ISSN 2377-8393

PALLIATIVE MEDICINE AND HOSPICE CARE

Open Journal

Openventio PUBLISHERS

Original Research

Hospice Africa Uganda's Experience with the Psychosocial and Economic Impact of Caring for Terminally Ill Patients

Nasur Buyinza, MSc, HSM, MPH*

Institute of Hospice and Palliative Care in Africa, (Hospice Africa Uganda), P. O. Box 7757, Kampala, Uganda

**Corresponding author*
Nasur Buyinza, MSc, HSM, MPH
Institute of Hospice and Palliative Care in Africa, (Hospice Africa Uganda), P. O. Box 7757, Kampala, Uganda; E-mail: buyinzan@yahoo.com

Article information
Accepted: October 20th, 2024; **Published:** November 4th, 2024

Cite this article
Buyinza N. Hospice Africa Uganda's Experience with the Psychosocial and Economic Impact of Caring for Terminally Ill Patients. *Palliat Med Hosp Care Open J*. 2024; 10(1): 11-22.

ABSTRACT

Introduction

Giving care to a patient at the end-of-life can be a challenging experience. The responsibilities of caregiving may include executing complex physical and mental tasks, financial planning, patient care, decision-making, emotional support and coordination of care. This mixed-methods observational study aims to identify the psychosocial and economic effects of caregiving for terminally-ill patients by carers on the Hospice Africa Uganda Kampala program. It used both quantitative and qualitative data of caregivers caring for terminally-ill patients attending Hospice Africa Uganda Kampala. Simple random sampling was conducted to select caregivers who were invited to participate in the study.

Results

Results indicate that the majority of patients who were receiving palliative care (60.9%, 103) had been diagnosed with cancer. Most participants (62%, n=105) had spent less than one year caring for their patients, while (18%, n=31) were cared for between 1-5 years. Our results show that the responsibility of caregiving has significant effects on the psychosocial well-being of caretakers. In particular, it reduced the amount of time they spent attending social gatherings and caring for their children, their religious commitment ($p<0.05$), as well as their level of fatigue and exhaustion ($p<0.05$), and negatively impacted job finding activities.

Conclusion

Terminal caregiving has significant effects on the psychosocial well-being and incomes of caretakers, and their ability to find a job alongside caring for the patient. Based on these findings, it is therefore recommended that caregivers be given ongoing support to help them provide care to their own family members and patients with life limiting illnesses early in the disease trajectory.

Keywords

Psychosocial; Economic effects; Caregivers; Terminally-ill; Patients.

INTRODUCTION

Caregiving can be a demanding job. This concern warrants more research so that accurate, timely and appropriate information can be provided to healthcare providers, carers and care recipients for decision-making.

According to Joanna Briggs Institute, a prolonged burden of caregiving can affect the caregiver's financial, physical and psychosocial well-being with resultant effects such as depression, anxiety, and catastrophic expenditure on healthcare which leads to other problems regarding psychosocial engagements.[1] When compared with carers of patients with curable conditions, caregivers attending to terminally-ill patients tend to have a poorer quality of life (QoL).[2]

One of the adverse physical effects of caregiving is the lack of sufficient sleep and rest accruing from the enormous responsibilities of caregiving. Other key issues associated with caregiving for terminally-ill patients include limited ability to meet financial obligations, lack of support from healthcare providers and limited knowledge of the patient's prognosis. It is further reported by a number of authors that a lack of support to caregivers may result in a breakdown in the role of caregiving to the patient, and this poses the danger of developing depression and other distresses to both the patient and caregiver.[3]

© Copyright 2021 by Buyinza N. This is an open-access article distributed under Creative Commons Attribution 4.0 International License (CC BY 4.0), which allows to copy, redistribute, remix, transform, and reproduce in any medium or format, even commercially, provided the original work is properly cited.

According to the findings of two studies, one on elderly female caregivers conducted in Uganda[4] and another one conducted in Botswana, desperate caregivers usually face disruptions in their education and suffer sexual abuse perpetuated by either relatives or family friends who are supposed to support them financially, especially in poverty stricken families.[5]

Several studies conducted on carers have concluded that caregivers experience various physical and psychosocial challenges.[5] However, few have reviewed and examined the geographic diversity and the conditions of caregivers in resource limited settings for patients with an array of problems exhaustively, since majority of these studies have used standards specific to carers of either cancer or human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) patients. The parameters used in these previous studies may not necessarily yield similar results for caregivers of terminally-ill patients with other medical conditions such as heart disease, etc. In a study on assistance from family members, friends and caregivers, it was stressed that patients who have a diagnosis of terminal cancer present a smaller burden on the caregiver when compared with their counterparts caring for patients with other terminal illnesses.[6] One interesting observation made by Sparkman is that many healthcare providers do not see patient caregivers as individuals in their own right with specific needs but as appendages to the patient. It has been observed that in certain situations, the needs of caregivers supersede those of the patients they are actually caring for. Kaplan has recommended that if these needs are not met, they may be a precursor of stress on the part of the carer.[3]

Available research data indicates that most studies previously done to explore the needs of caregivers were largely descriptive in nature, had small sample sizes, and only studied the needs of cancer patients.[7] Five interventions were evaluated *via* randomized controlled trials. A range of intervention approaches were identified including home care, respite care, social networks and activities, problem-solving and education, one-to-one therapy and group work. Harding and Higginson concluded that there was only a small body of evidence regarding the effectiveness of interventions for carers of cancer and palliative care patients; the bulk of the evidence came from a small number of studies that were graded as moderate to weak in terms of rigour.[8]

It is believed that the psychosocial and economic issues that arise from caregiving result in serious long-term effects on caregivers, such as depression, social withdrawal, large financial burdens and suicidal tendencies among others, especially for close relatives and spouses of the sick. Being the family carer to a patient nearing the end of their life can be a challenging experience. The responsibilities of care may include complex physical and medical tasks, financial planning, patient care and advocacy, decision-making, emotional support and coordination of care.[9] Furthermore, studies show that caregiving can have negative consequences on the health of family carers including increased fatigue, sleep problems, depression, anxiety, burnout and an increased risk of mortality.[10] Family carers of palliative care patients not only face the demands associated with caregiving, but also the grief and loss associated with their relative's impending death.[11]

