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KNOWLEDGE AND PRACTICES OF FAMILY CAREGIVERS OF TERMINALLY ILL PATIENTS AT THE TAMALE REGIONAL HOSPITAL

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Abstract

The goal of this study was to evaluate the knowledge of family Caregivers in caring for terminally ill sufferers, to assess the practices of household Caregivers in caring for terminally ill sufferers, to examine the factors affecting household Caregivers in caring for terminally ill sufferers at the Tamale Regional Hospital. The findings show that there is the need for a caregiver to be present and ready to offer help to the patients due to their inability to move. Terminally ill patients may mostly be immobile or incapable of performing basic life functions without external support. It appears from the engagement with respondents that, the latter have appreciable knowledge of the concept of palliative care and care for terminally ill patients. They understand the challenging situation of terminally ill patients and are equally aware of what constitutes care for the sufferer. Also, family caregiver showed evidence of knowledge of health workers role in palliative care. They indicated that health workers had a crucial role to play in giving palliative care to the terminally ill patient. Doctors had the responsibility of prescribing medications while nurses also educate relatives and caregivers on palliative care. More so, health workers assisted in the caring of patients by assisting caregivers to physically move patients. Caregivers who could not move their patients due to the latters weight had to be assisted by some health workers. The result also indicates health workers played a crucial role in caring for terminally ill patients, of which caregivers were aware. The study further found that the other effect of caring for terminally ill patients was financial demands. To overcome this burden, the study recommends that caregivers had to cut their expenditures and request financial support from relatives and friends as family support was also a mechanism used in coping with the burden of caring for terminally ill patients. Also, the Tamale Regional Hospital should incorporate the services of family caregivers in the care of terminally ill patients. Their competence would immensely contribute to the improvement in the health of terminally ill patients. Further, the Ministry of Health should develop policies that will lessen burden on family caregivers of patients suffering from terminal diseases.

INTRODUCTION

As argued by Karnik and Kanekar (2016), medical treatments like as artificial feeding and respiratory support can prolong peoples lives by providing secondary care, even when many modern medications and technologies do not cure chronic diseases. Despite this technological development in prolonging life, there are some sicknesses that life-sustaining mechanisms can fail to prove successful, especially where the patient is terminally ill. Steinbock, (2005) added that numerous nurses would have cared for patients who viewed death as a joyful release from severe agony and suffering if their ailments could be cured. If a patient is terminally ill, his or her family and health care providers may think that life-sustaining therapy is no longer in the patients best interests. The idea of discontinuing active, life-sustaining treatment may be disturbing for nurses whose education and practise are centred on life preservation.

This study defines a terminally sick patient as a patient who cannot be cured, even with the request of interdisciplinary therapy, or when vigorous medication is deemed insufficient for the patient. Miaskowski *et al.*, (2020) found that the average life expectancy for terminally sick individuals is six months or fewer. Terminally ill patients are often assisted by family caregivers. And because the profession does not often require a household partner, family caregivers are typically referred to as informal carers. The function is distinguished by the need for subjective aid as well as physical management or administration. According to The Narcotics and Board, (2020) relatives of terminally ill patients have essential roles to play towards the last stages of their family members life as they design the duration for patients, since the providing fair and credible caretaker assistance and cultivating a positive perception of end-of-life care have a significant impact on the patients physiological or expressive well-being (Penrod et al., 2011).

End-of-life care has become increasingly important in modern medical practise. According to Thorns (2010), this process begins with the diagnosis of a terminal disease and includes the patients desire for a dignified death as well as the mourning period that follows. Patients nearing the end of their life face unnecessary challenges and anguish. Family members, close friends, and informal caregivers of patients may face a range of challenges as they play critical roles in their loved ones end-of-life care before, during, and after death (McDaniel et al., 2004). When families of terminally sick patients are unable to ease their loved ones suffering after obtaining a death prognosis, they may experience pessimism, anger, guilt, and helplessness. As a result, they may be worried about alleviating their loved ones pain. The goals of treatment for terminally ill patients are to relieve pain, improve quality of life until death, and provide comfort after death (Do, 2017).

However, achieving these goals is not always easy. Because physicians, patients, and patients families must make judgments on treatment alternatives such as whether to employ medical technology to prolong a persons life, let the natural dying process to proceed, or offer palliative care for the patient. Palliative care is a type of medical therapy for individuals who are nearing the end of their lives. This type of therapy focuses on reducing the symptoms and stress caused by the condition. The goal is to enhance the patients and familys quality of life. Palliative care is provided by a team of specially trained physicians, nurses, and other professionals who work with a patients other doctors to give additional support. Palliative care is centred on the patients needs rather than his or her prognosis. It is suitable for patients of any age and at any stage of a serious disease, and it can be used in conjunction with curative therapy. The quality of life is prioritised by palliative care teams. They address the symptoms and stress associated with major diseases such as cancer, congestive heart failure (CHF), chronic pulmonary disease (COPD), renal disease, Alzheimers, Parkinsons, Amyotrophic Lateral Sclerosis (ALS), and others. In effect, palliative care will help to improve your quality of life.

Mausbach *et al.*, (2007) advised that while providing palliative and end-of-life care, the values, needs, and choices of patients and their families should be considered as the illness progresses. Patients and families have a variety of care alternatives, allowing clinicians to personalize their services to the patients and his or her familys individual needs. However, sometimes attention for a patient with a terminal disease is difficult. It contains extremely characteristics such as information, organising the diseases medication characteristics, providing relaxing maintenance, providing expressive assistance for the disappearing individual or either his or her special ones, or dealing with the psychosocial or spiritual problems extended by the disease (Karunamuni et al., 2021).

Although the assistance of household Caregivers has been the main principle of palliative maintenance for decades, a limited number of these interventions have been developed for Caregivers of victims at end-of-life (Becqué et al., 2019). Nursing practitioners, particularly those who care for patients with serious conditions, should be educated in palliative care skills as members of multidisciplinary teams. One component of palliative maintenance aid rescue is expert palliative care. However, a long-lasting, trustworthy, and vulnerable palliative care strategy must be integrated into major medical maintenance, population, and home-based maintenance, as well as assisting care providers such as household or neighbourhood recruitment. Therefore, palliative care should be viewed as a moral obligation for medical professionals (Rome et al., 2011). Despite increased awareness of end-of-life maintenance issues, there has been a lack of exercise in medical institutes or occupancy projects. While medical schools now provide some training in this sector, it is frequently insufficient to meet the needs of the students.

Furthermore, no extraordinary education has been provided to people or practising doctors. A study by the World Health Organisation, (2018) on non-communicable illnesses among 194 Member States in 2019 indicated that palliative care was accessible in 68% of nations and simply 40% of regions documented that the assistance attained at limited half of patients in necessity. Furthermore, research has found that tendencies covering the region of maintenance and the area of demise may not be similar, which may explain some of the experimental contradictions between proclaimed tendencies and the area of the casualty.

In some cases, the terms hospital care and palliative care are used interchangeably. Hospital care is a network of help delivery that provides palliative care/medicine when life expectancy is six months or less and corrective and life-prolonging medication is not prolonged. It is important to note, however, that while a hospital provides palliative care, soothing care is not provided by hospitals. The nursing home help delivery policy does not cover all available therapeutic analgesic maintenance modalities (National Quality Forum, 2006). Despite the fact that the majority of the primary care to deliver has limited and unconventional work in this context, patients are constantly given palliative end-of-life maintenance (Eifert et al., 2015).

Family caregivers may also experience burnout, which can cause early nursing home placement for the care recipient. Most alarming, family caregivers experience an increased mortality rate and are at a greater risk for abusing the care recipient as a consequence of stress and burden (Simon et al., 2020). Various programs and interventions have been developed to assist family caregivers to cope with the demands of caregiving. These support services include assistance with caregiving or related tasks and emotional or educational support that is provided to family caregivers by health professionals and community service providers. According to Taylor, (2019) some aspects of end-of-life care may seem paradoxical, and nurses may find it challenging to set aside their natural urge to do all that is possible to prolong life. Household caregiving is important to the well-being of victims with significant diseases. Household partners accomplish important duties like encouraging day-to-day tasks, organizing maintenance among several medical scrutiny givers, and giving medical maintenance. The significance of household Caregivers on the maintenance of patients with significant diseases has provoked the improvement of a variety of interventions formulated to improve caregiver well-being (Rosino, 2016).

