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Social-Economic Support Care Needs among Cancer Patients Attending Hospice/Palliative Clinic at Meru Level Five Hospital, Kenya

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Abstract Globally, cancer patients and care givers experience numerous social economic needs that range from and are related to financial constraints, transportation obstacles, accommodation, poverty and inflexible working conditions, non-availability of services, socio-cultural and gender-related factors among others. To establish the socio-economic supportive care needs among cancer patients attending hospice/palliative care clinic in Meru level five Hospital (in Kenya), a descriptive cross-sectional study design that adopted qualitative approach in data collection was used, with purposive sampling being applied to select the study respondents. To collect data, the researcher conducted two focused group discussions (one with male patients only and another one with female patients). Two sets of interviews were conducted (one interview with the cancer patients and another one with the key informants). Interview schedule was used to collect data through interview till redundancy was achieved, while focused group discussion guide was used to modulate focused group discussion. All interviews were recorded and transcribed. The study employed thematic qualitative data analysis where processing and analysis of qualitative data was carried out. Descriptive analysis was computed to analyze quantitative data and presented in form of tables. Qualitative results were presented in narrative with selected compelling exemplar quotes from the interview. A total of 22 respondents participated in the study, among which 19 of them were cancer patients while three were key informants working in the hospice clinic. The study findings revealed that cancer patients experienced numerous socio-economic supportive care needs. The needs ranged from high cost of treatment which are overwhelming and sometimes unbearable, National Hospital Insurance Fund (NHIF) challenges, financial constraints, travelling for long distances to access cancer related services, poor road network, lack of accommodation, stock out of essential medications and inadequate infrastructures. Therefore, the government should ensure improved health insurance cover, improved infrastructure in the cancer centers and decentralization of cancer services. The government should also carry out outreach services to reach those who live far from the cancer care facilities.

Keywords Cancer, Socio-Economic, Supportive Care, Needs

1. Introduction

1.1. Background of Study

Globally life expectancy for cancer patients which is coupled with poor quality of life has increased sharply, with more than 70% of these patients being unable to afford treatment and quality supportive care [1]. Unmet social economic needs among Arabs-Americans were established of which a significant percentage (52%) of patients who receive cancer diagnosis do not initiate or complete treatment due to inability to afford care services [2]. In Sub-Saharan Africa, cancer patients from rural areas and isolated urban centers encounter more challenges associated with their social economic lifestyle [3]. This has been associated with poverty among the patients. In addition, the sub-Sahara Africa, minimal resources and shortage of qualified work force are common and the major focus is in preventive and curative only [4].

In Kenya, it is estimated that 40,000 Kenyans are diagnosed with cancer annually while more than 27,000 Kenyans die from cancer within the first two years post-diagnosis [5]. Despite this cancer burden, the few consultants on oncology in Kenya are concentrated in major towns. This results in socio economic challenges to cancer patients since they are not able to get cancer treatment and other services timely. The high poverty index and lack of

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enough cancer treatment facilities leads to high cost of treatment in Kenya. Likewise, provision of palliative care for cancer patients revealed that more than 50% of Kenyan live below poverty line, which leads to financial constrains in accessing services for diagnosis, treatment and follow up for most of the patients [6]. As a result, 50% of cancer patients forego treatment due to challenges associated to socio-economic [7]. Similarly, in their efforts to access treatment, sometimes the cancer patients have to use their little savings, hence seeking and navigating care can be burdensome [8]. To mitigate against this burden and suffering experienced by cancer patients, the Kenya Health Policy framework (2012-2030) aims at establishing effective cancer management by enhancing supportive care. This motivated the conducting of this study to establish the socio-economic need experienced by cancer patients attending Meru Hospice Clinic in Kenya.

1.2. Research Objective

To establish the socio- economic care needs among cancer patients attending Meru Hospice/palliative Clinic at Meru level 5 Hospital in Kenya.

2. Methodology

2.1. Study Design

Descriptive cross-sectional study design that adopted qualitative approach in data collection was used. Descriptive design enabled collection of data as it was, hence describing the phenomena without influencing it, while cross section study design helped in collecting data at that one specific point in time [9]. Qualitative method was relevant in providing in-depth, detailed information based on an individual's experience, to identify unexpected outcome and to document interactions and responses [10].

