

Financial Toxicity Related to Advanced Cancer Patients' Care: Case study of Selected Households of Kiambu County, Kenya

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Abstracts

Purpose: The aim of this study is to investigate family caregiver's experiences on household financial burden related to cancer treatment/care following referral to a palliative care unit in Kenya.

Methodology: Case study approach was used to collect data from caregivers of advanced cancer patients following referral to a palliative care unit at Kijabe Mission Hospital in Kenya.

This approach is best suited to gain insight into economic implication of the rising cost of cancer treatment which has put a considerable financial strain on affected families, leading to adverse outcomes of caring for patients with advanced cancer. Semi-structured in-depth interviews, documentary data and field notes, observations were used to collect information relating to financial and economic impact of the careburden experiences from theoretical sample of 12 caregivers. This approach enabled an in-depth, multifaceted explorations of complex issues related to in their real-world contexts. The case study method was particularly chosen because of its richness to gain an in-depth understanding of an issue, event, or phenomenon of interest in its natural real-life context. A socio-technical coding matrix was used to analyze qualitative data thematically, along with additional themes that emerged from the data. All ethical considerations were observed accordingly.

Findings – Four (4) male and eight (8) female caregivers interviewed were between 18 to 67 years. The study reports families facing enormous financial strain and difficulties treating their patient with advanced cancer patient. Treating patient with advanced cancer is reported to drain resources threatening to bring vicious cycle of poverty and financial stability. Family members get frustrated at their inability to meet growing demands related to care, treatment and management of their patient in advanced stage of cancer. Financial concerns, catastrophic health expenditure (CHE) and distress financing (DF) as part of devastating effects of cancer, limited health insurance coverage and gaps in financing are among the key concerns identified.

Unique contributions to theory, practice and policy: This study builds evidence towards social and conomic consequences of treating advanced cancer diseases that affect household families and impact on life of patients with advanced cares. Hence, seeks to shape how multidisciplinary cancer care teams' practices to become more aware of the costs of their clinical decisions. Findings of this study also form basis of review of already existing policies related to insurance coverage provided by state agency to tailor it to chronic diseases. Further research is required to mitigate financial toxicity and additional financial safety nets

Key words: *financial burden, cancer, economics, Kenya*

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1.0 Introduction

Globally, the rising cost of cancer treatment has put a considerable financial strain on affected families, leading to adverse outcomes of caring for patients with advanced Cancer(Azzani, Roslani et al. 2015). Kenyans of all ages and socioeconomic backgrounds are adversely affected by Cancer. The majority of cancer cases are discovered at an advanced stage, when treatment choices are restricted, resulting in a poor prognosis and a high death rate(Altini, Solinas et al. 2020). Family members experience financial toxicity related to adverse outcome of treatment of advanced cancer patient.

Cancer mortality rate is reported at 72 percent for people in low- and middle-income nations (LMIC), where the incidence of cancer is lower than in high-income countries but survival rates are also lower(André, Banavali et al. 2013). Many people are sent home to die, and an even greater percentage do not have access to treatment centers. There is an increasing global health care costs related to cancer care due to improved treatment, and advances in care that have turned cancer into a chronic, manageable illness. Cancer care expenses are reported to be in three categories: direct and easily calculated clinical costs (i.e. medical costs); additional financial requirements of living with disease for the patient and their family (i.e. morbidity costs); and loss of income due to premature death (i.e. mortality costs)(André, Banavali et al. 2013).

The escalating expense of cancer treatment has placed a significant financial strain on affected families, resulting in disastrous outcomes and destitution. According to one study, patients in the lowest income quartile and those under the age of 65 have a higher chance of incurring both catastrophic health expenditure (CHE) and distress financing (DF)(Altini, Solinas et al. 2020). Financial toxicity is becoming more recognized as adverse outcome of cancer treatment. In one study to measure financial toxicity among gynecologic oncology patients, shows strong correlation with cancer changing self-reported health status, lower income, unemployment, cervical cancer and treatment with chemotherapy, all these were associated with high financial toxicity(Bouberhan, Shea et al. 2019). In a retrospective population-based registry study in Norway, reported life-time costs were higher for cancers with a 5-year relative survival between 50% and 70%(Chang and Abbott 2016). With the increasing complexity of modern medical therapies, it is becoming imperative to recognize the marginal cost and gains of increasingly sophisticated (and expensive) interventions. By understanding the incremental cost of a given intervention, investigators must help answer questions about healthcare resource utilization that are not answered by randomized clinical trials(Chang and Abbott 2016).

