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Short Communication

Ethical Challenges to Respecting and Meeting Patients' Requests: Lessons from Providing Palliative Care for Coronavirus Disease 2019 Patients

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INTRODUCTION

The World Health Organization (WHO) defines palliative care as: “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”¹ Thus, palliative care is associated with chronic, serious illnesses. However, coronavirus disease 2019 (COVID-19) is a novel disease presenting acutely with acute symptoms but requiring the level of care, even in an urgent manner that patients with chronic serious illnesses that are normally associated with palliative care require. Palliative care clinicians are uniquely equipped to address the suffering of COVID-19, especially where the health system is significantly strained. This is accomplished through high-level communication and symptom management skills and a transdisciplinary approach to address physical, emotional, and existential suffering.² It is within the ability and the ethical duty of palliative care to relieve suffering, physical pain and other symptoms.³

However, as the world accepts the role of palliative care in managing COVID-19, it is important to assess the ethical challenges that the palliative care provision system as we know it today is facing given the new context.⁴ Patients, caregivers, healthcare providers, and health systems can benefit from the extensive knowledge of the palliative care community by urgently considering to improve access to essential medicines, particularly opioids for the relief of breathlessness and pain the two key symptoms that patients with COVID-19 faces and the palliative care fraternity are well-versed in managing.⁵

COVID-19 has ravaged many parts of the world sparing no country or any sphere of life including economic, political and social arenas.⁶ The most significant challenge has been in the medical field. Clinical care is guided by the principles of medical practice; respect for autonomy, beneficence, non-maleficence and justice as popularized by Beauchamp and Childress.⁷ Some of the values that underpin the principles of respect for autonomy and justice that have been seriously challenged by the situation COVID-19 has placed the world and the interrelationship between these two principles will also be outlined. I will discuss some values that underpin the principles of respect for autonomy and justice that have been seriously challenged by the situation COVID-19 has placed the world in.⁸ The interrelationship between these two principles will also be outlined.

DOCTOR- PATIENT RELATIONSHIP

Healthcare is provided within the doctor-patient relationship of trust. To maintain this value of trust, the healthcare provider is obligated to respect the patient's autonomy and the inherent choices that they make. The principle of respect for autonomy is well-documented in the Universal Declaration of Human rights and many national constitutions.⁹ The Universal Declaration of Human Rights, National Constitutions and Rights Charters across the world detail the rights to access of highest quality of care, right to confidentiality, right to informed consent and the right to select the healthcare provider of choice.¹⁰ However, COVID-19 has brought questions on how feasible these guidelines, policies and internationally accepted laws are.¹¹

In respecting autonomy, there are directives for the recognition of choices made by competent patients so as to honor

their liberty, privacy and integrity as independent beings. In case of informed consent, the patient is given information regarding their diagnosis, the available treatment options, the side-effects of these treatment and what the outcome of non-treatment may be. This entails clear and detailed communication which might be in multiple sittings thus providing full disclosure on the elements mentioned above. However, in the context of a pandemic like COVID-19 these values and ethos are not assured or even practical.

CAPACITY TO MAKE DECISION ON HEALTHCARE PROVISION

Capacity is important as it enables the patient to use their right to decide what happens to their own body.¹² But the consenting person must be able to fully comprehend the information being given in form of a full disclosure, understand the options they have and eventually make voluntary decisions to receive or refuse treatment. In the context of COVID-19, where a lot is not yet known of the disease, where treatment is on trial bases and there is no standard treatment, it is questionable what full disclosure would mean. Further, is such a disease with severe negative outcomes (social and medical), presenting with sudden severe symptoms, capacity to make any well-informed treatment decision may be significantly limited. There is a likelihood of clouded judgment when making decisions for or against treatment or when giving consent for any recommended medical intervention. This is significantly complicated by the fact that access to the treatments being recommended is also curtailed by multiple other factors.

PRIVACY AND CONFIDENTIALITY

These values are key to respecting autonomy and form the core of this principle in regards to patients controlling information about and regarding themselves. However, an infectious pandemic demands that others are warned of the likelihood of contamination emanating from their interaction with the infected person. As such, personal medical information is collected and collated to be used in controlling the spread of an infection. The infected person cannot refuse to provide this information in this context. Nor can the treating health care providers withhold this information from the authorities by invoking protection by the clauses of confidentiality and privacy. It would be argued that authorities are justified in doing so in order to avoid massive loss of lives from the spread of infections. Further, the freedom and liberty of the infected person is limited and they cannot be free to be treated in the institutions of their choices as there are usually designated treating centers. Nor can they move or interact as they usually do. Thus, the right to privacy and confidentiality conflicts with the right to health begging the question of the obligation that we have to society *vis a vis* their obligation to respect our individual liberties. Considering the concept of triage, it's composition by clinicians and non-clinicians, the limited resources that guide towards its use, confidential information is thus shared with other health care workers and non-health care personnel who are not immediately involved in the patient's care.