Problem Statement

According to McLennon et al. (2014), the prevalence of persons with chronic disease or disability who require some sort of intermittent or long-term care will rise as the population ages. The majority of the care obligation will fall on family, such as spouses and adult children, and will drastically alter their daily life. Family members are no longer merely husband, wife, partner, significant other, son, or daughter, but also caregivers. According to McCorkle and Pasacreta (2001), familial or informal caregiving is a difficult, time-consuming task that frequently has an influence on the caregivers social, emotional, and financial wellbeing. The impact of giving care on carers social, vocational, and personal duties has been termed as caregiver load. Studies of family carers [see (Gitlin & Wolff, 2012; National Quality Forum, 2006; Rome et al., 2011; Wu et al., 2020)] reveal that stress and load might negatively impact their physical and mental health. Negative health consequences have been observed, including depression and overall poor health, including a weakened immune system and increased blood pressure (Mangan et al., 2003).

According to Rome et al., (2011) caring for patients with terminal illnesses is not widely reported among informal carers globally. This is due to the fact that prolonged hospitalisation occurs when a patients access to the clinic is broad for explanations properly recognised by the health coalition. Empirical investigations in Sub-Saharan Africa have shown that informal caregivers may fulfil the caring position adequately during the course of twenty-four hours in the hospital. Nonetheless, despite personal aspirations or problems, informal caregivers behaviours in caring for terminally ill patients have gotten less attention.

Despite this, family caregivers continue to express their curiosity about why patients must undergo extensive treatment, which has horrible side effects if there is no belief in the rational integrity of existence. They have also expressed concern about the impact it will have on them and the entire household (Taylor, 2015). Some patients at the Tamale Regional Hospital have been on access for an extended period of time due to terminal disease, which has a draining effect on their household caregivers. There is a subset of critically sick patients who anticipate prolonged mechanical breathing and a high level of medical care to increase their chances of survival. However, there is no baseline data at the institution on how these informal caregivers feel about caring for these patients. The researcher is of the view that there is lack of basic information on family caregivers of terminally ill patients in the Tamale metropolis. There appears to be no concerted attempt to investigate this trait and establish a comparable standard. There is no research which suggest any legal or compatible collaboration between researchers and family caregivers of terminally ill patients in Northern Ghana. This, therefore, provides the need for an empirical study on this concept at the study institution of which this study aimes to explore.

Purpose of the Study

The aim of the study is to explore and describe the end-of-life care knowledge and practices of family caregivers of terminally ill patients at the Tamale regional hospital, Ghana. This study thus provides insight into the contextual practices of caregivers caring for terminally ill patients that are frequently excluded through researchers and have effects on patients and caregivers.

Research Objectives

The specific objectives of the study are;

1. To evaluate the knowledge of family Caregivers in caring for terminally ill patients at the Tamale Regional Hospital
2. To assess the practices of household Caregivers in caring for terminally ill patients at the Tamale Regional Hospital
3. To examine the factors affecting household Caregivers in caring for terminally ill patients at the Tamale Regional Hospital.

Research Questions

1. What is the knowledge of caregivers in caring for terminally sick patients at the Tamale Regional Hospital?
2. What are the practices of caregivers in caring for terminally ill patients at the Tamale Regional Hospital?
3. What are the factors affecting caregivers in caring for terminally ill patients at the Tamale Regional Hospital?

Significance of the Study

The study would provide information concerning how caregivers over the years have cared for terminally ill patients in hospital settings in the context of the Northern region which has not been adequately captured. The information would provide direction to health professionals concerning the practices of caregivers in caring for terminally ill patients in hospital settings worthy of consideration and policy action. The findings, if published, would provide information to the Ministry of Health (MoH), Ghana Health Service (GHS), and the Tamale Metropolitan Health Directorate on the practices of caregivers in taking care of terminally ill patients. The findings would also serve as baseline data for the researchers at the study setting who may one day use it for references.

Definition of Terms

Caregiver Assessment - A systematic approach of gathering information that characterises a caregiving scenario and highlights the individual issues, needs, resources, and skills of the family caregiver. It approaches difficulties from the caregivers viewpoint and culture, focuses on the assistance the caregiver may require and the outcomes the family member seeks for support, and strives to preserve the caregivers own health and well-being.

Caregiver knowledge: Caregiver knowledge relates to a caregivers capacity to observe, understand, and make choices while dealing with the sick person.

Care Recipient — An adult suffering from a chronic sickness or disabling condition, or an elderly person who need continuing assistance with daily tasks. Furthermore, the client in need of help may require primary and acute medical care, as well as rehabilitation services (occupational, speech and physical therapies).

End of Life: Stage of disease that are anticipated to expire in casualty and for which no medication can remedy the underlying disorder.

End-of-Life Care: nursing maintenance given to people with diseases that are anticipated to end in casualty and for which no medication can remedy the underlying illness.

Family (Informal) Caregiver - any relative, partner, friend, or neighbour who has a substantial personal relationship with an elderly person or an adult with a chronic or disabling condition and provides a wide range of assistance for them. These individuals may be primary or secondary caregivers, and they may reside with or apart from the individual receiving care.

Terminally Ill Patient: A terminal ill patient is one that cannot be cured and will almost certainly result in death. These are individuals who has been certified by a physician as having an illness or physical condition that will result in death within 24 months or less of the date of certification.

LITERATURE REVIEW

Caregivers in Caring for Terminally Ill Patients

A caretaker is anyone who gives care to another individual in desire, such as a teenager, an aging parent, a wife or husband, a relative, companion, or compatriot. A caretaker moreover may be an expanded expert who gives care in the residence and in an area that is not the individuals house. The population who are not reimbursed to provide maintenance are named simple Caregivers and household Caregivers. This truth paper concentrates on household Caregivers who give care yearly for a loved one with pain, an illness such as dementia, and a disability. The household caretaker frequently has to organize the individuals everyday life. This can be enabled with daily duties like bathing, eating, or carrying drugs. It can moreover contain organizing workouts and formulating medical and economic judgments (Payne, 2010).

Caretaker pressure is due to the subjective or bodily stress of caregiving. Caretakers document largely increased categories of pressure than populations who are not Caregivers. Several Caregivers are assisting and are on-call nearly all day. Periodically, this suggests there is a limited period for function and further household components and partners. Many Caregivers may realize they are dominated by the proportion of maintenance their aging, unhealthy, and impaired family component desires. Although maintenance providing can be relatively demanding, it moreover has its satisfaction. It is adequate to be eligible to look after an admired one. Expending duration jointly can provide modern importance to your connection. Know that you require to receive maintenance of yourself to be eligible to attend for your adored one. Understand some directions to manage caregiver burden or discover reserves (Saniah & Zainal, 2010).

Anyone can bring caregiver tension, but more women Caregivers explain they have pressure and other fitness difficulties than men Caregivers. And some women have a greater chance for fitness difficulties from caretaker pressure, containing those who:

Look for a loved one who requires continual health maintenance or management. Caregivers of individuals with Alzheimers disorder and dementia are further inclined to have fitness difficulties and to be annoyed than Caregivers of individuals with situations that do not expect continual care.

Maintenance for a partner. Women who are Caregivers of partners are further liable to have great blood pressure, diabetes, and increased cholesterol and are twice as liable to have heart disorder as women who give maintenance for others, particularly as parents and youngsters. Women Caregivers moreover may be slightly inclined to obtain normal screenings, or they may not give sufficient rest and usual bodily workout.

Frau et al., (2021) indicated that every caregiver had a formal and important relationship with the person they were caring for. Caregivers frequently stated that they understood the individual better than anyone else and knew what was best for them. Their understanding of the individual they were caring for enabled them to predict the unfavourable impact of specific efforts and to suggest changes in approach. Their care decisions, specifically assuring that their household partners remained at the house for as long as possible, were motivated by the distinction of the significance of achieving their loved ones desires. The carers believed that their role was to support their household partners. They expected specialists to value their understanding of the individual and their impressions that they were working in the individuals best interests in the midst of the maintenance (Wu et al., 2020).

They were also sure that they were making the greatest decisions for their loved ones. Despite their lack of understanding and preparation to live as carers, they were determined to do what was appropriate and beneficial for their loved ones, which motivated them to accept the role of caring for their household partner at home. The profound household connection evolved as caregivers realised it was their responsibility to care for their families at home (Mangan et al., 2003). Nonetheless, knowledge of, and decision to develop in, the profession was cited as the genuine part of performing for someone one loves. Understanding what the individual anticipated and what was adequate for them equipped carers to carry out their caring responsibilities. Four of the patients receiving home care had their wishes implemented and died at home, while two died in the clinic and one in a hospice, which had been their final option and location of choice (Simon et al., 2020).

