



# Prolonged Hospitalisation of Terminally-Ill Patients and its Impact on Family Care Givers at the Benue State University Teaching Hospital, Makurdi, Nigeria

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## Abstract

The study determined the impact of prolonged hospitalisation of terminally-ill patients on family care givers in the Benue State University Teaching Hospital, Makurdi, Nigeria. A qualitative research design was adopted. The population of the study consisted of female family care givers to terminally-ill patients. The sample was 53 female care givers who were identified at the Female Medical Ward of the hospital. Key Informant Interview (KII) was conducted with the use of a structured interview guide. Data from the study were qualitatively analysed using Manual Inductive Approach (Thematic Approach). Findings revealed that prolonged hospitalisation has impact on the family finances, altered family life; reduce daily living activities and high level of depression among others. Female care givers prefer traditional therapy because it is less expensive. They rely on divine assistance since the patient has no hope of survival. Counselling implications were provided.

**Keywords:** Prolonged, Hospitalisation, Terminally-Ill, Patients, Impact, Care Givers.

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## INTRODUCTION

Prolonging hospitalisation of terminally-ill patients has aroused ambivalent feelings in the minds of so many, especially those directly involved in the daily care of patients such as nurses, doctors, physiotherapists, nutritionists and family members. Family care givers appear to have been challenged with problems associated with the care and comfort of terminally-ill patients coupled with the stress of coping with prolonged hospitalisation of terminally-ill family member. They always have to deal with death because terminally-ill patients do not always recover. This is owing to the fact that some see it as an overbearing waste of reasonable time and resources. These feelings however trivial have been closely observed to have impacted on the co-operative care of the terminally-ill patient. On the other hand, some see it as an indirect contribution towards the peaceful death of the terminally-ill.

Prolonged hospitalization occurs when a patient's admission in the hospital is being extended for reasons best known to the medical team. At the Benue State University Teaching Hospital (BSUTH), there are patients who have been on admission for a long time because of terminal-illness and this appears to have a depleting impact on their family caregivers. A terminally-ill patient on the other hand sometimes crudely called a dying patient refers to a person suffering from an incurable disease which would subsequently lead to death (Cotton, 2013). They are a cohort of critically ill patients who require prolonged mechanical ventilation and consume an abundance of healthcare resources in an effort to enhance their likelihood for survival (Hickman & Douglas, 2010). These categories of patients are found in the hospital especially in the Female Medical Ward of the hospital. This definition may however seem controversial as the natural ageing process and other mysterious causes could subject one to become terminally-ill. Some of these patients seem to be suffering from various terminally-illnesses as a result of long protracted diseases of which Cotton (2013) asserts that causes of which might have either eluded medical therapy, gone beyond reversal or even have no cure. Diseases like cancer, hepatitis, malnutrition, Aids (fully blown), renal failure amongst others are readily available causes (Valente, 2010) and are common among some of the terminally-ill patients on admission in the hospital. Despite scientific medical discoveries in prolonging the life of a terminally-ill patients, there still exist some speculation as to the need to prolong the life of a terminally-ill person or a hopeless case to the extent that some even consider euthanasia a better end care than prolong hospitalisation as it has effects on family caregivers. Thus, there is the need to weigh the effects of prolonging the hospitalisation of terminally-ills especially on female family caregivers.

Female family caregivers of terminally-ill patients at the BSUTH have expressed concern on why patients have to go through extensive treatments that have horrible side effects if there is no hope of a better quality of life. They have also expressed concern on the impact it has on them and the entire family. Valente (2010) asserts that most people would want to die peacefully with dignity because a lot of cancer patients do not want to go through extensive treatments that have horrible side effects if there is no hope of a better quality of life. The silent question however, is whether it is better to keep these patients alive at a huge cost, with no hope of recovery or to let nature take its course. Modern medicine has become so good at keeping the terminally-ill alive by treating the complications of underlying disease that the inevitable process of dying has become much harder and is often prolonged unnecessarily. The increased health care demand is such that primary care physicians do not have time to spend an hour with a patient or see and assess their reactions to medication adjustments. The easiest thing for the health care team is to

admit such patients to the hospital. Once admitted, they are likely to be seen by a dozen or more specialist who will conduct all kinds of test, whether they are absolutely essential or not which is common among terminally-ill patients hospitalised at BSUTH.