HUMAN DIGNITY

As Kant would say, autonomy belongs to moral agents who are able

to reason and rationalize. Human dignity is a fundamental characteristic of these rational agents and need to be fully respected. At the foundation of dignity, is the respect of personal choices irrespective of the consequences. However, in a pandemic, the right to personal freedom may be limited by public health measures such as lock downs, curfews and social distancing. We therefore find that personal dignity is tramped on in favour of common good.

Right, timely and quality information leads a patient to reason, rationalize and make a decision. However, in the context of COVID-19, with overstretched and overworked health care personnel, it is difficult to assure the access of all information that the patient may need to make a decision. This, it would be argued, further limits dignity and thus challenges the fronting of respect for autonomy as the key to care provision.¹³ With this and the fact that only those who can afford are able to access even treatments on compassionate use, the concept of global distributive justice is negatively negated and significantly challenged as a guide to global access to health care. Further, these factors are likely sources of moral distress for health care providers because of the way they limit the care they can offer for their patients.

RESOURCES

The concepts of equity and equality form the ethos of the principle of justice in medical practice. The world is racing to develop effective treatment and therapies towards COVID-19.¹⁴ But the question arises on modalities to be used in ensuring the equitable worldwide distribution of vaccines and therapeutics resulting from the current ongoing biomedical innovations. Absent broad agreement and buy-in on those plans, governments may prioritize their own populations, resulting in inequitable distribution of medical products both within and among countries. Those in dire need for this consideration are those who are moderately or severely sick with COVID-19.

It might be difficult to conceptualize how resources relate to the principle of respect for autonomy. The limited resources demands an allocation that will consider the welfare of the majority even if a particular patient demands the said resource. This personalized need and demand may be overlooked and curtailed. At the peak of the pandemic, scarce resources such as ventilators, ICU beds, dialysis machines and the human capacity are not available for all patients who may be in need. Thus, the patient's choices are limited by the virtue of the unavailability and inaccessibility of the resources. In this way, despite the choices and preferences that the patients make, their autonomous decisions and demands may not be respected. The access to the highest available or attainable quality of health care enshrined in the International Declaration of Human Rights, many constitution and other human rights documents are challenged.

The concept of first come first served has been the key guide in ensuring that equity in access is assured in health care. But in a pandemic, this might not be feasible thus requiring the health care providers to utilize other modalities of decision making. COVID-19 has taught the medical fraternity that the concept of triage is the best guide on who is to access limited resources when de-

manded by many patients. The triage system uses multiple factors and considerations to arrive at a decision. The presence of other diseases or health conditions, the physiological status and laboratory findings of the patient at the given time are some of the factors considered in the triage system by a multi disciplinary team made up of clinicians and non-clinicians. This eventually avoids biases that might arise if only 1 factor is considered and is considered in many Guidelines to Ethical Decision Making during COVID-19. With a triage system, there is rationing of available resources that a patient has at their disposal and that they can access even if they demand the same. These patients, who are unable to access these services are then recommended to receive comfort care only. How then can we fully apply the principles of respect for autonomy and just access to resources in such situations?

CONCLUSION

In conclusion, it is evident that there are specific challenges in attempting to respect and implement a patient's demands in the context of COVID-19. These challenge are not only faced by the health care providers but also by the patients themselves, their families and policy makers. Of note is the fact that in the normal health care systems, the default application of the principles of respect for autonomy and distributive justice has the presupposition that health care resources and infrastructure are available and need just to be contextualized to the given patient's needs and demands. COVID-19 has taught us that health care resources and infrastructures are limited all over the world. As such, we are called upon to interrogate the principles of medical practice further on their applicability not only based on the various diverse global contexts but also the presentation of the diseases that mankind is bound to continue facing.

This commentary would further be enriched if we look at the other principles of medical practice; beneficence and non-maleficence. Encompassing these other 2 principles might have a broader view and thus a deeper understanding on the confounding factors and challenges faced by clinicians in their practice.