Knowledge of Caregivers in Caring for Terminally Ill Patients

Carers are sometimes known as informal caregivers or lay caregivers, according to the American Cancer Society. The primary relative (caregiver) is usually a husband, partner, or an adult child. When family members are unavailable, close friends, coworkers, or neighbours may step in. Primary caregivers greatly assist patients and guide them in adhering to the rhythm of therapy, decreasing stress, and generally in all aspects of everyday life. Informal caregivers for terminally sick and dying patients encounter substantial obligations that can have a negative impact on their physical and mental health (McCorkle & Pasacreta, 2001). Informal caregivers knowledge and actions are displayed during any 24-hour period. Caregivers are expected to perform a variety of tasks, including supervision, decision making, problem solving, emotional comfort, physical care such as meal preparation, moving and handling, toiling, washing, and medication administration, and social care such as transportation and household organisation (Penrod et al., 2011). Family caregivers who lack the requisite knowledge and abilities may have feelings of insecurity about their role, as well as heightened stress and worry. Informal caregivers must retain their duties; they require significant support to reduce the load of giving care and must be supported, particularly in managing their own weariness and worry.

Practices of Caregivers in Caring for Terminally Ill Patients

Improving treatment for terminally ill patients is necessary not just in response to individuals who request assisted suicide, but also as a basic duty to all patients whose pain and suffering may be relieved by appropriate medical care. Pain and symptom relief for terminally ill patients in the hospital environment will make a significant difference in the patients and family caregivers quality of life. It can also help with recuperation time and give other significant medicinal advantages.

The patient and his or her family are the unit of care in palliative or end-of-life care. According to research with relatives of persons with life-limiting conditions, catering to the care requirements of families is critical (Becqué et al., 2019). Care requirements can be characterised not just in terms of particular family needs like getting information about the patients status, but also in terms of care needs that are vital to families like physical comfort.

Factors Affecting Caregivers in Caring for Terminally Ill Patients

Caring for terminally sick people can have both vocational and financial effects. Empirical research have found that, even when benefits for caring for terminally ill patients are provided, family members may face difficulties navigating the system. Family caregivers are sometimes confronted with issues related to the care and comfort of terminally ill patients, as well as the stress of coping with the protracted hospitalisation of terminally sick family members (Payne, 2010). Because terminally ill people may not always recover, they must always face with death. This is because some people regard it as an excessive waste of reasonable time and resources. Caregivers are frequently confronted with the disintegration of their own emotional domain, whether due to weariness or fear over a lack of expertise. Their adaptive capacity has been impaired, necessitating the assistance of health specialists (Payne, 2010).

Theoretical Review

Resiliency Model of Stress Adjustment and Adaptation

Because terminally ill people may not always recover, they must always face with death. This is because some people regard it as an excessive waste of reasonable time and resources. Caregivers are frequently confronted with the disintegration of their own emotional domain, whether due to weariness or fear over a lack of expertise. Their adaptive capacity has been impaired, necessitating the assistance of health specialists (Rolland, 1987). Many existing research on family stress and coping argue that life events and stresses lead to psychological distress. Each component of the Family Resiliency Model has been addressed in relation to the adaptation process. The Family Resiliency Model revolves around the concept of family adaptability. It refers to the consequence of a familys attempts to manage a crisis scenario. It is described as the familys ability to meet both individual-to-family and family-to-community social expectations within the community. Figure 1 shows the Resiliency Model of Stress Adjustment and Adaptation. Below are some stressors identified in the model.

Family Stressor

A family stressor is a pressure imposed on the family that causes changes in the family system (Miaskowski et al., 2020). Family pressures on a person with a mental illness are expressed by the ill relatives disruptive behaviours, symptoms, and poor social functioning. Although caregivers face a variety of stressors (e.g., function adjustment, economic stress, end-of-life decision making, etc.), the stressors that have been extensively researched and linked most consistently to caregiver well-being are the patients bodily and mental disability, as well as the following duties and obligations required to meet his/her demands. The enormous importance of the patients disability, the significant concomitant demands of caregiving, and the higher the negative effect on caregiver well-being are all shared (National Quality Forum, 2006).

Many analgesic care researchers provide discriminatory assistance for this impression. For example, researchers report that caregivers of oncology patients with injury had more despair and worry than caregivers of patients without disability. Patient discomfort has received little attention as a key source of strain for caregivers. Furthermore, empirical studies have shown that valuing expressions with dissatisfied and joyful attitudes elicit the same emotions in the viewer. When the individual involved shares a close accord, powerful manners elicit powerful feelings, and the emphasis of enthusiasm is significant (Penrod et al., 2011).

Family Adaptation

The Family Resiliency Model is based on the idea of family adaptability. It is the result of a familys attempts to manage a crisis situation. It is defined as the familys capacity to satisfy societal expectations from both individuals and families within the community. The degree of adaptation ranges from nonadaptation to maladaptation. Nonadaptation is defined by (a) individual family members positive physical and mental health, (b) optimal role performance and growth, and (c) the preservation of a family unit so that it can complete life-cycle duties. Maladaptation is represented by the negative end of the spectrum (Rosino, 2016).

Family Resources

All of the individuals and institutions that a family relies on to get through a crisis are referred to as community resources. This list of resources includes both informal and formal sources, such as other family members, extended relatives, friends, and churches. The latter includes, for example, medical and social services. In family adaptation, it was commonly acknowledged that social support was an essential mediator between stress and family adaptability (Peacock et al., 2014). Capacity, according to the Family Resiliency Model, is described as the familys ability to cope with crises (Schulz et al., 2007). Individual family members, the family structure, and community social support are all potential sources of assistance. Families can draw on a range of personal resources while coping with mental illness, including their members intrinsic intellect, education, training, and experience, as well as their personality qualities, physical, spiritual, and emotional well-being. They can also depend on sentiments of mastery, self-esteem, and a common ethnic identity among its members (Narcotics & Board, 2020; National Quality Forum, 2006; Schulz et al., 2007; Triberti et al., 2019). The National Coalition for Hospice and Palliative Care, 2(018) explained that there are two most significant resources for the family systems which are cohesion (the ties of unity running through the family life) and adaptability (the familys power to overcome problems and modify course). However, the family background may have an influence on these factors (World Health Organization, 2007).

Justification for Resiliency Model of Stress Adjustment and Adaptation

The resilience model of family stress, adjustment, and adaptation is particularly valuable for investigating both the potential of chronic disease to contribute to family adaptation and the resources and coping patterns in the family that promote family wellbeing. Many research have been conducted to investigate the influence of resilience characteristics, particularly social support. The existence of social support may explain why some people face greater life pressures and strains yet do not display signs of suffering (Aoun et al., 2005). Several research investigated whether the severity of the disease is a factor in determining family stress in various family subsystems. According to Rome et al. (2011), the quantity of additional or unique caregiving duties was substantially linked with the degree of stress.

METHODOLOGY

Study Design

Adoption of the qualitative approach was found desirable due to the focus of the study. Since the study was purposed to report the subjective views of caregivers in taking care of terminally ill patients, using the qualitative approach was appropriate. Personal experiences and perspectives of caregivers in caring for terminally ill patients were adequately reported using the approach. The qualitative approach hence helped to engage the study participants in face-to-face engagement and collect first-hand information and qualitative data.

Research Setting

The research was carried out in Tamale Metropolis. Tamale is the fourth largest city in the country and the hub of all business activity in the northern sector. It has a population of 672,000 people (Ghana statistical Service, 2021). It lies in the centre of the Northern area, bordered by the Sagnarigu District to the west and north, the Mion District to the east, East Gonja to the south, and Central Gonja to the south-west.

The Dagombas are the largest ethnic group, although there are also Gonjas, Mamprusis, Akan, Dagaabas, Kusasis, Frafra, Walas, Moshie, and Fulanis. Other nationals from Africa and other parts of the world can also be found in the city (GSS, 2021). Muslims dominate the city, followed by Christians, spiritualists, and traditionalists. The citys roadways are generally decent, particularly those that connect the city to neighbouring district capitals. The areas asphalt roads make it simple to commute from one location to another (GSS, 2021). In addition, 60.1 percent of the population is literate, while 39.9 percent is illiterate. Male literacy rates (69.2 percent) are greater than female literacy rates (51.1 percent). (GSS, 2021).