One of the goals of palliative care is to provide psychosocial support to patients and families facing terminal illness.[12] Psychosocial care has been defined as 'concern with the psychological and emotional well-being of the patient and their family/carers, including issues of self-esteem, insight into an adaption to illness and its consequences, communication, social functioning and relationships'.[13] Studies show that carers report the need for high-levels of information and psychosocial support.[14]

Unlike the US and a few other parts of the developed world where well over 40% of caregiving services are hired,[6] the provision of care to the terminally-ill in Uganda is largely informal, voluntary and usually done by relatives or close friends, similar to the situation reported by an Austrian study on care for poor terminally-ill gay men. Caregiving forms a majority of support services for the terminally-ill and those with physical disabilities especially in the homes. However, in developed countries like Australia with an aging population, the need for caregiving has increased tremendously. Although not well explored, the above and many more other reasons compel researchers to turn caregivers to terminally-ill patients into a major focus for global research.[7]

The majority of terminally-ill and palliative care patients share of the same preferences regarding the type of palliative care they wish to receive. About 50-70% wish to pass on at home with their loved ones besides them.**15** Palliative care places a lot of emphasis on respecting the patients' choices but meeting these choices and/or expectations requires appropriate support to the informal caregivers to ensure their safety and availability. According to Aoun, the sources of stress among families caring for terminally-ill patients include inadequate financial resources, lack of social support, transportation problems, physical restrictions, emotional strain, lack of knowledge regarding patient's outcome, and uncertainties in treatment amongst many others.[7] Even with technological and informational advancements on care and management of patients with terminal illnesses, caregivers still regularly face various types of distresses and physical exhaustion.

In a study on dementia patients conducted in the USA by Alexia M and colleagues, some insights drawn revealed a number of stress factors including inadequate counselling, emotional support and the need for palliative care intervention as some of the issues affecting caregivers for patients with dementia. They recommended further research be conducted to gain a better understanding of the problem.[15] Much as there has been some research about terminally-ill patients in Uganda, available literature on caregivers in a similar setting is scarce, especially on this topic.[16]

Hospice Africa Uganda (HAU) was founded in 1993 as a non-government organisation (NGO) and a model hospice-based in Makindye, Uganda with the aim of providing palliative care education and promoting the initiation of palliative care services in Uganda as well as other African countries. Its founding mission is to provide day and home-based care palliative care to patients with terminal illnesses and their families in a holistic manner. The organisation has grown over the years and opened new branches, Little Hospice Hoima and Mobile Hospice Mbarara, all of which offer clinical care and training to multidisciplinary professionals including doctors, clinical officers, nurses and other allied health professionals in addition to non-health professionals like social workers, spiritual and community leaders, traditional healers and community volunteers.

Clinical data with Hospice Africa Uganda indicates that most patients who are unable to access treatment, present conditions which are too late for anti-retro viral therapy (ART) and/or have tried available ART regimens but failed, will require palliative care at the end-of-life.[17] According to Merriman, a good number of such patients are young and in the productive period of their life, hence this results in foregone income, and the caregiving role is also left to the elderly and offspring. Stajduharet and colleagues pointed out that carers of young patients are at greater risk of developing psychological distress than those of elderly patients.[18] The need for more comprehensive and effective care and support for people with AIDS and their families appears to be on the rise in Sub Saharan Africa. Whilst capacity for HIV/AIDS care and treatment has grown, the diagnosis and management of pain, symptoms and opportunistic infections as well as the provision of terminal care to people living with HIV/AIDS (PLWHA) when curative treatment is no longer suitable or ineffective remains a challenge.[18]

Many cancer patients throughout Sub-Saharan Africa are dying in severe pain with uncontrolled symptoms, yet relief is possible using simple, affordable and appropriate palliative care services as long as it is provided by trained palliative care providers and carers.[17] Surprisingly though, before these caregivers take on the role as caregivers, they were either in school or were gainfully employed. This was found in a study conducted in Uganda by Ssengonzi on elderly female carers, and another done in Botswana where it was discovered that desperate caregivers usually face disruptions in their education and suffer sexual abuse perpetuated by those who are supposed to provide support, especially in families that are poverty stricken.[5]

In their study, Schulz and colleagues observed that caregivers go through a number of risky situations, the worst amongst them being that they are at risk of developing health problems, especially for aging spouses who, in a study by Cho, were reported to have negative physical health resulting from their caregiving role.[16]

Hospice Africa Uganda has observed that caregivers are comprised of children who have mostly dropped out of school, adults who have opted out of employment and daughters who have abandoned their marriages. These as well as other factors complicate the problem and can result in psychosocial and financial consequences to both the caregivers and their families.[18]

This survey seeks to identify the economic and psychosocial attributes of the caretakers of terminally-ill patients on Hospice Africa Uganda Kampala Program as well as assess the psychosocial and economic effects of the caregiving role on these caregivers. This can help to inform policy formulation and improve clinical practice in Hospice Africa Uganda as well as for other providers of palliative care. It also hopes to inform the wider healthcare fraternity, service users like patients and their potential carers, policy makers like Ministry of Health (MoH), parliament and other academics about the psychosocial and economic effects caregivers face when they undertake the work of caring for terminally-ill patients. Information is urgently needed to support both clinicians and decision makers to understand the burden of caregivers in Uganda.

Caregivers play a vital role in caring for terminally-ill patients yet very little recognition is given to them.[18] Caring for the sick stands out as the most culturally accepted way of showing love and affection in the African context. This survey seeks to understand the consequences of caring for terminally-ill patients on caregivers so as to prevent catastrophic psychosocial and economic consequences in families with terminally-ill patients.