ETHICAL CONSIDERATION

This is a commentary article and did not therefore require ethics review

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Original Research

The Psychosocial and Economic Effects of Caring for Terminally Ill Patients: The Case of Hospice Africa Uganda

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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

According to the findings of two studies, one on elderly female caregivers conducted in Uganda⁴ 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 adaptation 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 poten-

tial 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^2) 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-III 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).

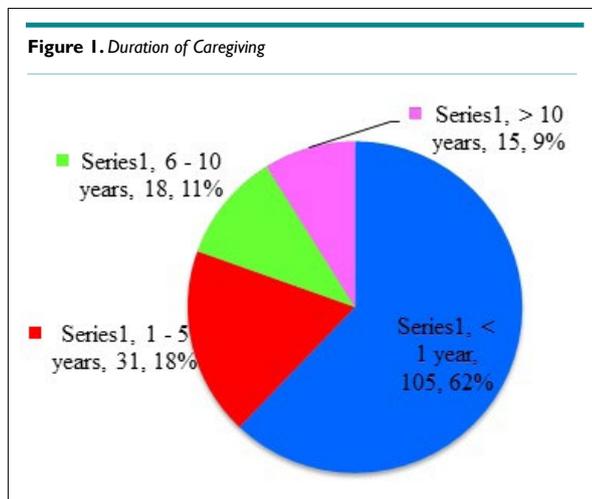


Figure 2 shows that most of the caretakers had caring sessions which were as long as 1-6-hours in a day (40%, n=67).

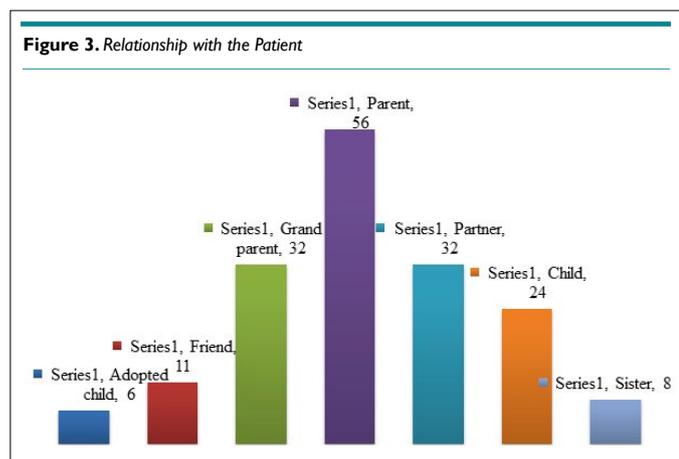
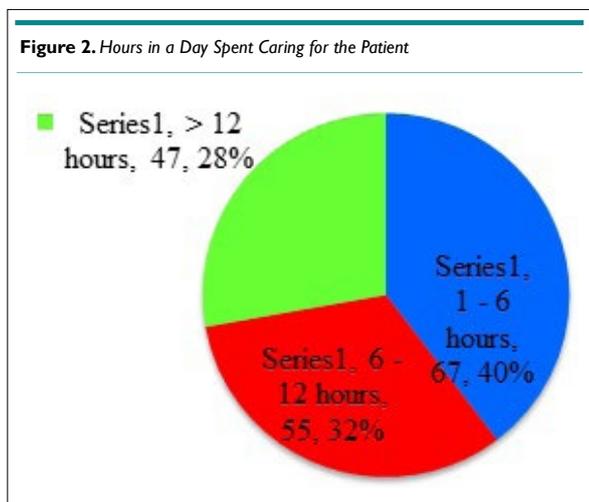


Figure 3 shows that most of the caretakers were parents (56), grandparents (32), and partners (32) to the patients.

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).

| 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

| 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 |

| 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).”

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).”

“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

“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-III 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 III 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(0.0%) | | |
| 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 |
| 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 | |
| < 1-year | 70 (66.7%) | 15 (14.3%) | 20 (19.0%) | 6.556 |
| 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-III 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 were 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 al²⁰ 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 responsibilities²⁶; 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 caregiv-

ing 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).

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Original Research

A Community Engagement Model to Drive Advance Directive Discussion and Completion

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ABSTRACT

Background

Advance directives (ADs) describe individuals' preferences for life-sustaining treatments and/or surrogate decision-makers, to help avoid unwanted, burdensome treatments at the end-of-life. However, only 36.7% of adults have completed an AD. There is growing interest in adopting a public health approach to end-of-life care, including ADs. We describe the experience of Honoring Choices Tennessee (HCT) which developed a pilot program, Advance Directives at Work in Tennessee (AD@WorkTN), to enhance AD completion by the general public workforce.