The debate about euthanasia and assisted suicide has highlighted pervasive and serious short comings in the care of terminally-ill patients. These patients as well as others who experience pain and suffering often receive inadequate relief for pain and other debilitating symptoms despite the fact that effective treatments are available (Smith, 1993). In addition, many physicians fail to discover treatment options and the possibility of forgoing treatment with patients in a timely and appropriate manner, leading to over treatment a sense of isolation and powerlessness on the part of patients and those close to them (Smith, 1993). Improving care for terminally-ill patients is critically important not just as a response to those who seek assisted suicide and euthanasia, but as a basic obligation to all patients whose pain and suffering could be alleviated with responsive medical care. Health care professionals at the BSUTH have a duty to offer effective pain relief and symptom palliation to patients when necessary. According to Cotton (2013) it should be in accord with sound medical judgment and the most advanced approaches available.

Alleviation of pain and the symptoms of terminally-ill patients at the BSUTH will make a powerful contribution to the patients' quality of life and that of family caregivers. It can also speed recovery and provide other tangible medical benefits (Clement, 1993). Physicians and Nurses particularly at BSUTH have an ethical and professional responsibility to effective pain and symptoms management. This responsibility must be understood as central to the art of medicine and delivery of medicine care. Attention to patient's symptoms should not be reserved for the end of life, nor should it be a sign that curative effects have been abandoned. Palliative care should be understood to include symptoms control at all stages of disease (Clement, 1993). Health care teams that provide care for terminally-ill patients at BSUTH have a responsibility to develop the ability to provide effective pain and symptom management to such patients.

When terminally-ill patients take charge of the last stages of life, they may challenge health caregivers to re-examine attitudes about life saving technology, autonomy and values about preserving life. Medical technology and laws to protect the sanctity of life may unintentionally prolong life regardless of the cost or the patient's wishes (Tulsky, 2008). However, female family caregivers to terminally-ill patients at the BSUTH fear prolonged suffering, uncontrolled pain and expensive cost of dying (Isaac, 2006), and worry about life saving technological futile treatment (Tulsky, 2008) and the impact it has on them and the family. The issue of prolonging hospitalisation of terminally-ill patients has become one of the controversial issues facing health care professionals, as they are challenged by their therapeutically responses to patients request for hastened death (Valente, 2010).

Exposure to chronic critical illness has devastating effects on patients and damaging psychological consequences for their family members. The proportion of female family caregivers exposed to psychologically taxing conditions at BSUTH will continue to mount, consistent with steadily increasing rates of patients admitted to an intensive care unit (ICU) (Zilberberg, Luippold & Sulsky, 2008). An episode of exposure to chronic critical illness by family care giver was observed at BSUTH to have exposed the patient's family to an uncertain trajectory of critical illness that includes recurrent infections, hospital readmissions, and decrements in the patient's condition over time. Moreover, it was observed that chronic exposure to psychological stressors depletes the internal and external coping resources of the family. Hickman and Douglas (2010) assert that historically, the delivery of care in an ICU has been

centered on the patients and marginalised the needs of the family. The admission of a patient to an ICU is often an acute, non-elective transition that elicits uncertainty for patients as well as their families.

