



Sources of Support for Primary Home Based Caregivers of Advanced Cancer Patients From AIC Kijabe Hospital, Kiambu County

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Abstract:

Eighty percent of cancer cases in Kenya present at advanced stages, when little curative care can be done and palliative care is their best option of care. Majority of the end of life care in Kenya is done in the home setting, yet little is known about the caregiver's lived experiences and their support systems. A qualitative study was conducted to explore this. A purposive sampling method was used to identify and recruit twelve participants from the Kijabe Palliative clinic database. Data was collected in patient's homes through in-depth interviews and direct observation. A thematic analytic method was used to analyze the data. This paper shall discuss the four main themes that emerged: family members, social and community networks, religious institutions and healthcare providers.

Key Words: advanced cancer, support, home-based caregivers

1. Introduction

The global and local burden of cancer is increasing. It is a leading cause of death worldwide. According to the World Health Organization (WHO), cancer accounted for 8.8 million deaths in 2015 (WHO, 2018). WHO (2018) reckon that 70% of the cancer burden in the world is in sub-Saharan Africa. It is the third cause of mortality in Kenya with an annual incidence of 28 000 per annum, and 22, 000 dying in Kenya each year due to cancer according to the Kenya National Cancer Control Strategy (2011). The Kenya Medical Research Institute (KEMRI), (2011) report that 80% of the cancer patients present in terminal stages. At this stage, curative care is unlikely, and palliative care is their best option.

Palliative care in Kenya has been growing over the past few years. The Kenya Hospice and Palliative Care Association (KEHPCA) 2015-report notes that they have managed to scale up palliative care services around the country. Currently, they have over 60 sites offering palliative care either within a hospital context or as a stand-alone facility. Majority of these offer out-patient services. Only three units offer inpatient hospice services in our setting with a cumulative total of fewer than fifty beds. This ultimately transfers the burden of end-of-life care to family members, who many a time are not well equipped or prepared to handle the challenges that come with taking care of the terminally ill.

The caregiver burden has been described extensively in developed countries and their effects on the primary caregivers. Sternberg, Ruland, and Miaskowski (2010) in their systematic review found more than 200 problems and burdens related to caregiving responsibilities in literature. They were broadly categorized as physical, social, and emotional and the burden related to caregiving. The most common physical problems included fatigue, weight loss, pain, and loss of physical strength, loss of appetite and sleep



disturbances. Anxiety and depression are the most common psychological disturbances.

In Nigeria, Akpan-Idiok & Anarado (2014) found that caregivers of cancer patients experienced different burden levels, with about half of the study participants terming their burden level as being severe. The same study showed that the forms of burden experienced were physical, psychological financial, and social. Streid, Harding, Agupio, Dinat, Downing J, Gwyther L & Selman (2014) interviewed primary caregivers of patients with incurable progressive illnesses, (the majority with HIV, few with cancer) in Uganda and South Africa. They found that one of the significant stressors for caregivers was just day-to-day patient care. Informal caregivers of patients dying at home in South Africa reported challenges with practical functional care. (O'Neilet *al.*, 2018).

The Kenya National palliative care guidelines (2015), advocate for palliative care to be offered by a multidisciplinary team to cater to all domains affecting the patients, caregivers, and their families. They, however, do not mention the players in the multidisciplinary team. The document reads; "Carers shall be provided with adequate resources for patient care. Regular team meetings and social gatherings shall be promoted to help reduce stress and burnout. Supervision, training and support shall be provided to health workers, family and community members." (National Palliative Care Guidelines, 2015, p 22).

2. The Problem

There is a growing cancer burden and majority of patients receive their end of life care at home. With the limited inpatient hospices in Kenya, the burden of end of life care, that is often a 24-hour job, falls mostly on the family members. There is a paucity of literature on caregivers' experiences and their sources of support as they care for the patients. Literature available also shows that overwhelmed caregivers lead a poor quality of life, and it does have a bearing on the quality of care to the patients and with possible lower quality of life for the patient as well (Litzelman, Kent, Mulika & Rowland, 2016). The question begs; who supports and takes care of the caregiver so that they can be able to provide quality end of life care to their loved ones?