In one study in India on financial toxicity reported determinants of financial toxicity reported several contributory factors including household income, type of health-care facility used, stage of disease, area of residence, age at the time of diagnosis, recurrent cancer, educational status, insurance coverage, and treatment modality(Boby, Rajappa et al. 2021). Financial toxicity is also reported to be associated with poor quality of life, accumulation of debts, premature entry into the labour market, and non-compliance with therapy. Studies have reported cost-coping techniques, including postponing or skipping care, were strongly related with high financial toxicity. Many responders reported high levels of financial toxicity among highly insured gynecologic oncology patients(Chang and Abbott 2016, Altini, Solinas et al. 2020).

Studies reviewed on cost-effectiveness analysis in cancer care report feasible models, initiatives and strategies that cushion families against financial toxicity(Chang and Abbott 2016, Carrera, Kantarjian et al. 2018, Altini, Solinas et al. 2020). Proposed ways include continued funding of biomedical research and pharmaceuticals that will be more objective on establishing return on investment for any given treatment modality, and cost-effectiveness analyses that will be instrumental in providing solutions to the inequalities in healthcare delivery. Factoring in changes in the way costs are distributed between carers and delivery services, changing patterns of service delivery, and the direct contribution patients will make to treatment costs in terms of co-payments and escalating costs of comorbidity in elderly populations have also been reported(Chang and Abbott 2016). It is widely reported that the future cancer expenses will be reliant on future cancer incidence, changes in death risk, and cancer-type specific costs, according to scenario models(André, Banavali et al. 2013, Bugge, Brustugun et al. 2021). It is said that treatment costs will also be gender and cancer specific. These factors are therefore critical for assessing equity of care and better understanding resource consumption associated with various cancers.

Literature reviewed report financial toxicity and economics of treating cancer greatly impact on the household families living with patient with advanced(Carrera, Kantarjian et al. 2018, Bouberhan, Shea et al. 2019, McMullen 2019, Boby, Rajappa et al. 2021). More specifically, African countries are hardly hit with resource-constrained settings. Therefore, multidisciplinary cancer care teams to be more aware of the costs of their clinical decisions on patients with advanced Cancer(Altini, Solinas et al. 2020). There is need for evaluation of implications of clinical decisions on patients receiving diverse treatment care modalities and specifically disease-specific cancer care pathways related to surgical, inpatient and day-hospital medical admissions, radiotherapy, drugs, outpatient care, emergency admissions, and home and hospice care. Thus, resource constraint-adapted therapy techniques are urgently required. One study has highlighted the need for adapted metronomic chemotherapy to address the growing problem of cancer in resource-limited countries(Bouberhan, Shea et al. 2019). Metronomic chemotherapy is a type of long-term chemotherapy. Chemotherapy is given on a regular basis at low, minimally harmful doses. It has recently emerged as a method of administration with no extended drug-free breaks. Metronomic chemotherapy is suggested as a viable alternative for controlling advanced or refractory cancer

As observed, Cancer places a considerable financial impact on families. Hence, patients' out-of-pocket (OOP) expenses should be reduced by strengthening the existing public health system. Furthermore, increased risk pooling mechanism coverage should be ensured. There is need for urgent strategies to mitigate financial toxicity among patients with cancer especially in the most deprived sections of society(Boby, Rajappa et al. 2021). This study could provide a basis for the development of such interventions to reduce financial toxicity among patients with cancer. Effective cancer service planning and a thorough examination of the economics of care delivery have been explored in developed countries, so far there are limited, or least non-existent studies done in Kenya. This study therefore seeks to explore economic and social consequences of advanced cancer patients among selected households in Kenya. It is expected that this study will set evidence for more studies in future to unveil household

financial burden related to cancer treatment while weighing costs and benefits of some clinical decisions as far as economics of cancer care/treatment is concerned.