Research evidence revealed that the uncertain trajectory of chronic critical illness exposes the patient's family to heightened levels of psychological distress. Symptoms of psychological distress affect more than half of family members exposed to the patient's chronic critical illness. Although symptoms often dissipate over time, a significant proportion of family members will remain at moderate to high risk of psychological distress well after the patient's death or discharge from the intensive care unit (Hickman & Douglas, 2010; Zilberberg, De Wit, Pirone & Shorr, 2008). Similarly, Valente (2011) study revealed that nurses reported struggle with religious and spiritual values, uncomfortable feelings and fears, inadequate skills and knowledge, personal experiences and the weight of professional responsibility. Ersek (1998) study found that the most challenging impact of prolonged hospitalisation of terminally-ill patients on mental health of caregivers was how to avoid burdening family members, to preserve dignity, avoid degrading therapies, affirm religious beliefs, retain control during disability and preserve life savings.

Family caregivers have many functions including, but not limited to domestic chores and household tasks, providing personal care and assisting the dying person with activities of daily living, managing symptoms such as pain and constipation, providing emotional and social support to the dying person, being a spokesperson, advocate and proxy decision maker and coordinating all aspects of the dying person's care (Stajduhar & Cohen, 2009). While family care giving has considerable rewards, including allowing caregivers to facilitate closure after death and helping them find meaning in their experiences (Stajduhar, 2003), it is physically exhausting, difficult to recover from, and fraught with emotional and financial burdens (Grande, Stajduhar & Aoun, 2009). Therefore, it is not surprising that the health and well-being of family caregivers often suffer when they provide end of life care at home (Stajduhar & Cohen, 2009; Stajduhar, 2003).

Recognition of family caregivers' contributions and the importance of assessing family caregiver's needs in practice have been acknowledged (Ferris, Balfour & Bowen, 2002). Within the palliative care literature, the experience of care giving has been described as fundamentally uncertain, in part because of the unpredictability of the trajectory (Farber, Egnaw & Herman-Bertsch, 2003; Kazanowski, 2005). There is a sense of a disruption in 'normal life' (Stajduhar & Davies, 2005; Wennman-Larsen & Tishelman, 2002) and experiences of helplessness and vulnerability are commonly noted (Broback, & Bertero, 2003; Milberg, Strang & Jakobson, 2005). Care demands can be particularly onerous towards the end of life, and emotional stresses can be particularly high as family members grieve successive losses, have vivid awareness of impending death and face an uncertain future. Social isolation is common (Boyd, Murray & Kendall, 2004; Strang & Koop, 2003) and obtaining support is hampered by the fact that many family members do not identify themselves as legitimate recipients of help, focusing instead on the dying person (Stajduhar & Davies, 2005; Harding & Higginson, 2001). High levels of psychological distress are common; for example, 41% to 62% of family caregivers providing palliative care in Quebec were reported to have experienced a high level of psychological distress compared with 19% of the general population. This percentage increased as the patient's health declined and as patients became less able to care for themselves (Dumont, Turgeon & Allard, 2006).

Many family caregivers have anxiety levels in the clinical range; higher than that of the dying patient's (Grunfeld, Janz, & Glossop, 2004; Sherman, 1998). Studies show that family caregivers experience levels of depression similar to patients and greater than the general population (Grunfeld, Janz, & Glossop, 2004). Psychosocial and mental health challenges are accompanied by physical burdens. Long hours of care provision are often associated with significant fatigue and sleep deprivation (Aoun & Kristjanson, 2005; Strang, Koop & Peden, 2002). The physical demands are often a result of excessive 'work' involved in care giving process and the 24 hour responsibility that many family caregivers have.

Evidence suggests that some family caregivers do not look after themselves well; they do not eat properly, often cease activities outside of home and postpone their own medical appointments (Coristine, Crooks & Grunfeld, 2004). In adding to this, many family members feel ill-prepared for caregiving roles (Stajduhar & Davies, 2005) and uncertain about their abilities (Cain, MacLean & Sellick, 2004); many feel pressured to provide such care (Stajduhar, 2003) yet feel ambivalent about providing it (Harding & Higginson, 2001). This is more challenging when the patient being cared for and the family caregiver have pre-existing tension in their relationship (Stajduhar, Martin & Barwich, 2007).