Methods

The AD@WorkTN initiative targeted adults in the Tennessee workforce by engaging human resource (HR) leaders in educational presentations. Each workshop provided resources to employers to integrate ADs into the employee orientation and benefits enrollment process. Educational materials, web tools, podcasts, AD forms, and a demonstration of how to complete an AD were included. Participants were directed to the HCT website which contains the state advance directive documents and with detailed instructions, as well as the co-branded MyDirectives app (MYD), to securely upload completed ADs. In April 2021 a HCT sponsored PBS documentary on advance care planning was produced with statewide distribution.

Results

Over a 2-year period, 58 workshops were conducted for 260 human resources leaders representing 958 businesses. As a result, 23 businesses have included ADs as part of the employee benefit process. Additionally, a 2-year multifaceted public outreach campaign between 2019-21 has reached 2,950 employees and 958 businesses. Approximately 81,500 Tennessee viewers have seen the Public Broadcasting Service (PBS) documentary on advance care planning. There have been 2,954 visits to the HCT website and 411 visits to the co-branded MyDirectives site.

Conclusion

AD@WorkTN is a promising model to promote integration of ADs into the employee orientation and benefits enrollment processes. Enhanced discussion and completion of ADs among employed individuals and enhanced public discourse such as podcasts and television productions may encourage intergenerational conversations about end-of-life care and documentation in healthcare records.

Keywords

Palliative care; Advance directives; Community outreach.

INTRODUCTION

Medicine is innovative, but there is a threat that individuals may receive burdensome therapies at the end-of-life that can contribute to suffering. Advance care planning documents, includ-

ing advance directives, living wills, and health care powers of attorney, allow patients to describe their preferences for life-sustaining treatments and/or surrogate decision-makers, to help them avoid unwanted treatments in the setting of terminal illness or incapacity.¹

The initiative to complete advance directives has its origins in healthcare systems. In the wake of the Cruzan Supreme Court case, the Patient Self-Determination Act was signed into law in 1990 with a goal of increasing patient involvement in decisions regarding life-sustaining treatments by ensuring that advance directives are available to health care providers. This law required facilities and organizations to not only discuss advance directives with patients, but also to develop institutional policies concerning advance directives and decisions to withhold or withdraw life-sustaining treatment.²

Unfortunately, despite these healthcare mandates, few adults have completed documentation of their advance directives. One systematic review examining studies published from 2011-2016 found that only 36.7% of adults had completed an advance directive.¹ To combat these deficiencies, there is growing interest in adopting a public health approach to end-of-life care, including advance care planning, and to engage the community in completion of these documents.³

Historically, embracing hospice and palliative care has been slower in the Southeast than in other US regions. However, having an advance care plan alleviates anxiety among patients, and (surviving) family members report improved satisfaction with the quality of care received.⁴ Patients are also more likely to receive care according to their preferences, have fewer hospitalizations, and overall less costly care. Surveys and focus groups of patients have demonstrated that there is an overwhelming preference for opportunities to plan for the end of life. Public education on advance care planning has been conducted in various settings, including the workplace, and is important to promote intergenerational discussion and completion of advance directives.

Here we describe a multifaceted, employer-based model of public outreach to enhance advance directive discussion and completion.

Context

Honoring Choices Tennessee (HCT) has been in existence since 2015 and is part of the national Honoring Choices movement that began in 2008. There are more than a dozen Honoring Choices organizations around the country, all with the common interest in helping Americans live their very best life. Honoring Choices is based on the training, principles, and overall methodology of Respecting Choices, the nationally and internationally recognized Advance Care Planning model developed by Gundersen Health System in La Crosse, Wisconsin. The Tennessee organization is sponsored by 12 organizations including the Tennessee Medical Association, the Tennessee Hospital Association, and the Tennessee Nurses Association. It has developed a public education website <http://advancedirectivestn.org>⁵ and sponsored Healthcare Decisions Day events at several large medical centers in Tennessee.

