

Family Caregivers' Perspectives of the Economic Burden Imposed through Caring for Family Members with Cancer in KwaZulu-Natal, South Africa

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Abstract

Background This study explored the perspectives of family caregivers on the economic burden imposed through caring for their family members who are living with cancer in KwaZulu-Natal.

Methods This study employed qualitative methods to explore the subjective experiences of the family caregivers caring for family members living with cancer, drawing from the interpretivist paradigm. Data saturation was reached after conducting 20 in-depth interviews among family caregivers. These family caregivers were either actively involved in caring for or previously had the experience of caring for a family member with cancer. Interview questions focused on the caregivers' perspectives of the economic burden of caring for a family member with cancer.

Results Three key themes emerged from the analysis of the research findings. These themes were: loss of income, financial coping prior to the cancer diagnosis, and financial challenges due to the cancer diagnosis.

Conclusions Cancer care giving can be financially taxing on families, and especially impose more strain on families with low household incomes. There is a need for health policy makers to consider exploring financial relief mechanisms for families caring for members living with cancer.

Background

Cancer is one of the non-communicable diseases (NCDs) that is increasingly becoming part of the leading public health problems, globally (1). It is estimated that 1 in 4 people in South Africa are affected by cancer, annually, either by having a family member or friend diagnosed with cancer or by personally being diagnosed with cancer (1). Cancer diagnosis has a greater impact on family members than on patients. Therefore, there is a need to understand the family caregiver's (FCs) psychosocial and economic needs and experiences in caring for their loved ones (2). Thus, the aim of this study was to explore the perspectives of family caregivers on the economic burden imposed through caring for their family members who are living with cancer in KwaZulu-Natal, South Africa.

NCDs, such as cancer, were once considered to only affect high-income countries (HICs) (3). However, cancer has now been found to account for a considerably high morbidity and mortality in low and middle income counties (LMICs), as well (3). Literature had previously focused more on the impact of NCDs at a household level in HICs, and therefore, researchers are beginning to unpack the effects of NCDs in LMICs, as well (3). The impact

is anticipated to differ between HICs and LMICs, as there is little to no financial risk protection, such as free health insurance in LMICs (3). Therefore, medical costs for NCDs, such as cancer, are seen to be by the households which then becomes a financial burden to the families (3, 4). The FCs receive little to no compensation for the financial burden they incur in the care giving process and they receive little financial support from the government (3, 5). This economic burden often goes unrecognised by health policy makers and society in general, especially in LMICs (6).

In addition to the psychosocial and emotional burden, care giving creates a financial burden for FCs, as care giving is not limited to physical and emotional support, but also includes financial support (2, 7). Studies have revealed that FCs adjust their working hours, as they need to either leave work early or take leave, often unpaid leave, resulting in reduced pay, while others work from home in order to fulfil care giving demands (2, 8, 9). This has long-term financial implications, as it affects FC's financial saving efforts (2). An Irish study revealed that, out of pocket costs of cancer care imposed a direct financial burden to FCs, especially for those in low-income households and contributed to considerable financial strain on FCs (6). In another American Study, many FCs reported to have lost most or all of their family savings, as a result of care giving, and others reported one or more drastic financial or social changes, since the patient's cancer diagnosis (10). Furthermore, high medical expenses may result in patients delaying or not adhering to treatment to avoid these costs (11, 12)

A review by Muliira et al, demonstrated that older African women with cancer often reported poorer health and were likely to suffer with multiple health complications, due to their poor economic situation that prevented them from obtaining an income to cover the cost of their illness (13). This was largely, as a result of unemployment, low education, low-income and residing in rural areas (13). A South African study of breast cancer diagnosis and distance from diagnostic hospitals revealed that breast cancer patients, who lived further away from the hospital, were diagnosed with advanced stages of cancer compared to those that lived closer to the hospital (14). This was mostly due to the unaffordable transportation cost to the hospital of which are increased as cancer patients are often

accompanied by their family caregivers resulting in more travel costs (14). The lack of medical insurance by many patients remains a key challenge to early access to diagnostic and treatment services (14). Medical insurance also reflects socio-economic inequities, since as it is only available to those who can afford it (14, 15). Poverty exacerbates the burden of cancer care and further complicates the caring process, including patient transportation to the hospital and access to treatment (1, 16). In the study by Maree et al., loss of employment and early retirement in order to care for the patient, were key drivers of drastic financial difficulties (1). Maree et al, determined that cancer, regardless of a person's socioeconomic status, is synonymous with high monetary costs (1).

