many of these deaths are associated with suffering that could be avoided and/or relieved if adequate and appropriate palliative care were provided.

Palliative care may be defined as an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification and careful assessment and treatment of pain and other problems in the physical, psychosocial, and spiritual domains (WHO, 2002a; Sepulveda *et al.*, 2003). Palliative care regards dying as a normal process and offers support to the patient and family during the patient's illness and in the bereavement period.

From the philosophy of palliative care, families become another major focus. In Tanzania and in many other African countries, the culture of extended families is strong and provides the highly needed physical and moral support to palliative care patients. Families are the main caregivers in the homes and community settings, as well as in hospitals. It is culturally unusual in Africa for a patient to be completely alone during his/her illness (Ankrah, 1993).

In palliative care having families around has been a crucial blessing but with virtually a number of unmet needs (Kikule, 2003). This situation analysis and needs assessment study was conducted in Dar es Salaam, Tanzania in the year 2001 as a baseline study for a community health approach for palliative care for patients with advanced cancers and HIV/AIDS. The objective was identified a range of needs as expressed by family caregivers.

A cross sectional study was conducted using both quantitative and qualitative data collection tools adapted from the Hoima Study – in Uganda (<http://www.who.int/cancer/palliative/rural/en>). The tools, which were interviewer-administered, were modified

to suit local conditions. Study population included caregivers that were caring for patients with advanced cancers and/or HIV/AIDS. Clusters of patients were identified through HIV/AIDS clinics and non-governmental organizations and the Ocean Road Cancer Institute. Systematic random sampling was done to obtain a sample of 40 caregivers from these centres. Appointment was made to meet the caregivers at home where the interviews took place. Among them 19, were caring for cancer patients and 21 for HIV/AIDS patients. Data was coded, entered and analysed using Epi- info 6 statistical computer programme. Frequency analysis was used to identify needs of the caregivers.

Ethical approval was obtained from the Research Ethics Review Committee of Ocean Road Cancer Institute and permission to conduct the study was granted by the City Health Authorities. Study subjects all signed consent forms and for those who could not read or write, the study was explained to them and they placed a thumb print indicating their acceptance. Out of the 40 key family caregivers, 95% were related to their patients either by blood or marriage. There were 24 (60%) females; and 52.5% of all caregivers had secondary and post-secondary education. About 15% and 32.5% had no education and primary school education, respectively. Only two caregivers had no earning activity; 22.5% were housewives, while the remaining 72.5% had a range of activities as employees or were self-employed.

All those caring for cancer patients were aware of the diagnosis, but four among those caring for HIV/AIDS patients described their patients had either tuberculosis, typhoid or were bewitched.

Sixty five percent of the respondents reported to receiving various assistances from a variety of sources. These were mostly from relatives and friends (62%), from NGO/voluntary agencies and faith-based care groups (15% each) and home based care group (8%). It was difficult for the caregivers to give the exact figure regarding the costs involved in the total care of their patients. However, monthly estimates were given based on the money spent for medications, as

summarized in Figure 1. The US\$40 was taken as a cut-off point in reference to the monthly minimum wage for government civil servants in Tanzania.

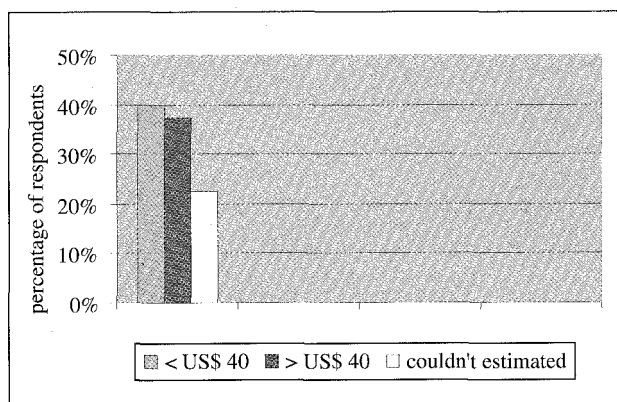


Figure 1: Estimated monthly expenditure on medication

The caregivers expressed a number of difficulties they faced on caring for their patients. Although the majority (44%) of the caregivers faced financial difficulty, a substantial number (25%) expressed concern of having no time for other activities, and 8% indicated they could “do with some relief”

About 57.5% of the caregivers preferred their patients to be nursed at home for the convenience and reduced cost. Twenty percent preferred to care for their patients in hospital or in close proximity to medical services. Of these 17.5% specifically requested discharge home to their villages, when they saw no hope of recovery and preferred death at home. The caregivers identified a number of key issues they needed to be looked into in order to improve their lot (Table 1). The expressed training needs of the caregivers included: how to help terminally ill patients confidently (67.5%); all about terminally ill patients (10.0%); and care for patients with tuberculosis (5.0%).