OPERATIONAL DEFINITIONS

Caregiver

A person who provides a patient the most assistance with one or more of communication, mobility, transport, housework, self-care and managing medication on a regular basis (carer).

Economic

Something which is justified in terms of economy or pertaining to the production, distribution and the use of income, wealth or commodities.

Hospice

The care aimed to give support services to people who are terminally-ill and to focus on comfort and an improved QoL other than cure.

Palliative Care

Is an approach that is aimed at improving the QoL for patients and families who are faced with life threatening illnesses by way of relief of pain and other problems such as psychosocial, physical and spiritual.

Psychological

What arises in or affects the mind or that is related to the mental or emotional state.

Social

Something that relates to society or its organization.

Effect

This is the change that is as a result or outcome of an action or other cause or to bring about.

Caregiving

Is the physical and psychosocial support provided by an informal or formal caregiver to a terminally-ill patient be it in their homes or health facility (carer).

Study Objectives

1. To determine the psychosocial effects of caring for terminally-ill patients.
2. To identify the economic effects of caring for terminally-ill patients.

METHODOLOGY

Study Design

Prior to data collection, the study was approved by Hospice Africa Uganda Research and Ethics Committee (HAUREC), which is fully accredited by the Ugandan National Council for Science and Technology (UNCST). A sample of 169 respondents was selected using systematic sampling. Patients whose reviews were scheduled during the period of study had their files arranged chronologically according to their time of review, and every third patient file was selected. Upon selecting a file, the caregiver caring for the patient corresponding to the file would participate in the study if he or she spoke either English or Luganda, was 18-years or older, had cared for a terminally-ill patient for at least six-months, and provided informed consent. If the caregiver did not meet the inclusion criteria, the following file was selected until an eligible consenting caregiver was chosen. The sampling resumed afterwards. The selected files were then separated from the rest for the whole study period and given unique colour codes so that they were not included in subsequent random samples. Respondents were given the option to leave the study at any time during the study. Questionnaires were administered by research assistants to gather information from all study participants. This survey was not designed to test any hypothesis. All domains relating to the psychosocial and economic effects were covered and all responses recorded. Caregivers were allowed ample time to provide their responses and to explore missed or unobserved issues.

A formula for coding the data was developed and analysis done using statistical package for the social sciences (SPSS). Statistical significance was assessed using the Chi-square (χ) test. Effects with a p-value<0.05 were considered statistically significant for this study.

In order to get in-depth information regarding the psychosocial and economic challenges faced by caregivers, two focus group discussions were conducted. A group of caregivers were purposively chosen based on the length of their caregiving as well as the complexity of their patients' conditions. Eight members were then randomly chosen amongst the group to participate in each of the two 40-minute focus group discussions. Both discussions were voice recorded and all responses carefully transcribed and verified. The identities of respondents, the patients they cared for and their responses have been kept confidential.

Research assistants were palliative care nurses and therefore trained to manage minor psychological effects which resulted from our interview questions. We however developed a distress protocol for use in case of major psychological effects. Fortunately, no serious psychological effects were registered during the survey period.

RESULTS

General Information about Respondents

Table 1 presents information regarding the age, gender, religious affiliation, education level and the marital status of the caregivers involved in the study, as well as the diagnosis of the caregiver's patient.

Table 1. *General Information of Respondents*

Variable	Frequency	Valid Percent
Age group		
15-25-years	33	19.5
26-33-years	24	14.2
34-41-years	14	8.3
42-49-years	36	21.3
> 49-years	62	36.7
Total	169	100.0
Gender		
Male	55	32.5
Female	114	67.5
Total	169	100.0
Religious Affiliation		
Born again	23	13.6
Catholic	38	22.5
Muslim	16	9.5
Pentecostal	58	34.3
Protestant	29	17.2
Did not specify	5	3.0
Total	169	100.0
Education Level of Caretaker		
None	18	10.7
Primary	31	18.3
Secondary	60	35.5
Tertiary	36	21.3
Did not specify	24	14.2
Total	169	100.0
Marital Status		
Single	61	36.1
Married	40	23.7
Separated	25	14.8
Cohabiting	25	14.8
Others	18	10.7
Total	169	100.0
Diagnosis of Patient Cared for		
Cancer	103	60.9
HIV	66	39.1
Total	169	100.0

Characteristics of Caregiving to the Terminally-Ill Patients

Referring to Figure 1, most of the caretakers had spent less than one year while caring for their patients (62%, n=105), followed by those who had taken between 1-5-years (18%, n=31).

Figure 1. *Duration of Caregiving*

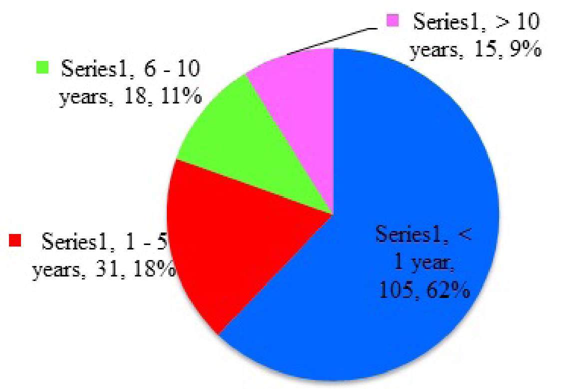

Figure 2 shows that most of the caretakers had caring sessions which were as long as 1-6-hours in a day (40%, n=67).