3. Literature Review

3.1 Caregiver burden

In this study, a caregiver is defined as an informal, unpaid family member who is responsible for the care of the patients. Caregiver burden, described as the stress or strain that caregivers feel as a result of taking care of patients, has been extensively described both in the developed countries, and there is now emerging literature from the developing countries. Sternberg, Ruland, and Miaskowski (2010) in their systematic review found more than 200 problems and burdens related to caregiving responsibilities in literature. They were broadly categorized as physical, social, and emotional and the burden related to caregiving. The most common physical problems included fatigue, weight loss, pain, and loss of physical strength, loss of appetite and sleep disturbances.

Their tasks usually include assisting with activities of daily living, administering medication, managing symptoms such as pain and watching out for adverse events (Ryn et al, 2011). Other caregiving tasks include home management, meal preparation, and transportation, helping the patient with ambulation, dealing with stool or urine



incontinence, managing finances, and other tasks. Often, the caregivers have more than one task. In the study by van Ryn, *et al* (2015), 21% of the caregivers surveyed took care of at least one other individual and 49 % were still employed.

3.2 Provision of health care at home

Butler & Holdsworth (2013) describe the protocols used to set up and run functional hospice-at home services in England. This is yet to be realized in Kenya as far as the author is aware. A study by Joad, Mayamoi & Chaturvedi (2011) found that the caregivers felt that they would have benefited from the greater physical presence of the healthcare providers in the home setting. This was because they felt inadequate to provide the care their patients needed, and they felt their patients would have received better care from the professionals. Some of the direct medical care such as changing dressing and pressure sores, attending to symptoms like pain and nausea would be easier for a healthcare provider.

3.3 Community-based palliative care

In developed countries, this takes the form of respite care services. There have been efforts to involve the community through community health volunteers in offering end of life care at the community level. In Uganda, Jack, *et al* (2011) reported about the impact of a community volunteer program to HIV/AIDS palliative patients. These were volunteers trained to provide support to patients in their home settings. It was noted to have a positive impact on the patients, families and the hospice team. The Kenya National Cancer Control Strategy (2011) in its document underscores the need to strengthen home-based palliative services. This too is echoed by the National palliative care guidelines (2015). The extent to which this has been achieved at a county or national level is not known.

3.4 Family support networks

Families have traditionally been the bedrock for support of each other during difficult circumstances. However, the realities of the day have challenged this with the rural-urban migration and the higher costs of living. In India, the source of strength and support besides religion is family members (Joad, *et al*, 2011). Streid, *et al* (2014) from Uganda also noted that some caregivers drew a lot of support from their families, communities. This support was in form of help doing day-to-day activities and in material gifts. Those that enjoyed a healthy patient-caregiver relationship also enjoyed rewarding interactions and were less likely to be psychologically distressed. However, this wasn't always the case. In fact, more often than not, the primary caregiver felt frustrated by the unavailability of extended family members and felt isolated.

3.5 Support from spiritual leaders

Majority of Kenyans are religious, with 82% being Christians and 11% Muslims (Kenya National Bureau of statistics, 2013). Many people, in difficult times, turn to religion. Some use religion to explain their illness. Others blame God or whoever Superior Being they worship whilst others draw strength from their religion during hard times. It is not



uncommon in our Kenyan settings to find patients and their families seeking prayer when someone is unwell. Some religious leaders even conduct prayers at the patients' homes, either by invitation of the family or the leaders' own conviction to visit their sick congregants.

In the study by Maree, *et al* (2017), many caregivers said that they turned to religion and religious practices as a coping mechanism. Selman, *et al* (2018) reported that patients and their caregivers' valued spiritual care from both health care providers and religious leaders. Their preferences on who should provide spiritual care were dependent on the individual patient or caregivers' preference, the severity of the distress or the skills of the healthcare provider. Nonetheless, the caregivers expressed desire in having healthcare workers who were competent in the provision of spiritual care, which they felt was a lacking component.