Providing care at the end of life can also result in occupational and financial consequences (Grunfeld, 2005; Grunfeld, Janz, & Glossop, 2004). Canadian-based research led by Dumont has found that the welfare state, the family and not-for-profit organizations sustained 71.3%, 26.6% and 1.6%, respectively, of all costs associated with end of life care (Dumont, Jacobs & Fassbender, 2009). An examination of Canada's Compassionate Care Benefit by Williams, Crooks and Stajduhar (2006) suggests that even where benefits are available, family members can experience challenges in negotiating the system. The study reported that family members were concerned about limitations of the benefit such as strict eligibility criteria and the relative short duration of assistance. In terms of workplace policy, many Canadian family caregivers have no paid leave or job security if they take time off work. A report from the Economist Intelligence Unit (2011) ranking the quality of end of life care around the world highlights that Canada suffers in the overall ranking because the cost of community-based care results in significant financial burdens to families.

Female family caregivers at the BSUTH appear to have been challenged with problems associated with the care and comfort of terminally-ill patients coupled with the stress of coping with prolonged hospitalisation of terminally-ill family member. They always have to deal with death because terminally-ill patients do not always recover. This is owing to the fact that some see it as an overbearing waste of reasonable time and resources. A patient's ability to be cared for and to die at home is heavily dependent upon the efforts of family caregivers. Considerable stresses are associated with such care giving including physical, psychosocial and financial burdens. Research has shown that unmet needs and dissatisfaction with care can lead to negative outcomes for caregivers. While many family caregivers also report care giving as life-enriching, some report that they would prefer alternatives to care at home primarily because of these associated burdens. At the BSUTH, little is known whether female family caregivers are going through associated burdens with devastating impact on them and the family, stresses associated with such care giving, including physical, psychosocial and financial burdens. Little is known whether female family caregivers at the Benue State University Teaching Hospital would prefer other alternatives to prolonged hospitalisation of terminally-ill patients. It is on this background that the study answered the following questions:

- What is the impact of prolong hospitalization of terminally-ill patients on family caregivers at the Benue State University Teaching Hospital?
- What are the preferred alternatives cares for the terminally-ill patient at the Benue State University Teaching Hospital?

## **METHODOLOGY**

The study adopted a qualitative research design. The population of the study consisted of female family care givers to terminally-ill patients who have been hospitalised for at least a month or longer who were identified at the Female Medical Unit of Benue State University Teaching Hospital. For easy accessibility and availability of data, the population was restricted to the adult female medical wards of the hospital. Therefore, any female care giver that was not from the female medical ward was not considered as the population of the study. The sample for the study was 53 female care givers who were identified at the Female Medical Ward (FMW) of the hospital and all participated in the study. They were identified as the researchers visited the Female Medical Ward of the hospital. The instrument used for data collection was Key Informant Interview (KII) to obtain information from the female family caregivers. A KII guide was designed by the researchers based on the research questions presented as Appendix. The KII was guided by sets of structured questions that were asked female family caregivers. The KII was conducted on one on one in the wards. The discussion was guided by the sets of structured questions where the researchers served as moderators during the sessions. The views and opinions of the participants were written down and recorded for content analysis. Responses were transcribed for content analysis where individual responses were categorized according to questions answered by identifying patterns and diversity, editing the contents to fish out repeated responses and to get the pattern and diversity of responses. A written permission to conduct the study was presented by the researchers to the Hospital management. The researchers were referred to the Head of Department in charge of Female Medical Ward of the hospital. The researchers explained clearly the purpose of the study to the Head of Department and the permission to conduct the study was obtained. Two nurses were directed to assist the researchers identify the female family caregivers at the wards. Having identified them, the researchers clearly explained the purpose of the research to them and sought their consent to participate in the study. Out of the number of female family caregivers identified, 53 consented to participate in the study while two declined participation.