Methods

Study Design

This study explored the perspectives of the FCs on the economic burden imposed through caring for their family members who are living with cancer in KwaZulu-Natal (KZN), using qualitative methods (17). The study was rooted in the interpretivist paradigm, in order to understand the care giving experiences and perceived financial burden through the subjective perspectives of the FCs (18). The interpretivist paradigm allowed the researchers to discover the participants' realities of their economic burden of care giving through their own perspectives, background and experiences of providing cancer care (18).

Study Setting

This was a community-based study conducted in three (Chatsworth, Wentworth and Umlazi) and two (Sobantu and Imbali) research sites in Durban and Pietermaritzburg, respectively, in the province of KZN, South Africa. The in-depth interviews were conducted in the participants' homes or at a setting that was preferred by the participants within the respective community.

Characteristics of Participants

The participants in this study were primary FCs residing within the study sites and who were or had previously been involved in the daily processes of caring for a family member with cancer. Only FCs above 18 years of age, currently living with or had previous experience of living with the family member with cancer, were invited to participate in the study. All participants voluntarily participated after signing the informed consent form. This study was approved by the University of KwaZulu-Natal Biomedical Research Ethics Committee (Ref: BE532/18)

Participant Recruitment and Procedure

The participants were FCs recruited through referral by cancer patients attending cancer support groups and non-government organisations (NGOs), such as, hospices and homes for the sick within the study sites. Leaders of the NGOs and the support groups, as instrumental gatekeepers, played an enabling role in accessing cancer patients, who then referred the research team to their primary FCs. The FCs of the late cancer patients were recruited through a snowball process with the assistance of other participants who knew them (17).

Data Generation

Data generation was achieved through in-depth interviews (17). The development of a flexible semi-structured interview guide, which allowed for follow-ups, probes and unplanned questions, was guided through the reading of the literature (19). Consistent with the literature-supported parameters for achieving data saturation, data saturation for this study was reached at 20 in-depth interviews (20). At the end of the interview, a short researcher administered questionnaire containing socio-demographic questions was completed.

Data Analysis

Interview recordings were transcribed verbatim by an experienced transcriber. Subsequently, the IsiZulu transcripts were translated into English by the first author. Transcripts were then transferred to the NVIVO 12 software for qualitative data analysis. Data were coded and organized into the identified themes. A thematic analysis was used to identify patterns within the data (21). A deductive analytical approach was used to develop themes, guided through the interview guide questions (22, 23). Emergent themes were populated with the relevant data from the participants in a form of verbatim quotes. The sociodemographic information sheets were scanned and saved in a protected folder in a computer and were used to create a table representing the participants general demographic characteristics. Pseudonyms were assigned to each participant's transcript to maintain anonymity and protect their identity (24).