2.0 Methodology

Using case study approach, we set out indepth interviews to investigage and better understand the patient journey and the direct and indirect costs families face, as well as the difficult decisions and choices they must make, and the socio-economic and psychological consequences of having a family member diagnosed with cancer. A case study is a research method used to develop an in-depth, multifaceted understanding of a complex issue in its real-world context. It is a well-established research design that is widely used in many disciplines, particularly the social sciences. A case study is an empirical investigation that investigates a contemporary phenomenon in depth and within its real-life context, particularly when the boundaries between phenomenon and context are unclear(Yin 2009). Green and Thorogood have further explain case study as an in-depth study undertaken of one particular 'case' which could be site or an individual(Green and Thorogood 2009). With this context therefore, case was selected households within Kiambu County having patients with advanced cancer following referral to a mission hospital in Kenya. Case studies, according to Yin, can be used to explain, describe, or explore events or phenomena in their everyday contexts(Yin 2009). Thus, aid in understanding and explaining causal links and care pathways that arise as a result of financial constraints while treating patients with advanced cancer. We recruited theoretical sample of 12 self-identified caregivers (cases) of adult patients with advanced cancers (stage 3 or 4) who were receiving follow-up care at Kijabe palliative care clinic. The in-depth interviews were conducted in the patients' homes for the convenience of both the patient and the caregiver. It enabled the researchers to observe the patient and caregiver in their natural environment.

Carefully formulated research question(s), informed by existing literature, and an understanding of the theoretical issues and setting(s) are all important in appropriately and succinctly defining the case(George and Bennet 2005). Importantly, each case had a pre-defined boundary that clarifies the nature and time period covered by the case study (i.e., its scope, beginning and end), the relevant social group, organization, or geographical area of interest to the investigator, the types of evidence to be gathered, and the priorities for data collection and analysis(Stake 1995).

In this study, the case was chosen not because it is representative of other cases, but because of its uniqueness, which was also the researchers' interest. This was the case, for example, in our study of patients with stage 3 and 4 (advanced Cancer) who were referred to palliative care. A number of cases were carefully selected in collective or multiple case studies which gave an advantage of allowing comparisons across multiple cases and/or replication(Stake 1995, George and Bennet 2005). This study attempted to get a "typical" case though with some limitations. By selecting a "typical" case, the findings may be generalized to theory.

In conducting case study, Stake describes critical step of having the research team accessible to the individuals and referral unit (palliative care unit), processes or other elements that made up the study's chosen unit of analysis at the site for the case study. Therefore, accessibility was crucial. The researcher had to know the sites well and cooperate with participants(Stake 1995). Case study research has occasionally come under fire for missing scientific rigor and offering little support for generalization. However, in this study, there several strategies that were put in place to address these issues for instance the use of theoretical sampling (drawing on a specific conceptual framework), respondent validation(Yin 2009). In the study we had participants' review emerging findings and researcher's interpretation giving their opinion on whether they felt these were accurate records and openness through the research process.

Thematic analysis was carried out following analytical procedure which involved repeatedly going over and organizing the large, rich detailed data. Prior to drawing comparisons between instances in collective case studies, it can be useful to analyze data pertaining to the invidual component case. Variations within each case was taken into consideration, as well as the connections between various causes, effects and outcomes of financial constraints on patients receiving care, treatment and support for advanced cancer following referral to a palliative care unit at a mission referral hospital(Miles and Huberman 1994). This was necessary to organize and code the data so that the essential issues- both those that come from literature and those that emerge from the data base can quickly be retrieved in the future. Ethical considerations were considered. Participants were kept anonymous, and their confidentiality and privacy were respected. All participants provided written consent and participated in the study voluntarily. Kabarak University's Ethical Review Committee and the National Commission for Sciences and Technology Kenya (NACOSTI)-NACOSTI/P/19/75630/27563-approved the study.

3.0 Findings

Lincoln and Guba report need to give the reader enough background information when reporting findings case studies so that they may comprehend the procedures taken and the reasoning behind conclusions (Lincoln and Guba 1985). In this study, we decided to report the findings from individual cases in a collective case study individually before combining information from many cases.

The male caregivers were 4 and the female caregivers were 8. All the study participants and their patients were Christians. None of the caregivers had tertiary level education; they either had primary or secondary school education. The youngest caregiver was 18 years old, and the oldest was 67 years old. The caregiving duration ranged from four months to two years as shown in table 1.