Figure 2. *Hours in a Day Spent Caring for the Patient*

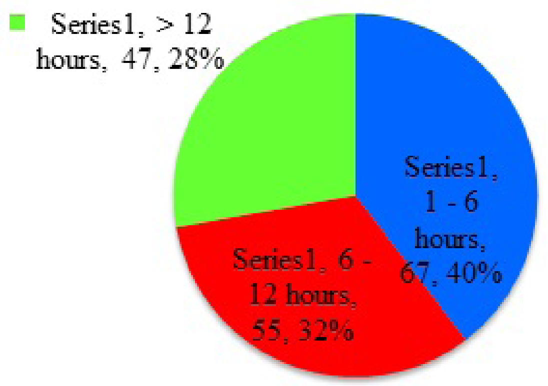

Figure 3. *Relationship with the Patient*

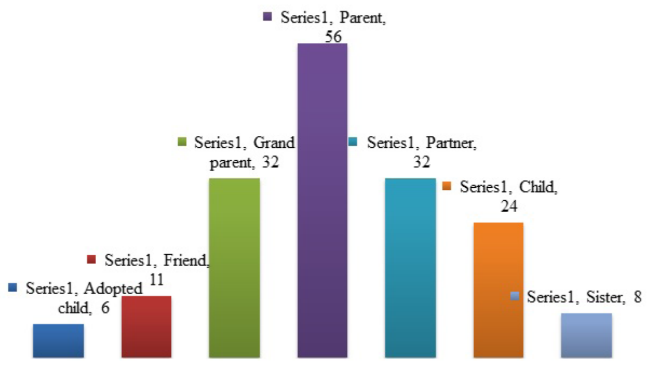

Figure 3 shows that most of the caretakers were parents (56), grandparents (32), and partners (32) to the patients.

Information Needs of the Caretakers

Table 2 shows the information needs of caretakers. An assessment of caretakers' needs revealed that most were aware of the patient's condition and state (72.8%, n=123) as well as the purpose of the patients' drugs (72.2%, n=122), received prior training in caregiving (52.1%, 88), and felt that the HAU medical team was doing enough for them and their patients (63.3%, 107).

Table 2. *Information Needs of Caretakers*

Variable	Frequency	Valid Percent
Are you aware of the patient's condition and its progression?		
Yes	123	72.8
No	46	27.2
Total	169	100.0
Do you know why the health worker gave you the drugs your patient is on?		
Yes	122	72.2
No	47	27.8
Total	169	100.0
Do you feel the medical team is doing enough for you and your patient?		
Yes	107	63.3
No	62	36.7
Total	169	100.0
Have you ever had a training in caregiving?		
Yes	88	52.1
No	81	47.9
Total	169	100.0

Assessment of the Economic Situation of Caregivers

Table 3 shows the economic situation of caretakers. Most caregivers registered a negative change in income as a result of caring for the patient (76.9%, n=130), and most of them found it difficult to meet their daily expenses at times (71.6%, n=121). Some did not see themselves relevant with regard to future job opportunities (69.8%, n=118). However, a significant majority of the respondents could somehow afford their basic household needs (51.5%, n=87).

More than half of the caretakers thought they had enough money for regular meals and reinvestment in other small income generating activities (58%, n=98), while majority said they depended entirely on another person to meet their own financial needs (87.6%, n=148).

Regarding her economic livelihood, one of the caretakers who participated in the focus group discussion said that:

"I questioned myself whether I would be able to manage the role alone, I feared for we didn't have money to care for the patient. I did not mind because it was

Table 3. *Economic Situation of Caretakers*

Variable	Frequency	Valid Percent
Have you registered any change in income as a result of caring for the patient?		
Yes	130	76.9
No	39	23.1
Do you sometimes find it difficult to meet your daily expenses?		
Yes	121	71.6
No	48	28.4
How do you see yourself with regard to future job opportunities?		
Have no hope	118	69.8
Have big opportunities	22	13.0
Do not know	29	17.2
Can you afford the basic need in your household?		
Some how	87	51.5
Yes all of them	60	35.5
No	22	13.0
Do you think you have enough money for regular meals, medical expenses, and reinvestment in other income generating activities?		
Yes	98	58.0
No	71	42.0
Do you have another job alongside caring for the patient?		
Yes	38	22.5
No	131	77.5
Do you think your involvement with the patient has somehow affected your own family income?		
Yes	140	82.8
No	29	17.2
Do you depend on another person to meet your own financial needs?		
Yes	148	87.6
No	21	12.4

Table 4. *Psychosocial Situation of Caretakers*

Variable	Frequency	Percentage
Do you think your involvement with the patient has somehow affected your marriage/ relationship?		
Yes	56	33.1
No	113	66.9
Has the caring role affected your education in any way?		
Yes	35	20.7
No	132	79.3
Do you get enough time to attend social gatherings?		
Yes	87	51.5
No	82	48.5
If you have children, do you get enough time for them?		
Yes	67	39.6
No	102	60.4
Do you think your involvement with the patient has somehow affected your relationship with God?		
Yes	36	21.3
No	133	78.7
Do you have another job alongside caring for the patient?		
Yes	38	22.5
No	131	77.5
Do you think your involvement with the patient has somehow affected your own family income?		
Yes	140	82.8
No	29	17.2
Has your role of caring for the patient somehow affected your relationship with your family?		
Yes	65	38.5
No	104	61.5
Do you sometimes feel fatigue and exhausted as a result of your caring role?		
Yes	122	72.2
No	47	27.8

my mother but of course the burden of caring for her was big. The fact that the patient is my own mother, I decided on this as an individual without remorse. I put every thought into the hands of God. When we were sharing the role with my sister, there was not much burden (Caretaker, FGD)."

When asked about what kinds of support caregivers would like to receive from others, some of their responses were as follows:

"*Support in securing food for the family, getting some money for up keep, turning the patient who is heavy, caring for other family members especially kids, washing clothes. Some are sharing the responsibility as a family (Caretaker, FGD).*"

"*My child (patient) does not have anybody else to care for him since I am the mother, no income no job, can't go to the garden, I left my job to care for my child since there is nobody else who can take care of him (Caretaker, FGD).*"

Assessment of the Psychosocial Situation of the Caretakers

Table 4 shows the psychosocial situation of caretakers. Majority of caregivers did not think that their involvement with the patient had affected their marriage/relationship (66.9%, n=113), their education in any way (79.3%, n=132), or their religious commitment (78.7%, 133). However, some of them said they did not get enough time to attend social gatherings (51.5%, 87). 122(72.25) respondents claim that they sometimes felt fatigue and exhausted as a result of the caring role, and 65(38.5%) admitted that their role of caring for the patient did not affect their relationship with their families.