Data collected were qualitatively analysed. Information obtained from the KII was immediately transcribed through Manual Inductive Approach (Thematic Analysis Approach). The responses of participants were classified into themes, patterns and diversity in views and opinions. The results of the patterns and diversity in views and opinions are presented in the results and discussion section.

## **RESULTS AND DISCUSSION**

**Research Question One:** What is the impact of prolong hospitalisation of terminally-ill patients on family caregivers at the Benue State University Teaching Hospital?

Results obtained from this research question revealed that prolong hospitalisation of terminally-ill patients has severe negative impact on the family finances. One of the respondents lamented that:

*...since this child has been hospitalized, I have been spending money on drugs and other related hospital expenses. As you can see, her father is late and I am the only one taking responsibility not only in the hospital but at home as well. My job is not paying regularly because government said they do not have money so it has been so traumatising... (Participant FMW).*

Participants expressed concern over the rising cost of hospital bill in the midst of dwindling finances and concluded that it was what they disliked about their hospitalisation. The result aligned with that of Grinfeld (2005) and Grinfeld, Janz and Glossop (2004). Canadian-based research led by Dumont has found similar result when they reported that the welfare state; the family and not-for-profit organisations sustained 71.3%, 26.6% and 1.6% of all costs associated with end of life care (Dunmont, Jacobs & Fesssbender, 2009). The result corroborated that of Grande, Stajduhar and Aoun (2009) that prolong hospitalisation is physically exhausting, difficult to recover from and fraught with emotional and financial burdens.

Other impact reported included alteration of family life, reduced daily living activities, poor medical attention and high level of depression similar to patients and greater than general population. This is similar to findings of Grinfeld, Janz and Glossop (2004) that psychological and mental health challenges accompanied by physical burdens, long hours of care provision associated with fatigue and sleep deprivation are common among hospital caregivers. One of the caregiver said that *...I have not been sleeping well since we came to this hospital, when we were at home I could sleep sometime because other family members could assist but now...* This was reported by Aoun and Stajduhar (2005) and Strang, Koop and Peden (2002). What could be deduced from the result in terms of implication is that the physical demands of care giving are often a result of the excessive work involved in the care giving process and the 24 hours responsibility that many family caregivers have. Psychologically, caregivers and their families are generally traumatised, felt alienated from family life, and reduce their daily living activities, expression of disappointment in the face of poor medical attention and high levels of depression similar to patients.

**Research Question Two:** What are the preferred alternatives cares for the terminally-ill patient at the Benue State University Teaching Hospital?

Findings revealed that female family caregivers would prefer traditional therapy because it is less expensive and since the patient has no hope of survival, relying on divine assistance since Medicare will not cure the illness again. One of the participants said that *...my brother, there is nothing God cannot do. I know that no medicine can cure mama again but if God wishes, she can be well again...* while others preferred to leave against medical advice (LAMA), few preferred euthanasia and others have no other alternative. The finding is contrary to that of Smith (1993) and Valente (2010) assertion that most people would want to die peacefully with dignity because a lot of cancer patients do not want to go through extensive treatment that have horrible side effects if there is no hope of better quality of life. Smith (1993) consistently argued that the debate about euthanasia and assisted suicide has highlighted pervasive and serious short comings in the care of terminally-ill patients. One of the caregivers lamented that:

*My worry is that medical team no longer pays adequate attention to my sister despite the fact that huge amount of money is spent daily. They usually come around morning, afternoon and evening but nothing special is done. They just observe her and go away without saying anything to us. When you complain they will write drugs for us to buy yet no improvement and changes in her condition are noticed. Sometimes I wonder what they are keeping her here (Participant FMW).*

The general consensus from participants is that patients receive inadequate relief for pain and other debilitating symptoms despite the fact that effective treatments are available. The result confirmed Smith (1993) that these patients as well as others who experience pain and suffering often receive inadequate relief. This result reaffirmed the findings of Broback and Bertero (2003) that helplessness and Milberg, Strang and Jakobsson (2005) that vulnerability are commonly noticed among caregivers. In addition, it aligned with Smith (1993) that many physicians fail to discover treatment options and other possibility of foregoing treatment with patients in a timely and appropriate manner, leading to over treatment, a sense of isolation (Dumont, Turgeon & Allard, 2006) and powerlessness on the part of patients and those close to them.