Research Population

The research population included caregivers of terminally patients (both in-patient and out-patient) who accessed services at the hospitals at the time of the study. Based on the rationale of the study to report on experiences of caregivers of terminally ill patients, caregivers were the population selected for the study.

Inclusion Criteria

Relatives (one each) of patients who are undergoing end of life care for their illnesses at the time of the study were included in the study.

Exclusion Criteria

Relatives of patients who are not undergoing end of life care for their illnesses at the time of the study were excluded from the study. Also, patients with terminal conditions who have not consented were excluded from the study.

Sample Size

Sample is the smaller unit or group which is selected as a fair representation of a larger population. The sample used for the study was thirteen (13) caregivers of terminally ill patients. Qualitative research mostly involves between four to twenty-five participants (Holloway, 1997). However, the final sample size of participants was determined by data saturation. The views of 13 participants were used as the final sample for the study when no new information was available for collection.

Sampling Procedure

Purposive sampling technique was used to sample participants. This is a sampling technique in which the researcher relies on his/her own judgement when choosing study participants to participate in a study. According to Graneheim and Lundman (2004), purposive sampling technique refers to a sampling method where the researcher relies on his/her own judgement when choosing study participants to participate in a study. The advantage of using this sampling technique is that, it is easy to sample respondents and these people usually have the right response for the questions asked. The sampling method has the weakness of being bias in the selection of study participants. At the site, researcher identified caregivers of terminally ill patients using the assistance of health workers. Identified sample were spoken to and those who volunteered their participation were further engaged in conversation. Only caregivers of terminally ill patient were identified and approached for onward engagement. This method was followed until saturation was attained.

Data Collection Method

The data was gathered from the respondents using face to face and telephone interviews. Before the interviews, participants were told that it would be used for academic purposes only and that, no information they offered was to be used against them. The purpose of the study was explained to them. An interview was scheduled with the respondents to gather the needed information. Only respondents who voluntarily consented to participate in the study were scheduled for face-to-face engagement. Engagement with the respondent was undertaken using English language and/or Dagbani (a Ghanaian local dialect). Interviews done using the local dialect was upon the request of respondents, as both respondents and researcher were fluent with Dagbani.

Respondents were either met at the hospital or via a telephone. Those who were met personally were engaged after they have been pre-informed of the purpose of the study. While they offered care for their patient, researcher observed their practice and noted how they cared for their terminally ill patient. Afterwards, they were ushered into a comfortable area within the hospital for further oral engagement. The researcher tape-recorded the session and also kept a diary record. Each session lasted about 20 to 30 minutes. 4 out of the 13 respondents preferred to have telephone engagement whiles the other 9 were face-to-face interview. Those contacted through telephone gave their contact numbers and a favorable time was scheduled for the telephone interview. They were called as scheduled and their views were recorded. Each telephone session also lasted for about 60 minutes. Participants felt free to express themselves with the open-ended interview questions. All responses as indicated were audio-recorded for further transcription and analysis. The entire process of data collection lasted for one week.

Data Collection Techniques

The following methods of data collection was employed to gather data from the respondents.

Semi-Structured Interview Guide

For data gathering, a semi-structured interview guide was created. It included five essential questions that served to identify the topics being investigated while also allowing the interviewer or interviewee to diversify in order to study a concept or response in greater depth. The flexibility of this technique, especially when contrasted to organised interviews, enables for the finding of information that is significant to participants but was previously overlooked as relevant.

Data Analysis

The data was analyzed using thematic content analysis. Content analysis is the process of organizing and integrating narratives, according to emerging themes and concepts (Virginia & Clarke, 2006). It is a procedure for analyzing written or verbal communication in a systematic and objective fashion to provide similarities or otherwise of observations made from interactions with respondents. After recording respondents views, the responses were transcribed. The first case was transcribed and used to develop a unique coding pattern for further analysis. The codes were used to develop major themes and sub-themes. Subsequent cases were further compared to the codes that have been generated to identify differences and similarities. This was done with each case to build themes and sub-themes. After the themes and sub-themes had been built, the observations made were written out by grouping them under themes and sub-themes. Themes built reflected the objectives of the study.

Ethical Consideration

The study gave paramountcy to ethical issues. The approved methods for conducting scientific research as laid down by the School of Nursing and Midwifery of the University of Ghana, internationally accepted research ethics as well as the IRBs research ethics guidance were duly followed. Researcher was in constant communication with the assigned supervisors to ensure none of the research ethics were being flouted. Experts in the field of nursing research were also contacted from time to time to evaluate the procedures adopted in conducting this research. Before data collection, researcher sought permission from the hospital management. Researcher identified herself as a student of the School of Nursing and Midwifery with a student identification card and an introductory letter. The hospital management were informed of the rationale behind the study and made aware of the methods proposed to collect data from their facility. The benefits of the study were explained to study participants before the interview. Study respondents informed consent was obtained. This was done through written information on the semi structure interview, and all the study participants were given the opportunity to ask questions before the start. Respondents were told that, participation in the study was strictly voluntary. There was no monetary reward for participating in the study nor any form of risk posed to participants. Respondents information was kept confidential. Respondents could withdraw from the study without any punitive measures against them. However, respondents were encouraged to provide their consent of participation. They were made to understand their significant contribution by sharing their experiences and views with the researcher.

Limitation of the Study

This study was limited in data and coverage as a qualitative research work. The population selected for the study was limited and could not involve participants from other facilities and geographical area. Therefore, findings from this study cannot be generalized to the end of life patients relatives population in the whole Northern Region or Ghana.

FINDINGS

Introduction

This research assesses palliative care and end-of-life care knowledge and practices of family caregivers of terminally ill patients at the Tamale Regional Hospital, Northern Region. To address this objective, qualitative data has been collected from family caregivers of terminally ill patients. A self-developed semi-structured interview guide was developed to sample the views of the respondents through a face-to-face interview session. The sample engaged in the interview was thirteen (13) family caregivers who voluntarily consented to their participation. This chapter presents the views of the respondents obtained through the engagement had with them. The views cover knowledge on caring for terminally ill patients, practices of household Caregivers, and factors that affect Caregivers in caring for terminally ill sufferers. The findings are presented under various themes and sub-themes.

Sociodemographic characteristics

Participants were engaged to provide basic personal information to offer some knowledge about the individuals being engaged. It was realized that most of the family caregiver were females. The youngest among the participants was twenty-nine years old with the oldest being sixty-one years old. It was also observed that the caregivers were mostly spouses of the terminally ill patient with a few being the children and siblings of the patient. it affirms the view that caregivers of terminally ill patients are often family members. None of the participants were friends. Sociodemographic information on participants is provided in

Table 1.

Table 4.1: Profile of Study Participants

PARTICIPANT ID	GENDER	AGE (YRS)	RELIGION	EDUCATION	OCCUPATION	RELATION WITH PATIENT
P01	Female	45	Muslim	Secondary	Trader	Spouse
P02	Female	27	Christian	Tertiary	Teacher	Parent
P03	Female	47	Christian	Basic	Trader	Spouse
P04	Female	44	Christian	No Formal Education	Self-employed	Spouse
P05	Female	61	Christian	Basic	Trader	Sibling
P06	Male	43	Muslim	No Formal Education	Trader	Spouse
P07	Female	45	Muslim	Basic	Porter	Sibling
P08	Female	53	Christian	Basic	Self-employed	Spouse
P09	Female	47	Christian	Basic	Trader	Spouse

P10	Male	33	Christian	Basic	Self-employed	Parent
P11	Female	42	Christian	Tertiary	Self-employed	Sibling
P12	Female	37	Muslim	Basic	Civil servant	Parent
P13	Male	31	Muslim	Secondary	Civil servant	Parent

End-of-life Knowledge and practices of Family Caregivers

Palliative care for terminally ill patients could be challenging owing to the amount of burden it places on the caregiver and the entire household. Moreover, caring for terminally ill patients requires a lot of knowledge and practices in other to be able to offer appropriate support to the patients. Participants, caregivers of terminally ill patients, were engaged to find out their knowledge and practices in palliative care and end-of-life care. Four (4) major themes and twelve (12) sub-themes were identified. The themes and sub-themes for palliative care and end-of-life care knowledge and practices of family caregivers of terminally ill patients are presented in Table 1.