Results

Table 1: *Family Caregiver Profile*

No.	Participant's Caregiver) Information			Patient's Information as Reported by the Participant				Household Income Stream			
				Participant Pseudonym	Age	Gender	Patient's Relationship to Caregiver	Cancer types Reported	Patient Alive at Time of Family Caregiver Interview?	Reported Household During Care giving	No. of Incomes
1	Thembi	48	F	Grandmother			Stomach		No	2	
							Cancer				
2	Candice	21	F	Aunt			Kaposi		Yes	0	
							Sarcoma				
3	Mandy	82	F	Grandson			Nasal		Yes	2	
							Cancer				
4	Zandi	27	F	Aunt			Lung Cancer		No	4	
5	Olivia	59	F	Grandmother			Leukemia		Yes	3	
6	Ingrid	73	F	Husband			Prostate		Yes	2	
							Cancer				
7	Wendy	61	F	Grandson			Leukemia		Yes	1	
8	Sanele	75	M	Wife			Uterine		Yes	2	
							Cancer				
9	John	84	M	Wife			Uterine		Yes	2	
							Cancer				
10	Andile	60	M	Wife			Breast		Yes	2	
							Cancer				
11	Max	63	M	Mother			Breast		Yes	2	
							Cancer				
12	Lucia	32	F	Mother			Breast		Yes	3	
							Cancer				
13	Tracey	73	F	Daughter			Colon		No	0	
							Cancer				
14	Cindy	61	F	Husband			Prostate		Yes	1	
							Cancer				

15	Steve	42	M	Father	Oesophageal Cancer	Yes	1
16	Linda	72	F	Husband	Lung Cancer	Yes	2
17	Mary	37	F	Mother	Squamous	Yes	3
					Cell Cancer		
18	Dora	34	F	Aunt	Breast Cancer	Yes	3
19	David	67	M	Wife	Breast Cancer	Yes	1
20	Lauren	30	F	Mother	Head and Neck Cancer	Yes	1

F-Female | M-Male

Fourteen of the twenty participants were females and relationship to the patients varied widely, with seven of the participants being spouses of the patients (Table 1). The youngest participant was a 21-year-old female who cared for her aunt who suffered from Kaposi Sarcoma. On the other hand, the oldest patient was an 84-year-old male who cared for his wife suffering from uterine Cancer. Three patients had passed on, at the time their caregivers were interviewed.

At least 65% of the participants had household incomes from two or more streams (Table 1) and these were inclusive of family members who were pensioners and were in receipt of a social grant. The participants with a single income stream were mostly old age South African Social Security Agency (SASSA) pensioners. However, all participants, irrespective of the number of their income streams, still felt that their household incomes were not enough to support the whole family, given the extra expenses brought about by the cancer illness. One participant reported to have no consistent source of income, as no one was employed in that household, however, they made money by doing people's hair, which was not an everyday activity.

Loss of Income

Participants shared on how the cancer diagnosis and care giving affected their financial income and that of their households in general. The dominant view was that the diagnosis and cancer care giving negatively affected their financial situation. Loss of income, depicted in Fig. 1, was one of the dominant themes that emerged from the interviews. This loss of income was as a result of having to work less often or having to leave work completely to focus on care giving.

There was a piece job that I had in Durban, it was affected because I had to be here in Pietermaritzburg to take care of her [my mother]. I couldn't stay [at work] for the week and come back on the weekend or month end, I had to keep coming back here [to check on my mother] (Max).

Sometimes when I have to be out working in other areas like Nongoma, but I can't because I have to be at home taking care of him [my father], and I get a call from someone who wants me to do a job for him, but I can't (Steve).

Well I was working at the time and I left work to look after her [my daughter] (Tracey).

A family caregiver reported that the loss of income was due to the ill family member not being able to work anymore as the money she made helped in the household and therefore getting ill meant one less income for the household.

She [patient] used to go out and get small jobs in people's houses.....she can't anymore because you would find that the sun is too hot and then her leg gets those watery pimples and swells up and becomes sore then she can't carry on (Candice).

For most participants, major financial loss was due to cancer care giving and medical expenses, such as cancer treatment, transportation to healthcare facilities, purchasing the recommended food for the patient and care giving resources.

Just recently trying to help him [patient], trying to get him treatment, I took out R4000..... at Estcourt I spent about R1000, and I was advised by others to also try Hammarsdale so tomorrow I must get someone to drive us to look for that place because I'm fighting for his life, even when I see that I'm not winning I just try (Mandy).

He [patient] uses it [pension grant] up on transport going back and forth to hospital like the cars, and he doesn't only go to one hospital, he goes to King Edward, Wentworth, Albert, St Aiden's and Mshiyeni (Steve).