2.2. Sampling and Recruitment Procedure

The study employed purposive sampling technique to select the study respondents for both individualized interview and for the two focus group discussions (FGD). A sample of six participants was selected for each focused group discussion. The size of the group was ideal to ensure that the group was small enough to enable all members to share their thoughts and yet large enough to create a diverse group [11]. First FGD was composed of male participants only while the second group was composed of female participants only for purposes of homogeneity. This approach of sampling enabled the researcher to select respondents who gave in depth information. This led to in-depth understanding of the supportive care needs for cancer patients. Census was used to select the four medical staff. Census method was appropriate due to the small sample size of the key informants. Recruitment of respondents was done with assistance of the nurses and oncologist who were working in the palliative clinic because of their prior knowledge about the patients.

2.3. Ethical Considerations

Prior to this study, the researcher got approval from all relevant institutions. Respondents were allowed to participate freely without coercion. Information sheet containing the purpose and content of the study was availed to the participants in order to make an informed consent. The researcher also ensured confidentiality of the information by ensuring that no details of the participants appeared on the transcript. Instead of the participants' names, unique codes were used. Additionally, there was no conflict of interest from the authors regarding publication of this study.

2.4. Data Collection

To collect data, the researcher employed two focused group discussions and a structured interview to both key informants and the patients. A common date was set for those who were to participate in the focused group discussion. The discussion lasted approximately one hour. The individualized interviews lasted between 25 and 35 minutes and were done till saturation of information was achieved. Saturation was achieved when no new information was coming from subsequent interviews and when further coding was not feasible. This was reached after 9 interviews. During data collection, ethical issues were adhered to my ensuring privacy and confidentiality through individualized interview and carrying out interview in a private room. The information from both interview and focus group discussions was recorded using a voice recorder and short hand written notes taken.

2.5. Data Management

The study employed manual thematic data analysis approach which followed the six phases as outlined by Braun and Clarke (2006) [12]. These included; familiarization, code generation, coding, reviewing of themes, defining themes and producing the report. Familiarization with the data was done which involved manual intelligent verbatim transcription of qualitative audio recorded data, followed by reading through the transcript severally in order to get familiar with the data. Generating of initial codes was done by coding each segment of data set that captured important information about research questions. Codes of similar aspects were collated into a broader theme which was deduced in line with the objectives of the study. Reviewing of themes was done to find out whether they were in harmony with the coded extracts after which defining and naming of the themes was done to refine each theme and then overall analysis, generating clear definition of theme names. In the final phase, report production was carried out by interpreting and explaining the data followed by descriptive narrative presentation of the results from both FGD and individualized interviews. Quantitative data was analyzed using descriptive statistics and presented in a tables.

3. Results

3.1. Socio-economic Needs among the Participants

The study sought to establish the socio-economic needs among the cancer patients attending oncology clinic at Meru level five hospital. The social economic needs identified included high medication cost, challenges in health insurance (NHIF), high transport costs, high cost of accommodation and frequent hospital visits. Other needs included inadequate medical resources and services, inadequate infrastructure, travelling long distances to seek health care and poor road network to the health facility. These are described in sections 3.1.1 to 3.1.7.

3.1.1. High Cost of Medication among Participants

All the participants reported that the high cost of medication was overwhelming and sometimes unbearable. One of the participant lamented how all her income was depleted due to the bank loan he acquired to finance her treatments

"I struggled to raise money…My income was depleted by this illness… no money… I took bank loan seven years ago which I have never fully paid..." (Participant 1).

On the same aspect another participant reported how he was unable to raise money for chemotherapy in one of the private health facility.

"After a scan, I was told that there is fluid in my chest…..thus the need to start more sessions of chemotherapy at a cost of Kenya, shillings (Ksh) 57,000 per session which I was to pay in cash. …..I was unable to rise that money…I went home. This is because I had exhausted my health insurance (NHIF) cover" (Participant 4).

Yet another lamented:

"The cost of treatment is high…like I take tamoxifen which I buy at ksh 150 per a tablet" (Participant 2).

On the same issue a participant in FGD said;

"There is this medication which I take every 3 months which cost me ksh 19000 every month. I need ksh 9000 to buy medication" (Participant 1 FGD).

These complaints by the participants were supported by one of the key informants who stated;

"Medication is a bit costly like some of the patients (especially for breast cancer) require a tablet that cost around ksh 190 per tablet that is 84 tablets in a month and should be continuous…. We are sticking to first line therapy only…Second line is too expensive for patients" (Key informant 2).