Table 4.2: Themes and Sub-themes from Transcribed Data

MAJOR THEMES	SUB-THEMES	CODES
Caregiver knowledge	1. Knowledge of the goals of palliative care	1. Patient might die 2. I think the patient will die 3. Care has a limit
	2. Knowledge of health workers roles.	4. Doctors give medicine 5. Educating family on medication 6. Nurses give medicine 7. Assisting nurses
	3. Knowledge of caregiver roles	8. Providing emotional needs
Caregiver roles/activities	1. Physical care/support	1. Grooming patient 2. Assisting to wear clothing
	2. Psychological care/support	1. Showing empathy 2. Showing love to patient
	3. Financial support	4. Paying medical bills 5. Buying drugs for patient
Caregiver challenges	1. Physical challenges	1. Heavy workload
	2. Psychological challenges	2. Limited rest 3. Fatigue 4. Hopelessness
	3. Financial challenges	5. Buying expensive drugs 6. Meals are expensive
Caregiver coping strategies	1. Physical strategies	1. Taking warm baths 2. Waking up early
	2. Psychological strategies	3. Using social media 4. Reading the Quran
	3. Financial strategies	5. Monetary gifts 6. Expenditure cuts

Theme 1: Caregiver Knowledge

Engagement with caregivers on their knowledge of caring for terminally ill patients brought up three (3) sub-themes. The knowledge on caring for terminally ill patients available to respondents was made known in the course of the interview engagement. The sub-themes include knowledge of the goals of palliative care, knowledge of health workers roles and knowledge of caregiver roles.

Knowledge of the goals of Palliative Care

Attempt to establish family caregivers knowledge of palliative care and end-of-life care showed some level of awareness among the family caregivers. They expressed their views and awareness of the goals of palliative care. Respondents generally described palliative care as the ability to identify patients needs. They consider the act of caring for terminally ill patients as being best described as ones ability to identify the unique demands of the patients and being able to offer such demands. Some remarks shared by respondents are these:

"Being around the patient all the time and carrying out activities the patient is unable to perform for example, help patient take the bath, help into the toilet and also help patient move" **[P08]**
"In caring for a patient, one takes care of the patient like a baby. One is responsible for helping the patient to bath and then feed" **[P13]**

Knowledge of Health Workers Roles

Respondents indicated their awareness of health workers roles and responsibilities when it comes to caring for the terminally ill patient. Their roles included giving education to relatives on the disease, medication and hygiene, prescribing medication, and helping patients to sit up. These are some of the remarks made by respondents:
"At the hospital, we were educated on how to take care of the patient and actually we have tried to do all of them...We were educated on his diseases condition, the need to drink clean and potable water. We should cover all our water sources to prevent contamination. We were educated on the bathing of the patient." **[P11]**
"We were also educated on sanitation situation of our surrounding, clearing the choked gutters, sweeping our homes and even hand hygiene" **[P05]**
"Maybe I would like to mention the support the nurses and doctors showed by taking care of the patient when we were admitted" **[P10]**

Knowledge of Caregiver Roles
Another aspect of respondents knowledge on caring for terminally ill patients was expressed with respect to their awareness of caregiver roles. They described the act of caring for terminally ill sufferers by identifying the need for family members to be patient and tolerant while caring for their patients. They indicated that caring for terminally ill sufferers required a lot from the family. It required relatives to be cooperative with health workers, tolerant, patient, empathetic and accommodating with the patient. Comments made as an indication of this observation are:

"One has to be patient. We humans are complicated and it is very delicate to care for someone, especially a love one" **[P05]**
"Taking care of the sick involves a lot of patience, time and empathy. One needs to put herself in the shoes of the patient" **[P03]**
"when caring for the sick, one needs to pay attention to the needs of the patient. This includes, the patient feeding, bathing and medications administrations." **[P10]**

Theme 2: Caregiver Roles/Activities
The knowledge and practices of family caregivers in caring for terminally ill patients were ascertained as part of the objectives of the study. On this, respondents made known various events and roles they undertook as they cared for their terminally ill patients. Three sub-themes were identified in finding out practice in caring for terminally ill patients. They were physical care/support, psychological care/support and financial support.

Physical Care/Support
Observations made bring to light a number of activities and roles family caregivers perform while caring for their terminally ill patients. Among the physical care and support activities were treatment management and administration of medications, conducting therapies, assisting with personal grooming and maintenance, and assisting patients to attend hospital appointments. Care for patients varied based on the peculiar needs of the patients as well as the medical condition for which they are terminally ill. Remarks made included:

"my patient could not eat by his self, so I had to assist in that to help the patient feed… bathing the patient, washing their cloths and other belongings and making sure their surrounding is clean by sweeping and mobbing." **[P03]**
"…helping the patient take his bath. Also, I would go to the house to take food prepared for the patient and send it to the hospital for him." **[P04]**
"…taking him for his dialysis was another activity which I carried out and help maintain the IV access clean" **[P13]**
"we use to feed our patient. Initially he was totally bedridden so we had to feed him. We also made sure we clean him twice daily that is morning and evening…" **[P08].**

Psychological Care/Support
Caregivers also reported to have offered some form of psychological care and support to their terminally ill patient this included conversing with patient, reassuring patient, empathizing with the patient, keeping company with patient, and showing love to patient. Some comments made by respondents are:

"I also stayed around the patient so that she would be feel lonely. We had interesting conversations." **[R10]**
"…looking at the way he was suffering I used to put myself in his shoes" **[R11]**
"The patient was someone who love to talk to people so we were always around him to keep him company." **[R03]**

Financial Support
The third of family care and support to terminally ill patient was in respect of financial support. Respondents made it known through the engagement that they undertook some financial activities as they cared for their terminally ill patient. This included paying medical bills, buying drugs, buying food, taking care of hospital bills such as laboratory fee and, buying water for patient. Remarks made by respondents include:

"Whenever we were required to buy medications, I would go to town and purchase those medications for him" **[P13]**
"hustle for money to feed ourselves and buy his medications and things we are required to buy." **[P11]**
"I had to also make contribution towards the patient medical bills." **[P05]**

Theme 3: Caregiver Challenges

A third major theme uncovered from the transcribed data was caregiver challenges, which were factors affecting care for terminally ill patients. This theme was developed as an evaluation of the things which become barriers to family caregivers as they offer care for their terminally ill sufferers. Under this theme, 3 (3) sub-themes were further realized. These are physical challenges, psychological challenges and financial challenges.

Physical Challenge

One factor observed to have affected care for terminally ill patients was physical challenge and stress. Family caregivers reported that the process of caring for their terminally ill patients presented them with a number of physical stress. They made mention having insufficient rest and sleep, considering it to be time-consuming, a tiresome or tiring activity, an increase in burden, reduced fitness, and a sense of weakness. The physical burden of caring for the terminally ill patient becomes also a factor affecting the attempt by family caregivers to care for their patients. Respondents made some of these comments:

"I suffer a lot from tiredness from taking care of the patient… I feel week sometimes and my whole body pains me. I feel I have lost weight in this last few months due to the care rendered for the patient and also grown lean." **[P05]**
"I now spend a lot of time to complete tasks I used to do in few hours. Time is no longer on my side, caring for the patient has taken all my time. I hardly complete my daily task now." **[P11]**
"It affected pretty everything about my time. Planning was key here. I had to make time to my contract work and also my patient. It was easy not strategizing in order to cater for all of this." **[P08]**

Psychological Challenges

Caring for terminally ill patients was uncovered to be a hectic task for family caregivers. Respondents indicated in their remarks that caring for a terminally ill patient could place some amount of psychological stress and challenge on them. They reported becoming scared and afraid of the thought of losing their loved ones, as well as contracting the disease. The fact of seeing their relative unable to perform basic life tasks due to their illness leaves them becoming emotionally strained. The thought of losing their loved ones lingers on their minds. More so, the problem of contracting the disease also becomes a challenge in caring for a terminally ill patient. The amount of stress experienced while caring for terminally ill patients becomes a factor affecting the way family caregivers provide palliative care for the terminally ill patient. Some respondents noted in their remarks:

"if he dies it wont be easy for us. He is the breadwinner of the family and everything depends on him. The thought of this really affects my mind and sometimes when am praying I get confused" **[P13]**
"The thoughts of the patient state worries me a lot and I keep thinking about it. He is going to live the rest of his life with one leg" **[P04]**
"The patient condition resulted from an infection which we can all contract if care is not taken. Initially I was scared and had to go do a test to confirm I dont have the infection." **[P05]**
"At times I felt the world was not worth it and the next minute it could be me…" **[P02]**