Table 1: Demographic details for the patient and caregiver

#	Patient Gender & Cancer	Caregiver age, Gender	Relationship	Duration of caregiving
1	79, M Prostate Cancer	53, M	Son	5 Months
2	75, M Prostate Cancer	21, M	Grandson	1 Year
3	89, M Metastatic Pancreatic cancer	41, F	Daughter	4 Months
4	32, F Gastric Cancer	26, M	Sister	1 year
5	63, F Esophageal Cancer	67, M	Husband	16 Months
6	40, M Cholangiocarcinoma	37, F	Wife	10 Months
7	84, F Metastatic Lung Cancer	42, F	3 rd Wife	8 Months
8	75, M Prostate Cancer	18, M	Grandson	18 Months
9	60, F Cervical Cancer	62, F	Sister	14 Months
10	67, F Esophageal Cancer	35, F	Daughter	2 Years
11	77, F Cholangiocarcinoma	41, F	In law daughter	1 Year
12	66, M Duodenal Cancer	61, F	Wife	10 Months

Above table shows patients and caregivers' characteristics

3.1 Experiences of Financial Toxicity among Patients and Primary Caregivers of advanced Cancer in selected households in Kenya

Study participants reported financial concerns, catastrophic health expenditure (CHE) and distress financing (DF) as part of devastating effects of cancer, limited health insurance coverage and gaps in financing are among the key concerns identified. On selected household families with patients and their caregivers of advanced cancer patients, families strained financially partly due to the lack of income from both patient and the caregiver, with additional healthcare costs. Often, the caregivers have to leave employment or farming as much as they would so that they can dedicate more time to the patient.

The reasons for visiting different hospitals varied; sometimes it was referrals from the smaller healthcare facilities, other times it was due to financial constraints. Caregivers reported their experiences:

“We started going to hospitals we went to Kiambu general, we went to Aga Khan, Kiambu, and we’ve gone to radiant, we went to Nairobi west, we’ve gone to many hospitals. In that process, someone suggested to us Kijabe hospital” CG 2

“ It has been 2 years of spending a lot of money.” CG10

“ Sometimes its abit difficult to get medicine, like this called Bicalutamide is hard to get it. There is no place to get it here in the rural areas, so we have to go to Nairobi to get it. And its expensive....” CG2

Concerning their financial sustainability and future, one grandson reported anxiety related to inability to repay borrowed finances to treat their family member:

“Cucu (my grandmother) has taken many loans to be able to care for them, and they have defaulted on the payments. I am scared that one day soon this land or some property will be auctioned” CG 8

In other cases, some family members suffered economic impact secondary to caregiving. Some family members were preoccupied with caregiving which stopped other engagements and their normal work or business they do for their living hence resulting in inability to meet day-to-day demands of life:

“...The time I would have spent looking for money is spent here taking care of her... I don't have a house help who could take care of her because I don't have money to hire one” CG 5

“If I could have 2 or 3 hours a day to do my own work, it would really help me financially. For now I cannot depend on anyone in the family I have to make sure he has eaten and taken his medication. So I cant go out for long....” CG1

“you see, I cannot to go to work now, I must first take care of him” CG2

“My farm is just bare, yes even here there's one of my own that is not ploughed, because of the work of taking care of him.... I even had a hotel I was operating, hotel business is good, but I had to stop it” CG8

“I used to farm pigs, chicken, but now I could not go on with it” CG9

Caregiver 5 who was taking care of his wife advanced esophageal cancer which required repeat esophageal stenting sold properties to finance treatment of cancer patient:

“I had cows that I have since sold one after the other so that I do not disturb my children. I have sold everything that I had. Goats, cows, everything is over because of this sickness because I have spent a lot of money..... I thought NHIF would help me, but it has not helped me much because I have still sold my property CG 5

A 60-year-old caregiver who left her marital home to care for her sister with advanced cervical cancer reported difficulties in accessing state-agencies (insurance) to help meet financial obligations related to treatment of their family member:

“She missed a chemotherapy session because the approval hadn't yet gone through...the next time we paid cash so that she doesn't miss another dose.... I had to make several trips to the NHIF head office in Nairobi to request them to pay for the radiotherapy and for the second type of radiotherapy that was directed to the uterus” CG 8

Poor pain management & quality of life due to financial toxicity was also reported among all families with advanced cancer patients. The impact of the financial strain was felt on two levels. The first was on the caregivers' families and their day-to-day needs. The second was on the impact of the care that the patient received, including their pain management.