Table 1 Caregivers' expressed needs

Expressed Needs	% of Caregivers
Financial support	72.5
Free drug supply	52.5
Income generating activity	37.5
Food supply	35.0
Training on caring for patients at home	32.5
Provision of protective gargets	25.0
Get an assistant at home	12.5

Life in an urban setting, particularly in Dar es Salaam City is somewhat different from rural settings in Tanzania when it comes to out-of-pocket expenditures. Most of the services are rendered in exchange for cash. However, the financial constraints are equally experienced in both settings though probably with difference in priorities (Sepulveda *et al.*, 2003; Kikule, 2003). The characteristics of the respondents in this study, most of whom were educated (85%) and employed (72.5%), suggest that they are potential earners but their working or earning time is being compromised while caring for their patients. Although financial concerns were to be expected, these findings underscore the importance of this constraint in the delivery of palliative care in Dar-es-Salaam.

HIV/AIDS pandemic in Tanzania has posed economic burden to most individuals, families and the nation at large, leading to a vicious cycle between poverty and HIV/AIDS (URT, 2001; UNAIDS, 2002). Also cancer in Tanzania is gradually becoming another catastrophic epidemic along with the rise in HIV/AIDS epidemic (Parkin *et al.*, 2003; Ferlay *et al.*, 2001). With a minimum wage of around US\$40 to a common Tanzanian civil servant, the additional burden of illnesses compromises the health of the whole family (UNDP, 2002).

The expressed needs of the caregivers had clear financial implications. There were hardly any who expressed psychological or spiritual needs which together with physical symptoms are the important domains in palliative care philosophy and quality of life. It is to be noted that a number of respondents indicated that their patients were easily tempered. This might be construed to mean that the care givers had psychological and spiritual demands, but further investigation is needed in this area (Sepulveda *et al.*, 2003; Kilule, 2003; Singer & Bowman, 2002).

The African culture of extended families and close friendships poses a strategic benefit for palliative care intervention where families are part of the teamwork (Ankrah, 1993; Kikule, 2003). Families are the immediate consoles to their patients; but are a group of caregivers that are less equipped with knowledge and working materials. Of course no one would expect them to entirely replace a nurse or a doctor. The respondents saw a need of training on how to care for and perform some procedures at home. Definitely the drugs (WHO, 2002b) and protective gargets like gloves and antiseptics are important materials needed at home.

The needs of caregivers of palliative care patients residing in urban areas would probably not differ from those in rural areas though the priorities would differ. However a need for an organized home-based care to meet the needs of both the caregivers and the patients remains a priority. Thanks to the Government of Tanzania through the Ministry of Health-National AIDS Control Programme and Tanzania AIDS Commission for identifying Home-Based Care as a priority under care and support strategy. Though currently the emphasis is more on HIV/AIDS, stretching the continuum of care to include cancer patients is highly recommended. Most of these cancer patients die in agony.

Though the expressed training needs sound broad, it indicates caregivers prefer to know more than most health care providers had imagined. The study did not reveal differences in need between caregivers for cancer patients as opposed to those for HIV/AIDS patients. It is recommended to devise a friendly training curriculum or guide for home-based health care providers to conduct patient-specific training to family caregivers in their homes.

Acknowledgements

I thank Cecilia Sepulveda, Vincent Habiyaambere, A. Marlin and A. Ullrich for their invaluable technical assistance. I am grateful to Florence Temu and Mary Haule of Ocean Road Cancer Institute, F.D. Mtango of Muhimbili University College of Health Sciences, Nandera Mhando of the University of Dar es Salaam and Angela Ramadhani of the Ministry of Health, Dar

es Salaam for facilitating the study. This study received financial assistance from the World Health Organization.

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