Financial Challenges

The burden of caregivers finances was also identified by respondents. Respondents indicated in the engagement had with them that caring for their terminally ill patients placed a great number of financial constraints on them. They noted the burden of transportation, cost of medication, and other relevant expenses. This drained them financially. To cap their burdens, respondents lamented the effect of their new role on their economic activities. This burden has become a factor affecting their care for the terminally ill sufferer. Comments made include:

"Not all drugs are covered by health insurance. We spend money in purchasing patient medications. Also, the patient is on special diet due to the condition. We separate the patient meal due to this and it cost to do this. The cost involves in transporting ourselves to and from the hospital is also something else" **[P03]**
"…food and medicine purchase are financial demanding. We had to buy his drinking water. The laboratory test too was financial demanding" **[P02]**
"Medications cover most of our expenditure…We also buy adult pampers all the time and Dettol to clean the patient" **[P11]**

Theme 4: Caregiver Coping Strategies

In view of the increasing demand and stress that caring for the terminally ill patient brings to family caregivers, it was found necessary to engage respondents on the mechanisms they adopted to manage the stress posed. These mechanisms are also relevant indicators of factors affecting palliative care for terminally ill patients. The sub-themes arrived at were Physical strategies, psychological strategies and financial strategies

Physical Strategies

Due to the burden of caring for a terminally ill patient, family caregivers devised mechanisms to effectively manage their time. It was indicated that being aware of their role could be time-consuming, there was the need to effectively schedule ones self so as to be able to combine social activities, education, and work. Other physical strategies were taking warm bats, sleeping, taking pain killers, working at night and gaining support from other people. Remarks made include:

"Now I use zoom meeting to hold some of my business discussion. I also postponed most the activities I think can be sorted out later so I can get enough time to care for the patient." **[P07]**
"I try to maneuver my way out. Most times I dont go to work and miss lectures too just to take care of the patient." **[P05]**
"There was a shift of time in all I did. I had to wake up early…I also slept late and had to limit my rest period...I adjusted all my activities to meet my patient demands and also my needs." **[P01]**

Psychological Strategies
Management of emotional stress and challenges was also uncovered from the transcribed data. Family caregivers devised means by which they coped with the emotional and psychological burden placed on them. They basically resorted to listening to music, taking rests, engaging in religious activities such as prayers, giving themselves the assurance of hope, receiving visits from relatives, using social media, watching the news and receiving assurance from relatives. Remarks made include:

"When every am stressed, I perform ablution and pray to my maker for support and this relieves me from the stress. Sometimes too, I have some recorded word of Allah which I play to help prevent me from thinking too much." **[P04]**
"Most times, my phone did help as I was always on the internet browsing using sites such as Facebook and YouTube. I use to watch Newsfile to prevent myself from being consumed with the suffering I was seeing." **[P02]**
"His Iman friends prayed for him. They came periodically to pray for him. They were very supportive to the patient psychologically. They offered word of wisdom to the patient. Some of my friends also came around to greet." **[P08]**

Financial Strategies
Family caregivers shared various strategies by which they managed their finances. Respondents admitted a cut in expenditure, buying only basic items, and receiving financial support from relatives, coworkers, friends and neighbors as means of managing their finances. Their remarks were:

"My salary comes in a monthly basis, so my little commitment was given. The donations really help and I didnt have to commit too much finances." **[P02]**
"I have cut off some of my expenditures. For instance, I no longer subscribe my DSTV due to the patient sickness. All this is to enable me raise money for his care." **[P11]**
"The support from friend and family helped limit my spending. It was also better cooking than buying food for the patient." **[P10]**

DISCUSSION

Theme 1: Caregiver Knowledge

Knowledge of the goals of Palliative Care

The unanimous response of caregivers on patient care was that the concept of palliative care for terminally ill patients was offering needs for the patients. Family caregivers shared the view that caring for the terminally ill patient was concerned with being aware of the needs of the patient and being able to offer them. Due to the inability of the patient, there is the need for a caregiver to be present and ready to offer to those needs. Terminally ill patients may mostly be immobile or incapable of performing basic life functions without external support. Family caregivers should therefore provide this support for which patients are unable to perform. Taking up this duty constitutes caring for terminally ill patients. It appears from the engagement with respondents that, the latter have appreciable knowledge of the concept of palliative care and care for terminally ill patients. They understand the challenging situation of terminally ill patients and are equally aware of what constitutes care for the sufferer. Similar to an assertion made by Nebel (2011) and Alam et al. (2019), informal caregivers for terminally ill patients appear to be aware of what constitutes care for the terminally ill patient. This knowledge, according to the authors can develop skills and feelings of certainty about their roles. With such knowledge expressed by respondents, it can therefore be deduced that family caregivers are certain about their roles and could rely on such knowledge to develop their skills and skill competence.

Knowledge of Health Workers Roles

The family caregivers showed evidence of knowledge of health workers role in palliative care. They indicate that health workers had a crucial role to play in giving palliative care to the terminally ill patient. Doctors had the responsibility of prescribing medications while nurses also had to educate relatives and caregivers on palliative care. Education for family caregivers included explaining the disease, information about patients hygiene needs and medications. This helped caregivers to become knowledgeable and competent about their caring roles. It also helped caregivers to be able to provide the best of care and support for their terminally ill patient to hasten their wellbeing and possible recovery. More so, health workers assisted in the caring of patients by assisting caregivers to physically move patients. Caregivers who could not move their patients due to the latters weight had to be assisted by some health workers. Health workers therefore did not only educate and prescribe medications for patients, but also provided physical support. It could therefore be seen that health workers played a crucial role in caring for terminally ill patients, of which caregivers were aware.

Knowledge of Caregiver Roles

Caring for terminally ill patients involves much effort from the caregivers. It was refreshing to have observed that family caregivers expressed such thoughts. They emphatically indicated that caring for terminally ill patients required relatives to be cooperative with health workers, tolerant, patient, empathetic, and accommodating with the patient. This confirmed assertion made by Center (2013) in his 2012 study on American caregivers. Giving care to the terminally ill patient also required some extra effort from the entire family. As respondents shared, it requires cooperation, tolerance, patience, and empathy. The family of the patient ought to cooperate with health workers whenever they visit the hospital to offer care for their patients. Caring for the patient demand lot of patients and tolerance. Since the patient cannot undertake certain basic life activities, caregivers need to be patient and tolerant with them. Recognizing that palliative care for terminally ill patients could be frustrating and burdening, respondents claimed it required patience and empathy. Kelley et al. (2013), Davis et al. (2014), and Schur et al. (2014) similarly pointed out the demanding and frustrating nature of caring for terminally ill patients. They, therefore, recommended the need for caregivers to understand the situation of the patient and more importantly, become accommodating to their situation. Caregivers must empathize with the patient and understand their situation. This would ensure that patient receives maximum care from family members. It could be inferred from this observation that family caregivers appreciate the challenging situation of their terminally ill patients, hence understanding the need to be patient and empathetic to them. Caregivers would therefore care for the patient with a sense of empathy.

Theme 2: Caregiver Roles and Activities

Physical Care and Support

Caring for the terminally ill patient requires a lot from the caregivers and other family members and relations of the patient. One activity performed by family caregivers was treatment management and administration of medications. This Wolf (2007) and Spillman et al. (2014) classify as fitness and health maintenance duty of the caregiver. It was indicated that caring for terminally ill patients involved providing treatment management activities and assisting in the administration of medications. Terminally ill patients do not require care only from nurses and their physicians, but also from their relatives. Family caregivers indicated they were involved in providing some assistance to the patient in respect of treatment management. Some were involved in massaging their patient, keeping them company, engaging them in social conversations, and taking patients for a walk. Nurses and physicians would not be permitted to always undertake these activities due to their demanding schedules of work. Family caregivers hence assumed the role of continuing treatment management processes. Williams et al. (2014) and Given et al. (2008) had similarly reported that caregivers of terminally ill patients played the role of healthcare professionals by massaging or offering therapy for the terminally ill patient. This gives patients maximum opportunity to receive uncurtailed support to enhance their health and wellbeing. Family caregivers also run errands to obtain medications for their patients. Terminally ill patients could obviously not be able to access pharmacies for their medications. Family caregivers, therefore, provide this assistance. This ensures that medications needed for treatment are always provided to improve the well-being of patients.