4. Methodology

This was a qualitative phenomenological study. A purposive sampling method was used to recruit patients from palliative care database of end-stage patients on home visitation from AIC Kijabe Hospital. Self-identified caregivers of adult patients with advanced cancers (stage 3 or 4) who are legal adults (over age 18) and understand English or Kiswahili were recruited. The caregivers ought to have taken care of the patients for a minimum of three months.

Once identified and agreed upon, the palliative team contacted the patient or caregiver to establish their availability for a home visit. This initial contact was made via a telephone call. If the patient and caregiver were available for the home visit, the researcher then sought preliminary consent via telephone to do the study in addition to the intended home visit. The researcher informed the caregiver and family that participated in the study was entirely voluntary and should they not wish to participate, the home visit by the palliative team would carry on as planned. Once preliminary consent was obtained, the home visit was scheduled. The researcher and one nurse from the palliative team would go for the visit. During the home visit, the researcher obtained written consent. No caregiver or patient refused to take part in the study.

The in-depth interviews were done in the patients' home for the patient's and the caregiver's convenience. It allowed the researchers to see the patient and the caregiver in context. In all instances, the patients were bedridden in their bedrooms, and the interviews took place outdoors, away from the patient. The interviews, all done in Kiswahili, were digitally recorded using an audio recorder, transcribed and translated into English. The interviews took on average 45 minutes to one hour. To facilitate the researcher's reflexivity, reflective notes were also taken. They included the researcher's reflection and personal accounts of the experience, the frame of mind and feelings, and even speculations about what the researcher was learning and interpretations of the meanings of events and emerging themes.

A thematic analytic process described by Braun and Clarke (2006), a six-stage process, was used to analyze the data. Braun and Clarke describe that the analysis can either be an inductive approach where the analysis is primarily data-driven or it can be a theoretic



process where the process is more analyst driven. Inductive thematic analysis was used, which gave the researcher the liberty to code the data without trying to fit into a pre-existing code frame or the researchers own analytic preconceptions. During the analysis, the researcher tried to keep in mind the anticipated themes as well as the emergent themes as advised by Ziebland and McPherson (2006). The emergent topics are those that were not specifically asked by the researcher but were directly or indirectly raised by the respondents. The anticipated themes were derived from the literature review

The first step was to familiarize with the data by reading and re-reading the transcripts. The second step was to organize the data in a meaningful way and generate codes. As this was data-driven (as opposed to theory-driven), the codes were derived from the entire data set. The researcher did this by highlighting the text and writing notes as different ideas came up. The third step was to search for the themes by collating the codes. The end of this process saw the preliminary development of themes and sub-themes. The fourth step was to review the themes, to specifically ensure that the data support the themes identified. Using the mind map earlier as a framework, the researcher went back to the entire data set to see if there was enough data to support each theme and sub-theme. The fifth step was to name the theme-which was a further refinement of the themes. The sixth and final step was to write the report. Ethical approval was obtained from the Research and Ethics Committees of both Kijabe Hospital and Kabarak University. Confidentiality and anonymity were ensured by using codes, and not the participants' names.

5. Results

Four main themes emerged from the study pertaining to caregivers' support systems.

Theme	Subtheme
Family	Financial support Modernization of the family structure
Social and Community Networks	
Religious institutions	Propagating Hope Role of Prayer
Healthcare Workers	Healthcare at home Phone calls

5.1 Family Members

5.1.1 Financial Support

Finances are often a cause of strain and families often chipped in to help the primary caregiver. For some, it was in the form of helping out with hospital bills, buying medicine and their food. One respondent- a grandson to a patient with prostate cancer said
“ *Our aunty lives in Nairobi- and she is the one who helps with buying the drugs and she brings them home.*” CG 2



In other instances, the extended family came together to financially support one family member (almost like a salary) to be the primary caregiver. In these instances, the caregivers felt that the support was inadequate but did not feel it was appropriate to tell the siblings. This was partly because they did not consider it a “payment” to care for their loved one, rather a token of appreciation. One respondent with a wife and 4 children taking care of his father reported:

“I can’t depend on that alone for my family (the family contribution)... if I got 2-3 hours a day to work somewhere so that I can meet my needs, I would be happy.” CG 1

5.1.2 Modernization of the family structure

In the traditional family set up, extended relatives often shared compound and lived within reach of each other. This has gradually changed, particularly due to rural-urban migration. Sometimes, there is limited or no family support making the caregiving task harder financially and psychologically for the patient and the caregiver.