Additionally, during the focus group discussion, some respondents said that:

"*When we saw some improvement in symptoms for our patient, the selfless care being offered by the hospice staff, it gave us hope and happiness in the caring role, the patient is much better now, seeing the patient bright and without major complaint and seeing a relieve in pain motivates me. The patient has gained some weight, looks better than before and this is encouraging (Caretakers, FGD).*"

"*There is no time to sleep especially when the patient cries at night, mine is also* *about the patient yelling at night, occasional constipation and turning of the patient makes my work a little difficult, before we thought of coming to hospice, people would say it is fever which needed investigations but nothing would be found. The patient was unable to sit and we would hold him all the time. There was always pain in my own body as a result of constant lifting of the patient. It hurts when they cry especially due to pain, my patient is very heavy. Sometimes she gets constipated and cries on opening the bowel (Caretakers FGD).”*

“My patient is very heavy with a swollen abdomen, unable to go to the toilet and this makes the work difficult. Little ability of the patient to bear down/open the bowel yet one has to keep holding him. Staying at home to care for the patient without going to work is very tiring. We need to go to the garden to till the land but it’s impossible. There were so many problems before coming to hospice but at least God has kept relieving some (Caretakers FGD).”

Yes, I have to stay around all the time, some of us have responsibilities in the church like attending meetings and prayer, social events like burial and others but can’t go for them. All of them are foregone since there is nobody else to stay with the patient (Caretakers FGD).”

“Family members do not contribute for the care of the patient, some do not visit as they used to, no social support or helping with the care, I left my husband and family to come and care for my sick mother and I am not sure but he might develop thoughts of marrying another wife” (Caretakers, FGD).”

Table 5. *Psychosocial Effects of Caring for Terminally Ill Patients on Caregivers at Hospice Africa Uganda Kampala*

Variable			X^2	*p*-value
	Do you think your involvement with the patient has somehow affected your marriage/ relationship?			
Duration of Caregiving	Yes	No		
< 1-year	34 (32.4%)	71 (67.6%)	2.856	0.414
1-5-years	9 (29.0%)	22 (71.0%)		
6-10-years	9 (50.0%)	9 (50.0%)		
> 10-years	4 (26.7%)	11 (73.3%)		
	Has the caring role affected your education in any way?			
Duration of Caregiving	Yes	No		
< 1-year	19 (18.1%)	86 (81.9%)	20.847	0.076
1-5-years	5 (16.1%)	26 (83.9%)		
6-10-years	5 (27.8%)	13 (72.2%)		
> 10-years	6 (40.0%)	9 (60.0%)		
	Do you get enough time to attend social gatherings?			
Duration of Caregiving	Yes	No		
< 1-year	46 (43.8%)	59 (56.2%)	22.684	0.000
1-5-years	12 (38.7%)	19 (61.3%)		
6-10-years	1 (5.6%)	17 (94.4%)		
> 10-years	2 (14.3%)	12 (85.7%)		
	Do you have enough time for your children?			
Duration of Caregiving	Yes	No		
< 1-year	30 (28.6%)	75 (71.4%)	51.978	0.000
1-5-years	6 (19.4%)	25 (80.6%)		
6-10-years	18 (100.0%)	0 (0.0%)		
> 10-years	13 (86.7%)	2 (13.3%)		
	Do you think your involvement with the patient has somehow affected your relationship with God?			
Duration of Caregiving	Yes	No		
< 1-year	74 (70.4%)	31 (29.5%)	10.624	0.014
1-5-years	18 (58.1%)	13 (41.9%)		
6-10-years	18 (100.0%)	0 (0.0%)		
> 10-years	12 (80.0%)	3 (20.0%)		
	Has your role of caring for the patient somehow affected your relationship with your family?			
Duration of Caregiving	Yes	No		
< 1-year	41 (39.0%)	64 (61.0%)	3.423	0.331
1-5-years	12 (38.7%)	19 (61.3%)		
6-10-years	4 (22.2%)	14 (77.8%)		
> 10-years	8 (53.3%)	7 (46.7%)		

The Psychosocial Effects of Caregivers Caring for Terminally-Ill Patients on Hospice Africa Uganda Kampala Program

Bivariate analysis (Table 5) shows that caretaking had statistically significant effects on the psychosocial well-being of the caretakers (*p*-value<0.05), such as whether caregivers had enough time to attend social gatherings (*p*<0.05) and for their children (*p*<0.05), their relationship with God (*p*<0.05), as well as their level of fatigue and exhaustion as a result of their caregiving role (*p*<0.05). Most caretakers who said that they got enough time for their families were those who had spent less than 1-year providing care. Most of the those who reported having enough time for attending social

Table 6. *Economic Effects of Caring for Terminally Ill Patients on Caregivers at Hospice Africa Uganda Kampala*