I know my stepfather, he went down [financially] because her [patient] medication and ensure [soft porridge] and the stuff she eats is very expensive. He used to have a lot of money, so he doesn't have money now because the stuff she needs, the pain killers, the ensure [soft porridge], the special foods you know all of that, its's costly, the petrol to hospital and back it's very expensive (Lauren).

On the contrary, one participant reported not to have been negatively affected financially or in any other way due to the cancer diagnosis or care giving. This was due to the cancer not being too severe on the patient that she was caring for.

Like I had mentioned that I was not affected in any way, nothing has disrupted my life at home or my money, there has never been a time where we had to wake up at night and had to rush her [patient] to the doctor, everything is as it was before she got sick (Olivia).

Participants were asked to describe their financial situation before their family members were diagnosed with cancer and before taking on the care giving role, this theme is illustrated in Fig. 1. The following statements arose: "we were prosperous" (Themb), "I could live" (Max), "I didn't really have any financial problems" (Tracey), "we were a bit comfortable" (Cindy), "I was able to go to work" (Steve), "it was much better" (Mandy), "financially, we were okay" (Zandi). These assertions show that most participants and their families were financially stable before the cancer diagnosis of the patient. Majority of the participants reported to have had a satisfactory financial status before their family members got sick and before having to take on the care giving role.

I had a nice job, I was getting paid well so I didn't really have any financial problems, I was living well and then she [patient] was working but then she was [medically] boarded in the end because she couldn't work, so they boarded her (Tracey).

I'd say we were okay [financially] because we could buy our groceries, eat well and pay our bills then when he [patient] got sick we reduced the money we spent even on bills, we started to pay less money and spent more money on trying to get him [patient] better (Ingrid).

I was able to go work out and stay for longer and come home with a fair amount of money, now I have to work close by and the people around here don't pay well (Steve).

Financial Challenges due to the Cancer Diagnosis

The participants were also asked to describe their financial situation after the cancer diagnosis and taking on the care giving role, this theme is presented in Fig. 1. The following statements emerged: "it's not that good" (Cindy), "it's very bad now" (Steve), "things have tightened a bit" (Linda), "it is non-existent" (Mandy), "we had to start cutting down on somethings" (Zandi), "it is difficult and there are a lot of expenses now" (Ingrid). Most

participants reported a drastic change to their own and the family's finances after the cancer diagnosis as compared to before the illness of their family members.

It made us poor, I don't think our family ever recovered till now (Thembi).

Well it is difficult now, like I said we have to use money to go to hospital, I have to buy fruits for him, carrots, apples and grate these things to make his juice to give him the nutrition (Wendy).

Life is very difficult that's the truth, money is never enough it's too little (John).

One participant reported that she had not experienced any financial changes before and after the cancer diagnosis of her family member.

Nothing has changed, nothing has been affected..... it is the same, like I said I think it is the type of cancer that she has that makes everything normal (Olivia).

Another FC reported that he did not experience any financial changes or difficulties before or, after, the cancer diagnosis of his family member due to the financial support from his employer as well as the sick family member's employer.

It's [financial situation] still the same because she does still get her salary..... My company also, they actually told me go there, speak to the doctor, and if something that is going to be done which is not in your reach just get it done, we will support you financially.....if the doctor gives me a note and I say this hospital, I can't do it because I can't afford it, they say not to worry, they will fit the bill (David).

Discussion

FCs participating in this study consistently asserted that care giving had adverse effects on the household's financial standing. Caring for a patient with cancer added to their financial distress as care giving comes with added unplanned expenses. Several households in this study survived on old age social grants provided to citizens above 60 years of age by SASSA, thereby making care giving financially challenging (25). Although some participants reported to have more than one source of income, it was perceived as not enough, given the high cost of managing cancer (1). Poverty exacerbated the caregiver burden of families that had no constant source of income, this was confirmed in this study as participants reported extreme difficulty in providing adequate care due to the lack of funds to finance care giving resources (1).