She further explained the cost of treatment as follows:

"Some patients are unable to pay for drugs in private chemists when there is stock out in our facility. This leads to missing out of medication ….actually some miss medication for months because they cannot afford to buy the drugs from private chemists. Other patients go home and keep calling you to ask whether drugs are available..... I had a prostate cancer patient who stayed for months without medication, hence disease progression" (Key informant 2).

3.1.2. National Hospital Insurance Fund (NHIF) Challenges among the Participants

Majority of the participants raised challenges related to the insurance cover (NHIF) which leads to delayed treatment. The same sentiments were echoed by the key informants and again during focused group discussion, as stated by one of the participants;

"Several scans were requested....but NHIF officer refused to approve the two scans……instead they approved only one" (Participant 2).

On the same issue, participants explained how they were unable to get treatment because they had exhausted their NHIF cover.

"Sometimes you are told that you have exhausted your NHIF thus you need to spend money …like I had exhausted mine in February.... I spend a lot of money from then till June… I spent a lot of money.....I almost gave up" (Participant 8).

Similarly another participant stated;

"After a scan I was told that there is fluid in my chest and I needed to start more sessions of chemotherapy at a cost of Ksh 57,000 per session which I was to pay in cash. …. I was unable to raise that money…I went home. This is because I had exhausted my NHIF cover" (Participant 4).

Another participant said that they sometimes miss treatment because of the delayed NHIF approval.

"Sometimes you miss your chemotherapy administration due to delay in authorization of NHIF… I was told to do MRI scan but is not yet done because NHIF did not approve it… I don't know why it is not approved even now… This long waiting for approval is leading to much suffering" (Participant 6).

On the same issue, another participant lamented;

"I have spent a lot of money because my NHIF card is not working, everything I pay in cash…like now am not sure what I will be told because am hearing it is a lot of money" (Participant 3).

Another participant made suggestion on NHIF cover services.

"On NHIF cover, there should be no waiting time for card to mature, you should be allowed to use it immediately you register and apply for the NHIF card. Choosing of the hospital should not apply to the cancer patients, they should be allowed to be treated at any outpatient service provider. Seeking for prior authorization by the insurance provider should be abolished for all cancer related services to avoid

delaying treatment time" (Participant 1).

3.1.3. High Transport Cost among Participants

High transport cost also contributed to social-economic support care needs for cancer patients. One of the participants stated;

"Transport to Kenyatta and back is high, (in case you are referred)…..... remember you can't go alone …… you incur transport expense for two persons every time you go to the hospital. If a patient is very ill, there is problem with transport like now see we are waiting for a taxi to come" (Participant 4).

Yet another participant lamented;

"Coming for treatment is a problem due to lack of bus fare which is around ksh1200 per trip" (Participant 5).

During the focused group discussion, one of the participants had the following to say about transport cost;

"Transport and accommodation is a problem because I come from far…. I come from Timau…I spend ksh 400 per day……. this is too much for me" (Participant FGD 1).

On the same issue, one of the key informants stated,

"We attend to patients from very far distances…. remember some patients can't come alone because of the illness….they are escorted by their relatives..… this is double cost of transport to the family" (Key infomant 1).

3.1.4. High Cost of Accommodation and Frequent Hospital Visits among the Patients

High cost of accommodation and frequent hospital visits was raised by several participants and also key informants. One of the participants stated;

"Like now I was told to undergo mammography…. I will have to come another day for booking and approval by NHIF, all that is cost" (Participant 1).

On the same aspect, another one stated;

"We were here yesterday but we were told to come today… we have arrived and told to come next week… We can't be seen because we had no appointment and patients are many…. all the same I have been given an appointment for 29th of January 2020, which is far way. We are worried because this scan is valid for one month thus we might be forced to come and do another one…. This has affected me a lot" (Participant 4).

Accommodation and frequency of hospital visits was validated by the key informants. One of them said;

"Accommodation is another challenge because patients are forced to be here for 3 days before everything is done. These patients are sometimes told to come biweekly or monthly which is very costly. Due to high cost, some patients are unable to return back for treatment…. For example when patients are sent to Nairobi they end up not going because they have never been there…. they don't have anybody in Nairobi to accommodate them. … they refuse to go saying they don't know Nairobi this leads to loss of follow up… They do fund raising to raise fund for treatment" (Key informant 1).