Question				**X^2**	***p*-value**
Have you registered any change in income as a result of caring for the patient?					
Duration of Caregiving	Yes		No		
< 1-year	73 (69.5%)		32 (30.5%)	10.333	0.018
1-5-years	26 (83.9%)		5 (16.1%)		
6-10-years	16 (88.8%)		2 (12.2%)		
> 10-years	15 (100.0%)		0 (0.0%)		
Do you sometimes find it difficult to meet your daily expenses?					
Duration of Caregiving	Yes		No		
< 1-year	61 (62.2%)		44 (41.9%)	4.200	0.241
1-5-years	15 (48.4%)		16 (51.6%)		
6-10-years	10 (55.5%)		8 (44.5%)		
> 10-years	12 (80.0%)		3 (20.0%)		
Do you depend on another person to meet your own financial needs?					
Duration of Caregiving	Yes		No		
< 1-year	93 (88.6%)		12 (11.4%)	1.399	0.706
1-5-years	28 (90.3%)		3 (9.7%)		
6-10-years	15 (83.3%)		3 (16.7%)		
> 10-years	12 (80.0%)		3 (20.0%)		
Do you have another job alongside caring for the patient?					
Duration of Caregiving	Yes		No		
< 1-year	32 (30.5%)		73 (69.5%)	16.678	0.001
1-5-years	1 (3.2%)		30 (96.8%)		
6-10-years	0 (0.0%)		18 (100.0%)		
> 10-years	5 (33.3%)		10 (66.7%)		
Do you think your involvement with the patient has somehow affected your own family income?					
Duration of Caregiving	Yes		No		
< 1-year	82 (78.1%)		23 (21.9%)	8.604	0.065
1-5-years	25 (80.6%)		6 (19.4%)		
6-10-years	18 (100.0%)		0 (0.0%)		
> 10-years	15 (100.0%)		0(.0%)		
Can you afford every basic need in your household?					
Duration of Caregiving	Some how	Yes all of them	No		
< 1-year	57 (54.3%)	35 (33.3%)	13 (12.4%)	11.801	0.073
1-5-years	20 (64.5%)	9 (29.0%)	2 (6.5%)		
6-10-years	4 (22.2%)	11 (61.1%)	3 (16.7%)		
> 10-years	6 (40.0%)	5 (33.3%)	4 (26.7%)		
How do you see yourself with regards to future job opportunities?					
Duration of Caregiving	Have no hope	Have big opportunities	Do not know	6.556	0.364
< 1-year	70 (66.7%)	15 (14.3%)	20 (19.0%)		
1-5-years	25 (80.6%)	2 (6.5%)	4 (12.9%)		
6-10-years	13 (72.2%)	1 (5.6%)	4 (22.2%)		
> 10-years	10 (66.7%)	4 (26.7%)	1 (6.7%)		

gatherings were those who had spent less than 1-year while care taking.

The Economic Effects of Caring for Terminally-Ill Patients on Caregivers on Hospice Africa Uganda Kampala Program

Caregiving had statistically significant influence on the changes in incomes of caretakers ($p<0.05$), and the fact that the caretakers could not have another job alongside caring for the patient ($p<0.05$) (Table 6).

The cross tabulations further revealed that caretakers who had spent more time caring for their patients (more than one year) were more likely to experience a change in income and also not to have another job alongside caring for the patient.

DISCUSSION

Attributes of Caretakers

With regard to their economic situation, 56.2% of caretakers who had provided care for less than one year were found to have registered a negative change in income as a result of caring for the terminally-ill patients, 64.5% found it difficult to meet their daily expenses while others did not have hope with regard to future job opportunities. However, some of the caretakers could somehow afford the basic needs in their household. Moreover results reveal that more than half of the caretakers thought they had enough money for regular meals, medical expenses, and reinvestment in other income generating activities, while others said they depended on another person to meet their own financial needs.

Generally, these results show that caretakers of patients who are terminally-ill with cancer have poor economic livelihood, which could have been caused by an array of factors, including the financial burdens associated with hospital bills, co-payments for household items, services such as transportation and home care needs, and lost income from lack of time to work. The additional burden to caregivers in terms of time associated with caring for patients receiving palliative care could have further impacted the economic hardship faced by caregivers. This includes costs for traveling to and from hospitals or Hospice for medical appointments, waiting alongside their patients for doctors' consultations, missing work, preparing for unnecessary surgery and medical procedures as recommended by non-palliative physicians who are privately consulted, neglecting their daily activities and relationships as well as attending to hospitalized patients under their care.

These results coincide with the findings of other researchers who found that the economic livelihoods of caretakers of terminally-ill patients where usually poor.[19] Governments therefore need to step up efforts to ease the financial burden for caregivers of terminally-ill patients as well as to provide training to caregivers to engage in income generating activities.

As for the psychosocial aspects of caregivers' lives, results show that a substantial proportion of the carers had a good level of psychosocial well-being given that most of them did not think that their involvement with the patient had affected their marriage/relationships. Most reflected that their caregiving role had not affected their education in any way since majority of them were out of school by the time they started caring. Most also did not think that the caregiving role affected their relationship with God. However, most of them said they did not get enough time to attend social gatherings. Many indicated that their role of caring for the terminally sick did not affect their relationship with families. This is contrary to what has been found by some scholars including Weitzner, Ferrell and Taylor who found out that such carers usually had distress from their families and therefore a poor QoL.[20]

Cultural differences between places where these studies were conducted could have contributed to the differing findings. In most African cultures, every member of the family is responsible for caring for a sick relative, as this is a sign of love and respect to the patient. This may not be the case where Weitzer et al[20] did their study. Moreover, given the differing educational aspirations and literacy levels in different places, there may be a difference in the number of respondents whose education was not affected as a result of caregiving. Some carers reported having felt fatigue and exhaustion as a result of their caring role. This could have arisen from the caregiving responsibility in itself as well as them having to witness their patients' suffering.

Psychosocial Effects of Terminal Caregiving

According to the results of this study, firstly, caregiving has a statistically significant effect on the psychosocial well-being of the caretaker, particularly with regards to whether caregivers get enough time to attend social gatherings ($p<0.05$) and for their children ($p<0.05$), their religious commitment ($p<0.05$), and fatigue and exhaustion as a result of the caring role ($p<0.05$).

Several studies have reported that caregiving disrupts social connectedness and activities as caregivers' energy and time are focused on the patient and their recovery.[21] A study on Australian caregivers revealed that more than half (58%) reported a major or a dramatic effect of caregiving on their lives and choices. Caregiving was reported to negatively affect holidays and time away (45.4%), travel (30.2%), available time for hobbies (25.6%) and available time for socializing (15.6%). These impacts resulted in social isolation and loneliness (32%), changes in family and other relationships (25%), a sense of grief and loss (24%), and limited time for personal relationships (11.1%).[22] In another study, almost half of the caregivers reported having no time for themselves.[23]

Secondly, the longer the carers spent giving care, the more likely they felt socially distant from their friends and family. One possible reason is that as time goes by, the patient's condition may get worse, especially for cancer patients. The demands on the caregiver may rise, thereby reducing the time he or she has with other family members and friends.