All the patients we visited had morphine syrup in their houses. However, we noted some patients and caregivers rationing the morphine-either giving a lower dose or longer durations so as to “stretch it out” as much as possible. Most of them also had with them lactulose, and only two caregivers mentioned challenges with constipation. The principal concern, however, was the cost of the morphine and the other drugs.

One caregiver whose patient was on morphine and lactulose reported:

“This time around, the drugs were a bit hard to get. It's hard sometimes because we are not well up financially...it has been 2 years of spending a lot of money” CG10

Another caregiver cited inability to attend events and meetings organized by the palliative department due to financial and logistical challenges.

“We didn't make it come (for the support group meeting), because we had come for clinic two days before that day. So we couldn't manage to come that soon” CG 1

Other families helped significantly with the finances. Some family members came together to financially support one family member to serve as 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

With families living with advanced cancer patients, fund raising arrangements is quite common approach to pulling resources to meet financial demands of treatment.

Reflecting on the support from community, 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 Harambee¹ (fundraising) but did not turn up nor send their contributions.” CG 6

In some other cases, some caregivers suffered economic impact of treating cancer to the extent that they had to borrow money from friends, community and from charity to help support their family member: -

“One time she got a stent at 9 am, yet we left the hospital at 5 pm yet we do not live far from the hospital. . She even thought I had forgotten her. It was because I had to look for money, and the people you are asking to lend you money are the same ones you have asked before. I looked for money until she was released in the evening.” CG 5

“ I loved him, but I did not have the money. I did not know what to do . I talked to the villagers and his uncles.

“ But the time I would have spent looking for money is the time spent here taking care of her” CG 4

Almost all caregivers felt that if there was a way that the financial burdens could be relieved from them, they would be able to deliver better care, feel less overwhelmed and they would be more present to care for their loved ones.

4.0 Discussion

The financial burden was a dominant theme. The reasons for the financial strains included increased healthcare costs and loss of income from both patients and caregivers. This was exacerbated for families already living below Kenya’s poverty line. In response to the question of what else could help them, the majority wished that there was a way to either relieve them of the health care costs or if they could get access to extra finances. Nayak and his colleagues recommended reducing the economic burden on oncology caregivers as one of the measures that could improve caregiver’s quality of life(Nayak, George et al. 2017). The availability of financial resources would afford caregivers more time to care for their loved ones, and not have to worry about looking for food, medicine, and other essential necessities.

The role of insurance in reducing this burden deserves special ` mention. The Kenya National Health Insurance Fund is making some strides in its attempt to cater to cancer care, particularly in terms of diagnostics, chemotherapy, and radiotherapy. However, its inefficiencies continue to cost some patients early and timely access to interventions and treatments. Its role in accessing palliative care services is also yet to be fully explored. Regardless of whether one is in the developed or developing countries, or socio-economic status, a cancer diagnosis has a significant impact on the patient and affected family(Azzani, Roslani et al. 2015). The impact of the financial strain in our setting that was particularly startling was ‘morphine rationing’. All patients had morphine in their houses, but either took inadequate doses or at longer time intervals so that the drug ‘doesn’t run out’. Another financial limitation was the quality and services that they could access, including support group meetings.

¹ *Harambee* is a Kiswahili word that means “to pull together.” It is a Kenyan tradition where communities come together to raise funds for a charitable cause.

This was similar to a Tanzanian study where caregivers expressed challenges in accessing the medication either as a result of cost, transportation or availability. Caregivers in that setting often sold their possessions or take on additional responsibilities in order to make enough money to pay for the medication (Walker 2011). The disease has the potential to induce or worsen poverty. Studies from the west have shown caregivers sometimes even declare bankruptcy as a result of caregiving-related costs (Singh, Chauhan et al. 2020). In this study, we saw one caregiver who had defaulted on loan repayments and lived in fear of their property being auctioned, and other caregivers selling land and livestock to raise funds necessary for treatment and care. This then leads to a vicious cycle.

6.0 CONCLUSIONS & RECOMMENDATIONS

The caregiver burden for advanced cancer patients in this setting is due to financial strains. At the policy level, Kenya should be reviewed to ensure the NHIF cover to provide affordable, accessible & sustainable medical cover to all for diagnostics and treatment should be made easier for patients with cancer. The study also seeks to shape how multidisciplinary cancer care teams' practice and becoming more aware of the costs of their clinical decisions.

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