On the same aspect, another key informant also stated,

"Sometimes they may come on Tuesday to do laboratory work and again on Wednesday for review then come again on Thursday for chemotherapy administration. This lead to a big accommodation issues. Sometimes we have patients who sleeps in the hospital awaiting treatment… Some sleep at the waiting bay others in the MCH clinic which is a bit sheltered (laughing), but otherwise we have patients who sleeps at the corridor awaiting treatment (Key informant 3).

3.1.5. Inadequate Medical Resources and Services in the Hospice Clinic

Participants reported to have been told to buy some of the medical resources and outsource service due to the lack of the same in the facility. This has contributed to support care needs. One of the participants explains how he bought biopsy kit which was not available in the hospital. She stated;

"Biopsy kit was not available…. I had to buy it at kshs7000 from Meru town while examination of the biopsy costed ksh 4000 which I did not have. I got it as a debt from my friends" (Participant FGD 6).

On the same aspect, one of the key informants stated;

"There are services that are not available in the hospital…. such services like endoscopy,, specialized surgical procedures, specialized blood tests, imaging tests and radiotherapy" (Key informant 3).

On the same issue another key informant said;

"Patients are referred to Kenyatta National Hospital for radiotherapy because we can only offer chemotherapy and surgical services... The machine needs to be of high quality…. like we have an magnetic resonance imaging (MRI) machine that cannot do pelvic scanning among others" (Key informant 1).

Yet another key informant stated;

"The main challenge is stock out… We tell them to buy drug outside but it is only one chemist that stock chemotherapy drugs in Meru…. if not in Meru, they can only get it from Nairobi… like we are sticking to first line therapy only. This is because second line is too expensive for patients" (Key informant 2).

3.1.6. Inadequate Infrastructure in the Hospice Clinic

Inadequate infrastructure entailed lack of good layout of the hospice clinic and physical structures, a situation which leads to suffering of patients. This contributes to support care needs for cancer patients. One of the key informants

summarized inadequate infrastructure by the statement below.

"There is only funding for drugs that are available… We have a waiting bay that was donated but there are no enough seats for patients… like during chemotherapy day….. the place is very congested….. We need to have a unit where we have good patients' flow….like patients are moved around because services are not under one roof…. There is no ablution block for this unit….. they go to casualty or those which are down there…. there are a bit far because like when we are administering chemotherapy they keep on going to the washrooms due to hydration" (Key informant 1).

On the same aspect, another key informant said;

"Infrastructure is a very big challenge… like now I am actually supposed to be talking to the patients but there is no room for me to attend a client in" (Key informant 2).

Similarly, one Participant stated,

"We stay in the queue for so long and there is nowhere to sit on. Enough seats are required in various places like at the pay point and laboratory" (Participant FGD 2).

Yet another participant in FGD said;

"Sometimes there are no seats on the queue thus you have got nowhere to seat" (FGD).

On the same aspect of infrastructure, another participant said;

"No toilets around… Urine start dripping before you gets to the toilet. We need all services under one roof, medication, and laboratory" (Participant 4).

3.1.7. Long Distance Covered by the Patients and Poor Road Network to the Facility

Another challenge was the long distance covered to access services. This was evident from the statement made by all the categories of the participants. One of the key informants stated

"They come from within the county and outside the county but many a times there are those who come from the village, 150 km from here…. you find that if it has rained heavily patients may show up late or may not be able to show up at all because the bodaboda (motorbike) they use to get to the main road may not be able to get to their homestead thus patients may not be able to walk" (Key informant 3).

Similarly another key informant said;

"We attend cancer patients from very far distances …. Meru teaching and referral hospital is the only hospital around….offering cancer treatment. Considering the distance of sometimes more than 500kms" (Key informant 1).

On the same aspect, one of the participants stated;

"1 come from far (Kianjai)… I sometime come to the hospital for three days in one week… I spend ksh 500 each time income here ….per week is ksh 1500." (participant 4).