MyDirectives (MYD) at <https://mydirectives.com/>, is a site which is co-branded with HCT and contains advance directive forms permitting individuals to upload their advance directives for storage in the cloud.⁶ The Advance Directives at Work in Tennessee (AD@WorkTN) is an initiative led by HCT to encourage Ten-

nesseans within the workforce, particularly those ages 30 to 65, to create an advance directive. The AD@WorkTN program has the following objectives: 1) to implement a public engagement, communications, and educational outreach about advance directives to human resources and benefits professionals at businesses, healthcare systems and higher educational institutions across Tennessee; 2) to disseminate educational materials and web tools that enable employers to institutionalize advance directives as part of their employee orientation and workplace benefits enrollment process; and 3) to increase the numbers within the Tennessee workforce that complete advance directives (ADs). The overarching goal of the AD@WorkTN program is to create a large-scale cultural shift across Tennessee whereby employers integrate Advance Care Planning into their employee benefits programs. This program allows for a multi-generational focus on ADs, positively impacting the future of health care for geriatric and other patients across Tennessee.

METHODS

Between July 2019 and June 2021, the AD@WorkTN program, as part of HCT, a number of resources were created including a patient-friendly website with ADs in English and Spanish with accompanying videos explaining both ADs and how to complete an AD. Educational materials explaining the importance of completing advance directives were produced both to train speakers and for distribution to workplace audiences. These resources were utilized in presentations to human resource (HR) leaders as well as during health fairs and 'lunch and learns' held for employees. Additionally, workplace audiences observed demonstrations about how to easily create one's own advance directive. The program co-branded with MyDirectives to include an app with Tennessee state advance care planning documents and instructions for completion. The MYD app also permitted secure uploading and storage of completed ADs.

In April 2021, HCT partnered with Public Broadcasting Service (PBS) affiliate WNKO in Memphis, to produce a documentary program edition of BestTimes, an ongoing series of programs produced by the affiliate. The production was timed to coincide with National Healthcare Decisions Day, a national program initiated by Honoring Choices in order to promote advance care plan completion on the day following tax-day. This production featured current data and messaging around the importance and convenience of advance care planning in Tennessee. The program aired statewide through the six local PBS affiliates.

Our overall study was designed to meet standards for quality improvement reporting excellence (SQUIRE) criteria, and this report meets the quality improvement minimum quality criteria set (QI-MQCS) domains for reporting quality improvement work.^{7,8} The Vanderbilt Institutional Review Board (IRB) has determined and approved this study as a quality improvement initiative. This work is supported in part by the Geriatric Workforce Enhancement Program, HRSA Grant: 1-U1Q-HP 033085-01-00.

RESULTS

Over a 2-year period, HCT produced 58 workshops and health

fairs, reaching 260 human resource leaders, 958 businesses and 2,950 employees. During the same time, there were 2,954 visits to the HCT site and 411 visits to the co-branded MYD site with 10 advance directives uploaded. The PBS documentary was seen by some 81,500 viewers statewide over a 3-month period (Table 1). Data analytics of the HCT site indicated that a sharp rise in visits correlated with numbers of workshops held and employees reached, while the MYD site showed a slower steady upward trend in visits throughout the intervention period (Figure 1).

DISCUSSION

Our results suggest that human resource directors and employers are willing to educate employees about advance directives and offer this service as part of the benefits program. Outreach to large numbers of individuals through health fairs and workshops is feasible. Our results indicate that employees visit the HCT site during the time frame of the educational intervention but the correlation between website activity and advance care planning completion is not a direct relationship. Translation to a completed advance care plan may be more gradual over a prolonged time frame.

Public engagement to create advance directives is a process with multiple interactive effects. Early completion of advance care plans continues to be a challenge. A systematic review of 795,909 US adults revealed that most ADs are completed by

persons with advanced disease states and are more likely to be completed by persons older than age sixty-five and/or in a nursing home.¹ Advance care planning documents are often general, lacking specificity for individual health status, and only represent a person's wishes at one time, requiring updates as health and surrogate decision-makers change.⁹⁻¹¹

Despite the challenges of advance care planning, this continues to serve an important purpose for guiding healthcare decisions. In one study, 42.5% of elderly decedents had required decision-making about treatments in the final stages of life, and 70.3% of those lacked decision-making capacity.¹² Of those who lacked decision-making capacity, the presence of a living will was associated with a strong agreement between stated preferences and the care received.¹²

LIMITATIONS

Time course of this study was short, and it may be too early to know the influence of the PBS documentary on driving traffic to the HCT site, and the influence of employee education on inter-generational discussion with older family members regarding advance care planning. Additionally, other social influences and individual factors affect visits to the HCT and MYD sites such as internet access or other connectivity issues.