Caregiver 10 who was taking care of her mother in law reported:

“Other times it is hard because currently she is at my place. And we are many; we are four. When she fell ill, she was brought to my place. Everyone left and went to their own homes, and the burdens were left with me.... Sometimes when they come to visit, they come empty-handed...I am the one to figure out all her meals and how she will stay here.....” CG 10

One of the consequences of this was having to formally organize for times when the primary caregiver would have to be relieved of their primary caregiving duty to attend to their own personal responsibilities.

5.2 Social and Community Networks

The neighbours and community also still play an active role in the care of the patients and the caregiver's well-being. However, the caregivers' expectation for their input is not as great as that for fellow family members. The roles they did were mainly two: Participate in *Harambees* to help financially in the care for their patients. The second was to help in practical chores like laundry, collecting firewood, keeping the patient company so that the caregiver could go the market, etc. One respondent taking care of his grandfather said:

“You see like this gentleman (their neighbor), he comes to give him company so that he may not get bored” CG 2

Another caregiver taking care of her mother with cholangiocarcinoma and bedridden reported:

“Her very close friend comes to wash her on alternate days” CG 11

Regarding support from government officials and leaders, caregiver 6 who was taking care of her husband with cholangiocarcinoma and reported:

I approached the senator, governor, and MCA, who promised to come for the Harambee (fundraising) but did not turn up nor send their contributions.” CG 6

5.3 Religious Institutions

5.3.1 Prayer



Caregivers turned to religion for support and encouragement. They believed that their faith would heal their patients, provide for their daily needs, and give them strength to deal with the day-to-day challenges of caregiving. They also depended on their faith, in a somewhat resigned manner, on the ultimate fate of their loved ones. One caregiver reported that members of her church formed her greatest support network.

“Those who helped me are those with whom we go to church with...My sister in Christ (fellow church member) hosted us while we were in Tenwek...They prayed for us a lot” CG 6

5.3.2 Propagating Hope

Participants in this study expressed a lot of hope in their loved ones recovery. To put it into context, nine out of twelve of the participants had died within two months of the data collection. The church and the religious institutions around Another respondent expressed the confidence she and her family had in God to heal their loved one.

“And we believe God will heal her...God has helped us...God led us....” CG6

Another caregiver taking care of her sister with terminal gastric cancer, who had two children said:

“ we pray that God heals her so that she can raise her children.....Even the church members usually come home to pray for her and they tell her that she will recover....” CG 4

5.4 Healthcare Providers

5.4.1 Healthcare at home

Healthcare providers available in the home setting provided guidance and help to the caregivers, in various forms. These were either nurses or clinical officers that were from nearby facilities or neighbours to the patients that would do house calls. They helped the patients with tasks as dressing changes, administering intravenous fluids, and sometimes just the reassurance that the caregivers were doing the right thing. This came at an extra cost, but the convenience, especially to the patient, was welcome.

“ someone usually comes home and gives her fluids on alternate days because now she is not eating anything” CG 9

“ There is a nurse who comes to help to clean the wound, and now it is clean” CG 8

5.4.2 Phone calls

Caregivers greatly appreciated the phone calls made by the palliative department to check on the patient, and on the caregiver. They found that to be useful particularly in encouraging the patient, which in turn encouraged the caregiver.

Caregiver 4 who supported her sister through pregnancy, and delivery with stage 4 gastric cancer mentioned:

“What I will add is about Kijabe doctors because they have helped her a lot; they even call her on phone.... they really talk to her and advise us.... they have really taken care of her” CG 4



6. Discussion

The principal source of support was from the family members. The neighbors, the community and the church also played different roles that were considered valuable by the caregivers.

