‘We Are Managing’: Challenges and Coping Strategies of Family Caregivers in a Short Term Hospitalization in the Eastern Region of Ghana

Gladys Mawufemor Agbenyefia (Phd)
SDA college of Education, P. O. Bos AS 18, Asokore-Koforidua.

ABSTRACT: Caring for a sick relative is not without challenges. Family members who leave their homes to care for a sick relative in an unfamiliar hospital environment encounter more challenges than those who provide care in their familiar home environment. This hospital ethnography was carried out in one of the secondary hospitals in Ghana. Thirty-two caregivers were sampled using the purposive sampling technique. Data was collected through the semi structured interview guide. Using the qualitative exploratory case study, the study revealed that the challenges facing family caregivers are multidimensional. These challenges are classified into three major groups: institutional, environmental, and financial. In response to these challenges, caregivers developed different strategies such as denying themselves some pleasures of life, developing faith in God through prayers and giving the identification card given them by the hospital authority to other relatives who are not recognised by the health professionals as caregivers.

KEY WORDS: coping, strategies, family caregivers, hospitalisation

INTRODUCTION

Ill-health is a fact of life and in its severe form, disruptive and exacts a heavy toll not only on the sick, but also on the members of their social network. As ill-health prevents the sick from engaging in basic daily activities, family members, friends and neighbours come in to assist the sick. Sapountzi-Krepa et al. (2006) also indicate that, family caregivers’ involvement in care for the hospitalised results in an increase in survival rate of care recipients (patients).

In the quest to alleviate the sufferings of the sick, caregivers are confronted with many challenges which require pragmatic measures to overcome.

Even though caring for a loved one at the hospital not a new phenomenon, family caregivers’ active involvement in hospital care is on the increase globally.

Globally, studies on caregiver burden or challenges and coping strategies abound in literature. However, while most of these studies are European or Western based in terms of geographical location, majority are also based on long term ill-health conditions rather than a short-term hospitalisation. Caregiving burden has been study by different authors over the years.

CHALLENGES CONFRONTING FAMILY CAREGIVERS

Even though literature reveals the positive impact of care on the lay caregivers, they are also confronted with some challenges. Family caregivers suffer physically, emotionally, financially and socially. This sometimes makes them pay less attention to their own needs. Some caregivers express negative emotions as anger, depression and anxiety (Wacharasin & Homchampa, 2008). Financially, the time spent in giving care may result in job loss and or loss of wages. The social life of the family caregiver is also compromised in most cases as the desire to see the sick well takes precedence over their entire life. The work of the caregiver is described as all-embracing as they are seen performing many care activities. Writing on the experience of caregivers, Oliver et al (2013:847) state: “the home of a dying patient has been compared with a hospital u

Furthermore, lack of knowledge as to what to do and sleep deprivation are also identified as problems facing the family caregiver (Wacharasin & Homchampa, 2008). According to Goodhead & McDonald (2007), possible systemic barriers limiting caregivers’ access to services may include health professionals failing to recognise caregivers as patients in their own right.

Establishing a relationship between income and caregiving burden, Andrén and Elmståhl (2007) indicate that caregivers with low income status experience more caregiving burdens than caregivers with high income levels. Further, caregivers who live away from their homeland or far from relatives experience a higher burden just as urban dwellers experience more burdens than rural dwellers. Andrén and Elmståhl (2007) further indicate that caregiving has both a direct and an indirect cost to the caregiver. The direct costs

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are those involving the provision of personal care, pharmaceuticals, medical consultations and physician services, among others while indirect costs comprise loss of earnings by family caregiver since they have to relinquish employment and value of time lost from caring activities. Social isolation, loss of sleep, energy and mobility were also identified.

To Glitin (undated), the economic well-being and employment status of caregivers are affected during the care giving period in that the participation of women in the workforce is changing. However, she did not explain further how it is drastically changing. Hynes et al. (2012) also indicate that family caregivers expressed frustration concerning the fact that fuller explanations were not given them by health professionals about the disease trajectory and management of their patients conditions. This often results in fear, isolation and anxiety. Also, travelling to and from the hospital as a result of the hospitalisation of a loved one is seen as an added physical and emotional burden on the caregiver (Morgan et al., 2014). Lay caregivers experience the challenge of getting access to information about the disease condition, unclear roles and responsibilities as health professionals become inconsistent in recognising their roles (Toscan et al., 2012).

In their study on the challenges facing informal caregivers in Uganda, Emanuel et al. (2008) identify financial assistance, pressure to stop attending school, take embarrassing jobs, transportation difficulty from home to care center, having to work fewer hours or stop work entirely due to time and energy needed to take care of the sick are some challenges they face. However, informal caregivers mentioned the ill conditions of their loved ones as most worrying. Even though caregivers consider hiring someone to take care of their sick in order to have more time to work, have time for themselves and other close family members, they find the cost of such services as the greatest obstacle.