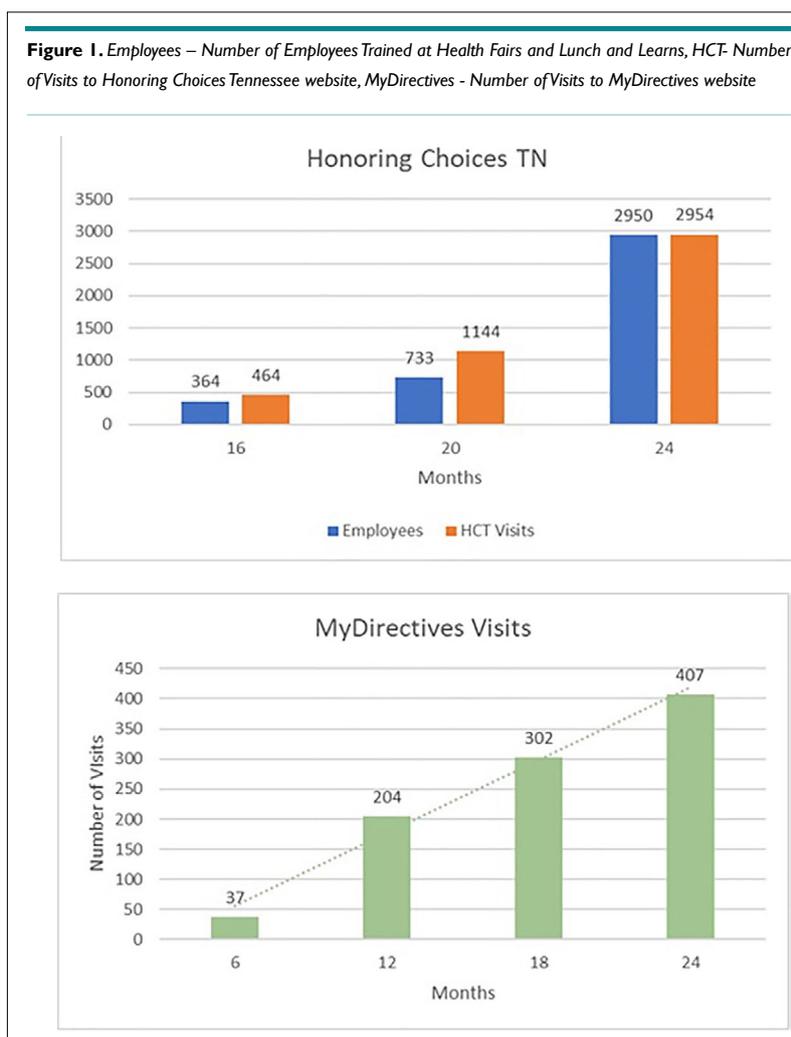


Table 1. HCT- Honoring Choices® Tennessee Website, MYD-MyDirectives Website

| Interventions | Date | Cumulative Nnumber | | |
|--------------------|------------|--------------------|----------------|-----------------|
| Workshops | Oct 20 | 11 events | 154 businesses | 364 employees |
| | Feb 21 | 38 events | 674 businesses | 733 employees |
| | June 21 | 58 events | 958 businesses | 2,950 employees |
| PBS Documentary | Apr/May 21 | 9 broadcasts | 18,500 views | |
| Outcomes | Date | Cumulative Number | | |
| Visits to HCT Site | Oct 20 | 464 | | |
| | Feb 21 | 1,144 | | |
| | June 21 | 2,954 | | |
| Visits to MYD Site | Dec 19 | 37 | | |
| | June 20 | 204 | | |
| | Dec 20 | 302 | | |
| | June 21 | 407 | | |

CONCLUSION

AD@WorkTN is a promising model to promote integration of ADs into the employee orientation and benefits enrollment processes. Enhanced discussion and completion of ADs among employed individuals and enhanced public discourse may encourage intergenerational conversations about end-of-life care and enhance documentation in healthcare records.

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AUTHOR CONTRIBUTIONS

KLH, ET, JSP: Concept, design, analysis, interpretation; EH, SR: Preparation of manuscript.

INSTITUTIONAL REVIEW BOARD APPROVAL

The TVHS Institutional Review Board (IRB) has determined and approved this study as a quality improvement initiative.

CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest.

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