Thirdly, caregiving affected caregivers' religious commitment. Their caregiving duties may have affected the amount of time they can spend praying, or their religious faith. The spiritual aspect of the caregiver's QoL has not received adequate attention.[24] A few studies have shown that patients and caregivers have parallel spiritual tasks when dealing with cancer, such as finding meaning and hope in the midst of the patients' suffering while also posing existential questions about the meaning of life.[25] Spiritual well-being may provide a stress-buffering effect for caregivers. Higher-levels of spirituality are associated with lower-levels of psychological distress and improved well-being for caregivers. In addition, it has been shown that one's ability to maintain religious faith and find meaning in one's life mitigates the adverse effects of caregiving stress on mental health. Spirituality can insulate caregivers against the feeling of hopelessness, help caregivers derive meaning from the experience of the patients, and provide them with an existential perspective on hope and suffering. However, this was not observed for the caregivers who participated in this study.

Lastly, as the number of years of caregiving increase, most caregivers feel increasingly exhausted. Caregivers caring for family members with serious illnesses have been found to experience as much distress as the patients themselves as caregivers witness the patient's suffering daily. The fatigue and exhaustion could also come from the caregiver's emotional burden that comes with loss, daily activities, stressful life events, as well as strife in the relationship with the patient which can get increasingly overwhelming over time.

Economic Effects of Terminal Caregiving

Caregiving had a statistically significant effect on the incomes of caretakers ($p<0.005$), but most caregivers are still able to afford meals, own medical expenses and daily necessities. Caretakers who have spent more time caring for their patients (more than one year) were more likely to experience a change in income and also less likely to have another job alongside caring for the patient.

Caregiving creates a financial burden for family members not only due to the expenses incurred from providing care, such as from purchasing special equipment and medication, but also the opportunity cost of doing so, which is the loss in income and benefits as caregivers take time off income-generating activities. Other studies have also found that about 40% of caregivers experience long-term financial pressures related to their caregiving responsibilities[26]; 22% reported missing one or more months of work; and 41% used personal savings to fulfil their caregiving responsibilities.[27] Caregivers may not experience as many extraordinary expenses when they are caring for someone at home. However, they do bear the costs of having to travel to and from the hospital for regular patient check-ups, including the cost of a taxi hire and their meals at the hospital.

In some cases, families pay to provide additional nursing support for a family member in hospital or to get a private room for the patient. Even when palliative care is provided for free, some caregivers still incur costs from travelling to and from the palliative care centre, feeding the patient and providing bedding for the sick. Financial expenses become more pronounced for caregivers as they spend a longer duration providing care, as shown in the results.

However, this study has found that even though caregiving has generally affected the incomes of caregivers, most are still able to afford meals, medical expenses and daily necessities. One reason is that it is prevalent in Ugandan as well as other African cultures for relatives and friends to provide a strong level of mutual support to one another in times of need. This can involve sharing food and money, as well as helping to stand in for the caregiver to care for the patient from time to time. During a focus group discussion, one caregiver reflected that family members shared the responsibility of having to care for the patient as well as providing for the family.

Still, caregivers who have provided care for a longer duration are less likely to have another job. As discussed earlier, patients' conditions usually deteriorate with time and thus end up requiring more care. The caregiver therefore has to spend more time with the patient, leaving little or no time for self-care as well as to look for other jobs.

Many caregivers are unable to work, forced to take leave without pay, have fewer work hours, in low paying jobs, or work from home to manage the demands of their caregiving role. Employers tend to be less willing to employ workers who have caregiving responsibilities to avoid employee absenteeism and lost productivity. In 2007, over 520,000 employed caregivers in Canada missed at least one day of work per month to provide care, collectively missing nearly 1.5 million work days per month due to caregiving responsibilities. Over 313,000 employed caregivers reduced their hours of paid work to provide care, resulting in a collective impact of 2.2 million hours per week.[28]

CONCLUSION

The number of families caring for individuals with terminal disease will continue to rise as we face an aging and ailing population. Being a family caregiver to a patient with a life limiting illness is a challenging experience. Caregiving can have negative consequences on the psychosocial and economic well-being of the caregiver. One of the goals of palliative care is to provide psychosocial support to terminally-ill patients and their families.

This study shows that caregiving has a detrimental economic and psychosocial impact on care givers. Caregiving statistically affected the amount of time they spend on attending social gatherings; have for their children, their religious commitment, as well as the level of fatigue and exhaustion they face as a result of the caring role.

Caregiving has statistically significant influence on incomes of caretakers as well as their ability to find employment alongside caring.

Further work needs to be done to understand the psychosocial and economic challenges experienced by caregivers to patients with life limiting illnesses in other parts of Uganda and the world. Comparisons of results garnered from additional studies of such nature can go a long way to inform palliative care service delivery, training and policy formulation.

Ultimately, palliative care providers need to understand that some issues affect not only patients but their caregivers as well. Palliative care providers, trainers as well as decision-makers need to appreciate their occurrence and to develop skills to handle them effectively.

INSTITUTIONAL REVIEW BOARD APPROVAL

This study has been approved by the Institutional Review Board (IRB).