6.1 Family

One may infer that it is normal practice for extended family and community to be involved in caring for ill relatives and to support bereaved families. These findings resonate with published accounts of caregivers who reported their expectations of moral support from family and community members and the value of such support in easing their burden of care (Amoateng, *et al*, 2015).

Recent studies in the context of palliative care in Africa argue that modernization, evidenced by rural-urban migration and changes in traditional family structures, has culminated in attrition of extended kinship and community support systems for ill persons (Gysels, Pell, Straus, & Pool, 2011; Powell & Hunt, 2013). This was noted in most of our participants. One caregiver was tasked with the primary role, while other family members were more detached and away in urban areas. The caregivers, in their assessment, felt that there was a lack of family cohesion, and sometimes felt socially isolated from the rest of the family as a consequence of the caregiving.

Regardless of the situation, caregivers chose to care for their loved ones. Reluctance to do so would have been perceived as socially and culturally objectionable. (Mnyaka & Molthabi, 2005). While the fear of being in breach of social and cultural norms might render it difficult for caregivers to openly express their struggles to the rest of their family members, they may felt comfortable enough to express it to the researcher. This was the case in half of the interviews. These findings are consistent with BurrIDGE *et al* (2007) who suggested that failure to disclose reluctance might be indicative of two things: the participants desire to give desirable responses and caregiver reluctance being deemed a taboo topic.

6.2 Social and Community networks

The social and community networks are still present and play various roles in the support for the caregiver. Other supporters tended to be involved in practical activities, such as doing laundry, collecting firewood, bathing the patient, and watching over the patient so that the caregiver can go to the market. This kind of support was considered valuable by the caregivers. It also seemed expected from the caregivers, maybe because of the communal nature of the African society. In America, Cagle and Kovacs (2011) also reported on caregivers receiving support from multiple areas including family, friends, and neighbors.

6.3 Role of religion

Majority of caregivers depended on religion and their faith to help them. Its findings are similar to those of Maree, *et al* (2007) in South Africa who found that almost all caregivers turned to religion for coping. Given the perceived need for caregivers for spiritual support and the perceived absence from health care workers, there may be a role for the church or other religious organization to fill this need. In addition, these findings may identify an educational need for healthcare workers in the area of spirituality and end of life care.



6.4 Other healthcare workers

Caregivers appreciated help from healthcare workers, both in and out of the hospital. Enhanced access to professional advice is a viable way to increase caregiver's confidence in their ability to carry out practical aspects of home-based care. Nurses and other health care workers can provide information and skills training on various aspects need to offer quality home-based care (Bee, Barnes & Luker, 2009).

Caregivers in this study appreciated phone calls from the palliative department or receiving advice or instruction via telephone guide them on what to do. Telehealth has been used in the West to support and guide caregivers and provide online support group meetings (Chi & Demiris, 2015). In a study in Kenya, Uganda, and Malawi, healthcare workers were able to access patients in homes even without running water or electricity to support caregivers through a simple but sophisticated form of telehealth. Even where caregivers did not have airtime, they were encouraged to 'flash' the healthcare providers who would then call back and respond to the patients' and caregivers needs (Grant, Brown, Leng, Bettega & Murray, 2011).

7. Recommendations and Areas for further study

This study recommends training the community health workers, church-based workers, and volunteers and equipping them with simple palliative care manuals that have simple protocols will be a useful way to maximize skills available at the community level, in communication with palliative care nurses, clinicians and doctors. The second recommendation is that family debriefing meetings should be done with the primary caregiver and other support persons where necessary so that they can all be on board on what the patient and primary caregiver needs. The debriefing meetings should include a session/talk on how the other family members should support the primary caregiver.

8. Conclusions

Families, neighbors, religious institutions and other healthcare providers constitute their support system. However, the primary caregivers feel that extended family members should be able to do more to assist them in their role. They all desire for more physical presence of the healthcare providers. There is need to find a way to bridge the gap between what the caregiver's needs are and the resources availed to them.

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