Family caregivers also performed personal grooming and maintenance for terminally ill patients. These activities have similarly been documented by Schulz (2007), The Scottish Government (2010), Buckner and Yeandle (2007), Girgis et al. (2014), and Angelo et al. (2013). Caregivers enumerated some of the activities performed for terminally ill patients as assisting with feeding, bathing, toileting, washing their clothes and other belongings, sweeping their surroundings, and other forms of personal grooming. Some of the patients were bedridden. These patients could not for instance feed on their own nor could they also bathe. They required this function or need to be performed externally by a caregiver. Caregivers, therefore, had the responsibility to feed the patients and also wash them. This affirms positions made by Milne and Quinn (2009) that caring for the terminally ill patient involved feeding, toileting, and bathing. Nebel (2011) similarly indicated providing meals, toileting, and medication administration as some practices undertaken by family caregivers for terminally ill patients. Moreover, caregivers washed the clothes and other necessary belongings of the patients such as their bedspread, similar to what Nebel (2011) had observed in his earlier study. Caregivers perform these activities since it is essential to keep the patient in a healthy environment. It is therefore the responsibility of family caregivers to keep the patient in a healthy environment, one which is devoid of any filth.

Psychological Care and Support

Among the number of caregiver roles identified was psychological care. It was uncovered that caregivers offered psychological and emotional support to the terminally ill patient. Patient did not only require physical support but also required emotional support. Similar to assertions made by Stajduhar and Davies (2005), care for terminally ill patients involved affectionate function and responsibility. Caregivers understood the psychological constraints and burden their patients might be going through at that moment. Hence, they offered the best of emotional support to the patients. Caregivers maintained conversation and interaction with the patients. Being admitted at the hospital can be a lonely situation. The patient becomes deprived of all social activities such as having social interactions with friends and other relatives. This makes patients lonely and feel isolated. Caregivers became a confidant for the patients by always engaging them in conversations. In such conversations, caregivers had the opportunity to assure their patients of gaining total healing and also being able to return to their normal lives. Through conversations, caregivers showed empathy and love to their patients. This allowed patients to receive emotional support and gain a sense of care from their families. Block (2001) believes that simulated and intense conversations are useful in strengthening connection and building affection with the terminally ill patient. Caregivers were always present in the company of their patients. Their physical presence in the company of the terminally ill patients was one of the greatest emotional support patients received. This helped patients to overcome loneliness. This revelation is refreshing and worthy of commendation. Caregivers could be acknowledged for their effort in supporting terminally ill patients emotionally. Nebels (2011) report has therefore been affirmed with the findings of the current study, since both studies uncovered emotional comfort as one of the numerous functions of the caregiver.

Financial Support
Caregivers also supported their terminally ill patients in respect of giving them financial support. Terminally ill patients become deprived of the opportunity to be engaged in any kind of gainful employment. Being admitted at the hospital implied they would be out of work. This situation also affects their economic and financial status. It is through the support of caregivers and relatives that terminally ill patients could receive adequate palliative care. The financial responsibility of palliative care therefore becomes the sole responsibility of the family caregiver. This role was, fortunately, being taken up by family caregivers. Similarly, Wolff (2007) and Spillman et al. (2014) indicated that caregivers dealt with economic and other valid financial consequences of palliative care. Respondents indicated that they bore the full financial responsibilities of giving palliative care to terminally ill patient. This included paying of all medical bills including laboratory fees, and purchasing of drugs, buying food for patient and associated transportation fees. The care for terminally ill patient is financially demanding of which the family caregiver is expected to bear. Family caregivers took up all the financial demands of palliative care. This observation affirms earlier report made by Nebel (2011), Spill et al. (2014) and Wolff (2007) who had reported that family caregivers roles included financial support and care for the terminally ill patient.

Theme 3: Caregiver Challenges

Physical Challenge
Care for terminally ill patients was characterized by physical stress. Williams et al. (2014) and Schur et al. (2014) agree that caring for a terminally ill patient could greatly influence the caregivers body. Family caregivers noted the process of caring for their terminally ill patients presented them with a number of physical stress. Carpentier (2010) similarly mentions that function modification for caregivers influences their bodily and subjective fitness over the duration of care. The event is physically demanding hence, resulted in caregivers having a number of negative experiences. They mentioned having insufficient sleep or distorted patterns of sleep, increase burden, reduced fitness, and a sense of weakness. Caring for the terminally ill patient is physically demanding. Caregivers spent much of their time with their patients. They could not have for themselves enough sleep or rest. Those who could even sleep reported having distorted patterns of sleep. Relatedly, caregivers experienced weakness in their body. They exert much energy while taking care of their patients. Some for instance indicated the lifting of patients, which could be physically demanding and stressful. The amount of physical burden and stress placed on caregivers could also affect their health status. They may become ill health, reducing their ability to care for their terminally ill patients. This was observed in earlier studies by Carlsson and Rollison (2003), Hudson (2004) and Grande et al. (2009).

Psychological Challenge
One of the challenges that confronted family caregivers who cared for terminally ill patients was the psychological stress that they faced. Nebel (2011) puts it that caregivers are often faced with the breakdown of their own emotional sphere either by exhaustion or concern over lack of knowledge. It was observed that caring for the terminally ill patient could be psychologically demanding. Psychological stress was pointed out in the conversation with family caregivers. The caregivers lamented the amount of emotional stress and imbalance they faced. Caring for the terminally ill patient, according to family caregivers is emotionally disturbing. They become emotionally drained by the thought of losing their loved ones or contracting the disease. Atsua and Igyar (2017) indicate that the thought of terminally ill patients not always recovering could be emotionally and psychologically traumatizing for the caregiver. Caregivers become frightened without being certain about the future status of their patients. This affects their state of mind and challenges them in also offering emotional and psychological support to the terminally ill patient. Alam et al. (2019) similarly reported in their study that caring for terminally ill patients is affected by problems associated with fear. The thought of contracting the disease was also a reason for their psychological and emotional stress. Family caregivers did indicate they sometimes become scared of contracting the disease for which their loved one has been rendered incapacitated. This destabilizes their mental state. Such a state of mind could also be transferred to caring for the terminally ill patient. Caregivers emotional state reflects in their approach and behavior in caring for the patients. It would not be wrong therefore to deduce that family caregivers are not able to emotionally support terminally ill patients. Their practice of care for terminally ill patients is also affected by the psychological stress faced.

Financial Challenges
Financial burden was also a challenge confronting family caregiver in caring for their terminally ill patients. The process of caring for terminally ill patients comes with many financial expectations. This affirms earlier observations made by Hall et al. (2011), Funk et al. (2010) and Hudson (2003) who pointed out the cost and economic difficulty in caring for terminally ill patients. As observed from the study, terminally ill patients are not able to undertake any economic activity to support the financial aspect of their treatment care. Treatment for them obviously require some financial commitments in respect of buying medications and other recommended treatment, visiting the health facility to attend appointments, and feeding. Not being able to engage in any form of economic work means their inability to personally provide for their economic needs. Family caregivers, therefore, take up this responsibility. The financial burden of caring for terminally ill patients affects family caregivers. Caregivers lamented the increasing financial burden placed on them as they care for

their terminally ill patients. They admitted being financially constrained, though some form of financial support is at times rendered by relatives and friends. From the foregoing, caring for terminally ill patients is affected in respect of financial burden. Caregivers ability to offer constant care for terminally ill patients would be determined by their financial ability.

Theme 4: Caregiver Coping Strategies

Physical Strategies

The extent to which caregivers are burdened requires their adjustment to their new functions. Family caregivers adopted some strategies to cope with the burden faced in caring for their terminally ill patients. Chief among these mechanisms is time management. As pointed out, caring for terminally ill patients could be time-consuming. Caregivers spend much time around their terminally ill patients. This results in the neglect of other responsibilities including work, school and family duties. Hence, caregivers indicated they consciously managed their time in order to be able to attend to other social and economic activities. They did this by effectively scheduling themselves, which allows them to combine social activities, education, work and other important activities. Managing the little time they had gave them the opportunity to reduce the amount of stress faced in caring for their patient. With time management, caregivers were able to organize themselves, balance their life and take up other activities expected of them in their society. Being able to manage ones time also meant reduced stress and worry.