This study has confirmed that cancer and the care giving thereof are financially taxing on the families of the patients, which is consistent with the findings of Hanly et al., where it was found that out of pocket costs of cancer care enforces a direct financial burden on FCs, especially in low-income households (6). This study confirms the findings of Girgis et al., where FCs needed to leave work early or take leave from work to fulfil care giving duties, thereby resulting in reduced pay (2). The ill family member might also have to leave work due to the severity of the illness, resulting in more than one loss of income in that household. This study has shown that the main cause of financial loss for FCs and their families are cancer care and treatment related expenses. Consistent with the study findings by Dickens et al., most participants in this study reported transportation and travel costs to medical facilities as some of the most financially taxing challenges (14). Financial strains caused by cancer care giving may provide a plausible explanation for the reasons why patients miss hospital appointments. If transportation to healthcare facilities could be freely provided for patients, full adherence to medical treatment and hospital appointments could be ensured. Free transportation could also lighten the burden of travel costs and financial strain on families, especially those from low-income households.

This study has revealed that cancer care giving causes unfavourable financial changes for families, as most participants in this study confirmed that their financial situation changed for the worse after the cancer diagnosis of their family members, and this is consistent with

the literature (10). Although many participants in this study were from low-income households, they reported that life was manageable before the cancer diagnosis and that their financial situation worsened with the cancer invasion. This study has also shown that a cancer diagnosis can have long term financial effects on families, culminating in the difficulty to recover financially even after the patient has passed on. This study has confirmed the findings of Shin et al that cancer medical costs differ depending on the type of cancer (16). One participant in this study confirmed this as she reported that her finances were not affected by the patient's cancer diagnosis as the cancer type was easily manageable and not severe. It can be confirmed that the costs of cancer care will differ based on the cancer type, cancer stage and severity of the illness. This study has also highlighted that additional financial assistance can be beneficial to FCs and may lessen the financial strain associated with cancer care giving, as one participant reported not to have had any financial difficulties due to cancer care. He was assisted by his employer who provided financial support for medical procedures and allowed flexible working hours to make time for care giving responsibilities without pay cuts. This participant's family member left work due to the severity of the cancer, however, she was still getting a salary from her employer, which was helpful to the family. This implies that, if employers could offer financial support, in as far as practically possible, a cancer diagnosis can be financially manageable for families who are affected and thus lightening the financial burden associated with cancer care giving. The same could be done by SASSA where families, especially low-income households, can be subsidised for the additional expenses that arise from care giving.

Strengths

This study explored the perspectives of the FCs on their economic experiences of caring for a family member with cancer in low-income households and provided a platform for the participants to share their experiences and voice their challenges as caregivers. This study

is an important contribution to the corpus of knowledge, in so far as the economic burden of cancer care within low-income households in the South African context is concerned.

Limitations

The findings of this study are based on the personal experiences of FCs of low-income households of which 95% of the participants cared for patients who were not under medical insurance nor did they utilise private healthcare facilities, hence they were only treated in public hospitals. Therefore, the findings of this study cannot be completely transferable to other FCs who care for patients who utilise private healthcare facilities or are under medical aid cover as their experiences and perceived economic burden may differ.

Conclusions

The results of this study have asserted that cancer care giving can be financially taxing on families, especially in low-income households. A cancer diagnosis has a long-term negative impact on the finances of the families affected, thus making the financial recovery difficult. It can be concluded that financial support for families caring for members with cancer can lighten the financial burden of care giving.

List Of Acronyms

FC- Family Caregiver

HIC- High Income Countries

KZN- KwaZulu-Natal

LMIC- Low and Middle-Income Counties

NCD- Non-Communicable Disease

NGO- Non-government Organisation

SASSA- South African Social Security Agency

Declarations

Availability of Data and Materials

All data generated and/or analysed during this study are available from corresponding author on reasonable request.

Competing Interests

The authors declare that they have no competing interests.

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Authors' Contributions

MPC designed the study, collected data, carried out the analyses, and wrote the paper. KH and TG analysed data and supervised writing up of manuscript. All authors have read and approved of the final version of the manuscript.

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