4. Discussion of the Results

The findings of the study showed that the high cost of treatment is overwhelming and sometimes unbearable. The high cost of treatment is attributed to high cost of medication especially when there is stock out, investigations, frequent visits to the hospital, transport, meals and accommodation because of distance to the facility. All of these necessitate out-of-pocket expenses. This is in line with the study by the national research which indicated that cancer patients have got higher financial needs [13]. Cost of medication, transport and accommodation was evidently a big concern for the cancer patients. This was attributed to the fact that majority of the patients live in rural areas and far distance from the facility thus frequent visits to the hospital and high transport cost increases the cost of treatment. This is in line with another study which further stated that in Kenya, those who live in remote areas travel a hundreds of kilometers to seek medical service [14]. Those patients who travel from rural areas may incur huge amounts of money in transport, accommodation and food which can exceed treatment cost [10]. The study further showed that some patients were unable to afford treatment due to lack of money. This is line with a study on unmet social economic needs among Arabs-Americans that indicated a significant percentage (52%) of the cancer patients who receive cancer diagnosis do not initiate or complete treatment due to inability to afford care or fear of financial catastrophe which results to non-attendance to diagnosis, delay and abandonment of treatment among patients with early cancer symptoms [2]. It is also in line with another study conducted in Lincolnshire which indicated that patients from rural areas endure much suffering on the socio-economic domain especially where patients have to travel long distances to access services leading to practical, emotional and financial challenges [3]. NHIF challenges experienced by cancer patients include delayed approvals and exhaustions of the cover before the year ends, hence missing of treatment services.

The study also revealed that hospice/palliative clinic had inadequate infrastructure and resources. It also revealed that the layout of the hospice clinic was not ideal. The study also showed that nonmedical amenities such as toilets were not within the hospice clinic forcing patients to go at a far distance to access these services. This study concur with another study by Fitch which pointed out that support care needs are nonmedical needs for cancer patients [15]. The study also found out that not all medication supplies and services are available in the hospital thus forcing patients to outsource from the private chemists. This study corresponds to the study which showed that cancer patients experiences negative impact in their cancer trajectory due to lack of essential resources patients [16].

The study revealed that distance covered by the patients to access services was a challenge since some patients could cover a distance of around 300kms. Meru level five hospital hospice clinic is the only facility in the region that offers cancer related services especially chemotherapy treatment and some patients are required to go to Nairobi for more services. This is in line with a study in Kenya which highlighted that most of the cancer centers in Kenya, are concentrated in the capital city Nairobi thus cancer patients from rural areas end up travelling over 600kms to seek for cancer treatment in the city [17]. Similarly in Kenya, those who live in remote areas travel a hundreds of kilometers to seek medical services. Accommodation and welfare for the patients who come from far was also mentioned as one of the challenges affecting cancer patients [14].

Poor infrastructure and road network was cited as one of the contributor to more suffering. This is in line with a study conducted in Lincolnshire which indicated that cancer patients from rural areas endure much suffering especially where patients have to travel long distances to access services leading to practical, emotional and financial challenges [3].

The study also found out that lack of adequate rooms and furniture, drug stocks and other treatment services coupled with inadequate human resources led to inadequate holistic services to the patients hence more needs for cancer patients. This is similar to a study by Grant who observed that in sub-Saharan Africa, incurable diseases, coupled with minimal resources and shortage of qualified work force are common. These infrastructure related items were reported to affect service delivery to the patients and consequently pose unmet needs to the patients [4].

The study revealed that majority of the respondents had NHIF related support needs which included, delayed approval, partial approval of the request or partial payment of the hospital bills, getting services from the NHIF selected facilities only and exhaustion of the NHIF cover. This led to high cost of treatment, psychological stress and delayed treatment. The study also showed that some of the patients were unable to get treatment in time because their pre-authorization forms had not been approved. Furthermore they cited partial approval of the investigations as a big challenge. Several participants stated that NHIF approved just part of the investigations requested for or partially paid part of the hospital bills, hence out of pocket expenditure to them. It was evident from the study that sometimes patients missed chemotherapy administration due to delay in the processing of NHIF pre-authorization request. However, some of them benefited from waiver system that was introduced by the hospital after the management realized that some of the patients were missing treatment. The study also showed that majority of the patients was unable to get services through NHIF after their insurance cover for that year was exhausted. Patients suggested the reduction if NHIF cards maturity time to reduce out of pocket expenditures associated with cancer treatment and services.

5. Conclusions and Recommendations

The study results showed that the socio-economic supportive care needs experienced by the cancer patients range from high cost of treatment, NHIF challenges, financial constraints, long distances to access cancer related services, poor road network, lack of accommodation, stock out of essential medication and inadequate infrastructures. From these findings, there is need for the government to ensure improved NHIF cover that will reduce cost implication associated with cancer treatment and services. Further, the study recommends that the government should ensure that cancer services are decentralized to the peripheral facilities and carry out outreach services to avail cancer treatment services close to the patients, in order to reduce transport cost, accommodation challenges and distance covered to access services.

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