Psychological Strategies

To manage their emotional stress, family caregivers basically resorted to listening to music, taking rests, engaging in religious activities such as prayers, and giving themselves the assurance of hope. Caring for terminally ill patients has been seen to be emotionally draining. Family caregivers could become emotionally traumatized, broken, and unstable. To overcome this, social and religious strategies were adopted by family caregivers. Some caregivers indicated they resorted to listening to music as their way of managing their emotional stress. Music, according to some caregivers gave them a soothing effect that calmed them cognitively. Others also took to sleep. These strategies, according to Schulz (2007) decreased the struggle of the caregiver. Religiously, caregivers opted to pray. They engaged with their object of worship as a source of relief. Others also assured themselves with the hope of their terminally ill patient recovering from the sickness. These individuals remained optimistic about the situation, irrespective of the intensity or gravity of their patients illness. These strategies were pointed out to be effective in managing the emotional stress associated with caring for terminally ill patients.

Financial Strategies

One other effect of caring for terminally ill patients was financial demands. To overcome this burden, caregivers had to cut their expenditures and request financial support from relatives and friends. Caring for the terminally ill patient requires a great amount of financial commitment. Caregivers managed this burden by cutting their expenditures. Being aware of the increasing financial requirement in caring for terminally ill patients, caregivers were pressed with cutting their expenditures. This allowed them to continually satisfy the financial burden of caring for their terminally ill patients. On the other hand, requesting financial support from relatives and friends was also resorted to. Family caregivers admitted to receiving extra financial support. This became a strategy for which they managed themselves financially.

Family support was also a mechanism used in coping with the burden of caring for terminally ill patients. Caregivers are expected to receive support from relatives and friends, as well as from other people in the community. Support received from relatives included financial support, taking care of the patient, and providing emotional encouragement. As mentioned earlier, relatives are financially supported in care for terminally ill patients. Relatives provided money to take care of terminally ill patients. The care for patients, as identified is financially demanding. Hence, having a pool of resources would enable caregivers to manage the financial burden associated with palliative care. Other forms of support also included offering emotional encouragement and taking turns in caring for the patients. Relatives did not only offer financial support but also gave emotional and psychological support to caregivers and terminally ill patients. They shared words of encouragement which was crucial in improving the mental and psychological state of terminally ill patients. Taylor (2003) similarly indicated that demand for public support is crucial for family caregivers of terminally ill patients. Caregivers require external support since their effort may mostly not be enough to address the challenges and demands of terminally ill patients. External support hence enables caregivers to effectively care for their terminally ill patients and cope with the stress associated with their roles.

SUMMARY, CONCLUSION AND RECOMMENDATIONS

Summary

Palliative care for terminally ill patients has not been extensively documented in the literature. The issue is worse in sub-Saharan Africa, where the practices of taking care of terminally ill patients have received less attention in the literature. Having identified the lack of base-level information in the Tamale metropolis about knowledge and practices of family caregivers in caring for terminally ill patients, the present study became perfectly needful. A descriptive study design using the qualitative approach was the main design used in the study. A sample unit of thirteen family caregivers from the Tamale metropolis was sampled using the purposive sampling technique. To obtain qualitative data, face-to-face interviews were conducted. The interview guide used in collecting data was self-developed by the researcher. The instrument was scrutinized and vetted to ensure its validity. After tape-recording respondents, responses were transcribed and analyzed using a thematic content analysis approach.

Reflexivity and Insight Gained by Researcher

In qualitative research, the researcher takes on the role of the instrument, participating in data collection, data administration and analysis. As a result, it was critical to consider the researchers biases, a concept known as reflexivity (Polit& Beck, 2012). The researcher worked as a general nurse in medical unit for over 7 years, where she encountered caregivers who took up care giving roles informally.She is interested in the knowledge of family caregivers on end of life care, their knowledge and practices.

Prior to data collection and analysis, the researcher believed that family caregivers had little or no knowledge on caregiving roles. After data collection and analysis, it was observed that most family caregivers were able to identify patient needs and were also able to describe most caregiving activities of which the researcher had no prior knowledge on before the research was investigated. These potential biases were however taken into consideration before data collection and analysis.

Implications of the study

The findings of this study has several implications for nursing education, nursing research, nursing practice, and policy making.

Implications for nursing education

There is a need for nursing education to incorporate palliative care education within undergraduate programs in order to meet the professional and personal demands while providing care to clients especially with the increasing number of ageing population .An increasing number of clients will require variety of services especially in their own homes where family centered care is key. Knowledge and knowledge and practices acquired in this area will help teach family caregivers the right skills to assist in caring for their relatives.

Implications for nursing research

The existing findings suggests that family caregivers understand their role in caring for the terminally ill. It suggest that they have sufficient knowledge on palliative care and were able to describe their various roles in caring for them.

These findings could serve as a baseline for future nursing research in the following areas;

1. Explore the knowledge and practices of nurses on end of life care of terminally ill patients.
2. Explore the socio cultural beliefs affecting family caregivers in caring for terminally ill patients.

Implications for nursing practice

End of life care is a crucial component of Palliative care in nursing practice and as such the needed relevance must be attached to it. Nurses should equip themselves with the needed knowledge and skills so that they would be able to coordinate care in consultation with their patients, family caregivers and other team members.

Implications for policy making

The government should institute various health policies which would reduce the financial impact of caring for terminally ill patients on caregivers and their families.

In addition, Government should put in measures to subsidize treatment cost of patients suffering from terminal conditions so as to lessen financial burden on family caregivers.

Study Limitations

It will be appropriate if the study is replicated in other parts of the country in different health facilities because participants drawn for this study were taken from one health facility in the Northern region of Ghana which might therefore not indicate the true reflection of the situation in the entire country. However, strict measures were put in place to avoid biases. It can also be replicated using a quantitative approach and the same population to establish the resiliency components of the resiliency model of stress adjustment and adaptation within the family context because this was not explored in this study.

Recommendations

Based on the findings of the study, the following recommendations have been made;

Ministry of Health and health facility management

Recommendation to Ministry of Health

1. The ministry should develop policies that will lessen burden on family caregivers of patients suffering from terminal diseases.
2. The ministry should also liaise with Government to put up Palliative care centers across the country to help ease pressure in the public health facilities.

Recommendation to the Tamale Regional Hospital

1. The health facility should incorporate the services of family caregivers in the care of terminally ill patients. Their competence would immensely contribute to the improvement in the health of terminally ill patients.
2. They should also put up palliative care protocols in the various units to help family caregivers in care giving roles.

Conclusion

Family caregivers of terminally ill patients within the Tamale metropolis unanimously had sufficient knowledge of palliative care for a terminally ill patient. They described the activity as one which involves awareness of the needs of the terminally ill sufferer and adequately attending to the increasing needs of the patients. Family caregivers also had information on the demands of palliative care on the family. The need to be patient, accommodating, empathetic, tolerant, and cooperative was equally known by family caregivers. The observations made imply that family caregivers sampled from the Tamale metropolis understand their role in caring for terminally ill patients. Their knowledge and information about the role are accurate, recommendable, and refreshing to the process of healthcare. This suggests that education on palliative care for terminally ill patients has been appropriately disseminated among family caregivers.

In terms of competence and practice of family caregivers, activities done included treatment management and administration of medications, conducting therapies, assisting with personal grooming and maintenance, and assisting patients to attend hospital appointments. It was clear from the findings that caregivers undertook most of the caring needs required by terminally ill patients. Family caregivers adequately assisted their terminally ill patients. With such observation, it is concluded that a family caregivers competence in caring for terminally ill patients could be described as appropriate and enough. They performed their duties as caregivers to complement nurses and other healthcare professionals who offer healthcare to terminally ill patients. Caregivers roles also included psychological and financial support. They offered emotional support and comfort to their patients as well as taking up all financial responsibilities associated with caring for the patient. It could be deduced then that, family caregivers in the Tamale metropolis do not neglect their terminally ill patients. They do not neglect their functional roles as caregivers to terminally ill patients.

Factors that affect family caregivers in caring for terminally ill patients included caregiver challenges and coping strategies. Caregiver challenges included psychological burden, physical challenges and financial constraints. Caring for terminally ill patients was psychologically demanding and physically burdening. Financially, caregivers lamented the amount of financial investment and demand expected of them. To overcome these stresses, caregivers resorted to some mechanisms which aided them to adapt to their roles. The strategies ranged from social approaches to financial approaches and religious strategies. There is therefore the need for caregivers to navigate through their roles by resorting to varied mechanisms. This would surely enable them to cope with the burden of caring for their terminally ill patient.

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