Participants generally preferred traditional therapy, some divine assistance, some LAMA and others without alternative. The result disagreed with the finding of Clement (1993) on the ground that alleviation of pain and the symptoms of illness or disease make a powerful contribution to the patient life. It can also speed recovery and provide other tangible medical benefits. Argument that the result aligned with were advanced by Hickman and Douglas (2010) and Zilberberg, De wit, Pirone and Shorr (2008) that although symptoms often dissipate over time, a significant proportion of family members will remain moderate to high risk for psychological distress well after the patient's death or discharged from the intensive care unit therefore, may prefer alternative treatment.

Follow-up question on why they preferred alternative treatment revealed that medical technology and laws to protect the sanctity of life un-intentionally prolong life regardless of the cost or the patient's wishes as found by Tulsy (2008). Female family caregivers to terminally-ill patients at the BSUTH fear prolonged suffering, uncontrolled pain and expensive cost of dying. One asked rhetorically that *...what about the suffering and the pain? Does one have to pay money for one to die...?* This confirmed Isaac (2006), and worry about life saving technological futile treatment as reported by Tulsy (2008) and the impact it has on them and the family. Valente (2010) concluded that the issue of prolonging hospitalisation of terminally-ill patients has become one of the controversial issues facing health care professionals, as they are challenged by their therapeutically responses to patients request for hastened death.

The silent question however, is whether it is better to keep people alive, connected to machines at huge cost, with no hope of recovery or to let nature take its course. Modern medicine has become so good at keeping the terminally-ill alive by treating the complications of underlying disease that the inevitable process of dying has become much harder and is often prolonged unnecessary. The implication is that the increase health care demand is such that primary health care physicians do not have time to spend an hour with a patient or see and assess their reactions to medication adjustments. The easiest thing for the health care team is to admit such patient to the hospital. Once admitted, they are likely to be seen by a dozen or more specialist who will conduct all kinds of tests whether they are absolutely essential or not.

## CONCLUSION

The study highlighted the debilitating effects of prolonged hospitalisation of terminally-ill patients on female caregivers and their family members directly involved in their care. It also exposed the feelings of female family caregivers that aside the inevitability of prolonged hospitalisation of terminally-ill patients there are no better placed options for the care of the terminally-ill beside the hospital. They would preferred other alternatives like traditional therapeutic attention, will of God among others if the patients has no hope of living again considering the effect it has on family finances.

## Counselling Implications

There is the urgent need for counsellors to provide caregivers and hospital workers with the appropriate techniques of self-management behavioural changes so as to help them manage themselves and their patients. Counsellors should ensure that caregivers acquire skills that are related to managing terminally-ill patients to help them cope with the trauma associated with prolonged hospitalisation of terminally-ill patients.

Hospital management as part of their corporate social and welfare responsibility should establish counselling clinics and where available, it should be made functional and effective. They should sensitise hospital caregivers to be attending counselling sessions based on their needs.

Government should put in place policy to provide terminally-ill patients caregivers free counselling services for taking care of their patients. Female caregivers in hospitals should be given motivation as reinforcement to encourage more female caregivers to be attending voluntarily counselling services in hospitals.

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### **Appendix: Interview Guide**

1. How long has your patient been hospitalised?
2. What actually did the doctors said is the problem?
3. In your view what impact would you say prolonged hospitalisation has on you and the family?
4. What are the reasons why you don't like prolonged hospitalisation?
5. What other alternatives besides prolonged hospitalisation would you prefer if you had a choice?
6. Why did you prefer such alternatives?
7. What other challenges do you face in the cause of giving care to your patient?