REFERENCES

1. He Leow MQ, Chan SWC. Factors affecting caregiver burden of terminally ill adults in the home setting - A systematic review. *JBI Libr Syst Rev.* 2011; 9(45): 1883-1916. doi: 10.11124/01938924-201109450-00001

2. Stajduhar K, Funk L, Toye C, Grande G, Aoun S, Todd C. Part 1: Home-based family caregiving at the end of life: A comprehensive review of published quantitative research (1998-2008). *Palliat Med.* 2010; 24(6): 573-593. doi: 10.1177/0269216310371412

3. Payne S, Smith P, Dean S. Identifying the concerns of informal carers in palliative care. *Palliat Med.* 1999; 13(1): 37-44. doi: 10.1191/026921699673763725

4. Ssengonzi, R. The plight of older persons as caregivers to people infected/affected by HIV/AIDS: Evidence from Uganda. *J Cross Cult Gerontol.* 2007; 22: 339-353. doi: 10.1007/s10823-007-9043-5

5. van Deventer C, Wright A. The psychosocial impact of caregiving on the family caregivers of chronically ill AIDS and/or HIV patients in home-based care: A qualitative study in Zimbabwe. *S Afr J HIV Med.* 2010; 18(1): a718. doi: 10.4102/sajhivmed.v18i1.718

6. Emanuel EJ, Fairclough DL, Slutsman J, Alpert H, Baldwin D, Emanuel LL. Assistance from family members, friends, paid caregivers, and volunteers in the care of terminally ill patients. *N Engl J Med.* 1999; 341(13): 956-963. doi: 10.1056/NEJM199909233411306

7. Aoun SM, Kristjanson LJ, Hudson PL, Currow DC, Rosenberg JP. The experience of supporting a dying relative: Reflections of caregivers. *Progress in Palliative Care.* 2005; 13(6): 319-325. doi: 10.1179/096992605X75930

8. Harding R, Higginson I. Working with ambivalence: Informal caregivers of patients at the end of life. Support Care Cancer. 2001; 9: 642-645. doi: 10.1007/s005200100286

9. Funk L, Stajduhar K, Toye C, Aoun S. Home-based family caregiving at the end of life: A comprehensive review of published quantitative research (1998–2008). *Palliat Med.* 2010; 24(6): 594-607. doi: 10.1177/0269216310371411

10. Schulz R, Mendelsohn AB, Haley WE, Mahoney D, Allen RS, Zhang S, et al. End of life care and the effects of bereavement on family caregivers of persons with dementia. *N Engl J Med.* 2004; 349(20): 1936-1942. doi: 10.1056/NEJMsa035373

11. Candy B, Jones L, Williams R, Tookman A, King M. Interventions for supporting informal caregivers of patients in the terminal phase of a disease (Protocol). Cochrane Database Syst Rev. 2011; (6): CD007617. doi: 10.1002/14651858.CD007617.pub2

12. Macleod R. Setting the context: What do we mean by psychosocial care in palliative care? In: Lloyd-Williams M, ed. *Psychosocial Issues in Palliative Care.* New York, USA: Oxford University Press; 2008.

13. Olivia D, Myer G. *Feeling Better: Psychosocial Care in Specialist Palliative Care.* London, UK: National Council for Hospice and Specialist Palliative Care Services (NCHSPCS); 1997.

14. Andershed B. Relatives in end-of-life care -- part 1: A systematic review of the literature the five last years, January 1999-February 2004. *J Clin Nurs.* 2006; 15(9): 1158-1169. doi: 10.1111/j.1365-2702.2006.01473.x

15. Diwan S, Hougham GW, Sachs GA. Strain experienced by caregivers of dementia patients receiving palliative care: Findings from the Palliative Excellence in Alzheimer Care Efforts (PEACE) Program. *J Palliat Med.* 2004; 7(6): 797-807. doi: 10.1089/jpm.2004.7.797

16. Cho E. A proposed theoretical framework addressing the effects of informal caregivers on health-related outcomes of elderly recipients in home healthcare. *Asian Nurs Res (Korean Soc Nurs Sci).* 2007; 1(1): 23-34. doi: 10.1016/S1976-1317(08)60006-7

17. Merriman A. *Audacity to Love: The Story of Hospice Africa.* Dublin, Ireland: Irish Hospice Foundation; 2010: doi: 10.1002/PON.2024

18. Stajduhar K, Cohen R. Family caregiving in the home. In: *Family Carers and Palliative Care.* In: Hudson P, Payne S, ed. Oxford, United Kingdom: Oxford University Press; 2009.

19. Yabroff KR, Davis WW, Lamont EB, Fahey A, Topor M, Brown ML, et al. Patient time costs associated with cancer care. *J Natl Cancer Inst.* 2007; 99(1): 14-23. doi: 10.1093/jnci/djk001

20. Weitzner MA, Mcmillan SC, Jacobsen PB. Family caregiver quality of life: Differences between curative and palliative cancer treatment settings. *J Pain Symptom Manage.* 1999; 17(6): 418-428. doi: 10.1016/s0885-3924(99)00014-7

21. Stenberg U, Ruland CM, Miaskowski C. Review of the literature on the effects of caring for a patient with cancer. *Psycho-oncology.* 2010; 19: 1013-1025. doi: 10.1002/pon.1670

22. Fisher D, Briggs H, Carers Association of Australia. Warning: Caring is a health hazard: Results of the 1999 national survey of carer health and wellbeing. Australia: Carers Association of Australia; 2000.

23. Schofield HL, Herrman HE, Bloch S. A profile of Australian

family caregivers: Diversity of roles and circumstances. *Aust N Z J Public Health*. 1997; 21: 59-66.

24. Northouse LL, Katapodi MC, Song L, Zhang L, Mood DW. Interventions with family caregivers of cancer patients: Meta-analysis of randomized trials. *CA Cancer J Clin*. 2010; 60(5): 317-339. doi: 10.3322/caac.20081

25. Taylor EJ. Nurses caring for the spirit: Patients with cancer and family caregiver expectations. *Oncol Nurs Forum*. 2003; 30 (4): 585-590. doi: 10.1188/03.ONF.585-590

26. Fast J. Caregiving for Older Adults with Disabilities: Present Costs, Future Challenges. IRPP Study. 2015. Web site. https://irpp.org/wp-content/uploads/2015/12/study-no58.pdf. Accessed on June 15, 2021.

27. Armstrong P, Clow B, Grant K, Haworth-Brockman M, Jackson B, Pederson A, et al. *Thinking Women and Health Care Reform in Canada*. Toronto, Canada: Women's Press: 2007;

28. Research on Aging, Policies and Practice. Employment consequences of family/friend caregiving in Canada. Web site. https://rapp.ualberta.ca/wp-content/uploads/sites/49/2018/04/2011EmploymentConsequencesFFCaregiving.pdf. 2011.