Ae-Ngibise et al. (2015) reports that in Ghana, family caregivers for people living with mental disorders are confronted with challenges of emotional distress and stigma as they are all the time found thinking about their sick relatives. Family caregivers are also faced with economic burdens and non-availability of social support for them. This notwithstanding there is so much burdens on their time as caregiving demands spending most part of your time with the sick. Klopper, van Dyk, and Pretorius (2015) also report a lack of social support for lay caregivers in Namibia.

Citing Cigrang et al. 2003, Prouty. A. M et al (2016) indicate that cancer patients have the highest percentage of religious coping response than other people with serious illnesses and that believing in God has given them hope. Writing on Burden and Coping Strategies of Caregivers to Alzheimer's Patients, Pratt et al (1985), found that caregivers employed three internal coping strategies of re-framing the problem, confidence in problem-solving, and passivity and five external coping strategies of spiritual support, extended families, friends, neighbors, and community services to cope with their burdens (Pratt, 1985:28). O'Brien (1993:131) discovered that caregivers developed a more problem focused than emotion focused coping strategies in dealing with their challenges. Problem-focused coping refers to cognitive and behavioral efforts to deal with the source of the problem or stress directly. Emotion-focused coping refers to cognitive and behavioral efforts directed at dealing with the emotional reaction arising from the stress.

THEORETICAL FRAMEWORK

This study is based on the theories of McCubbin et al. (1996) and Lazarus and Folkman (1984). Resiliency Model of Family Adjustment and Adaptation (RMFAA) by McCubbin et al. (1996) indicates that families are confronted by stressors at any point in time and the resources available to the families determine how they appraise the stressors and this subsequently influence how they adjust and adapt to the stressors or challenges. In this study, the major stressor that confronted the caregivers is caring for a sick relative in a hospital environment and the resources available to these caregivers actually influenced how they coped with all other stressors that confronted them in the care environment. Similarly, Stress and Coping Theory of Lazarus & Folkman, (1984) focuses on how individuals and families assess stressors and how they use coping mechanisms to manage them. Family caregivers in this study exhibited different coping strategies that are discussed below.

Methodology

This article is an excerpt from my PhD thesis. It looks at the challenges that confront family caregivers in an attempt to care for a sick relative at a health facility. It also discusses some coping strategies this caregivers employed in order to care for their sick relatives in an unfamiliar professional environment. Data were collected before and during the Covid 19 pandemic using the qualitative exploratory case study design. The choice of this research design was influenced by the aim of the study to derive an in-depth understanding of the main challenges that confront the caregivers and how they are able to cope with them. According to Creswell, (2014), qualitative inquiry typically focuses on relatively small samples selected purposefully and unique cases which are informative. This makes the qualitative design most appropriate. The study was carried out in the adult medical ward of the hospital. Relatives and non-relatives of patients on admission who spent three or more days at the hospital constitute the population for the study. Data was collected using multiple approaches such as observation, individual in-depth interviews and focus group discussions. Even though the population under study is not hard to reach, the researcher used the snowball sampling technique in recruiting participants purposefully. This is due to the fact that there were more family caregivers in the hospital who cared for patients in other wards who were not of interest to the researcher. Since the population was those in the medical wards (male/female)
and those who care for their relatives in the same ward know each other, the snowball sampling was considered most appropriate as one caregiver introduced the researcher to other caregivers in the medical wards. Thirty-two (32) caregivers were sampled for the individual in-depth interviews. Two focus groups made up of six (6) and eight (8) discussants respectively were also sampled for the study. The semi-structured interview guide and digital audio recorder were used to collect data from all participants. All data collected was managed systematically and analysed using Nvivo Pro 11.

PRESENTATION AND DISCUSSION OF RESULTS

Socio-Demographic Characteristics of Participants

A total of thirty-two caregivers were recruited for the study. In this study, the socio-demographic characteristics of participants important to the researcher include variables of sex, age, educational qualification, marital status and relationship to the patients. These variables were considered important because they affect an individual’s status and social class greatly and these in turn also influence the caregivers’ ability and strategies to cope with challenges. For example, a person’s occupational status affects his or her income level which will in turn affect his/her ability to solve financial problems. Similarly, a person’s age or maturity influences his or her ability to cope with and manage stressful conditions. From the data collected, the above variables were found influencing the caregivers’ challenges and coping strategies greatly.

Table 1: The socio-demographic characteristics of participants

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
<th>Percentage</th>
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<tbody>
<tr>
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<tr>
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<td>20 – 29</td>
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<td>30 – 39</td>
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<td>40 – 49</td>
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<td>50 – 59</td>
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<td>60 – 69</td>
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<tr>
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<tr>
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<td>56.3</td>
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<tr>
<td>Secondary</td>
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<tr>
<td>Relationship to the Patient</td>
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<tr>
<td>Daughter</td>
<td>12</td>
<td>37.5</td>
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<tr>
<td>Son</td>
<td>3</td>
<td>9.4</td>
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<tr>
<td>Spouse</td>
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<td>Siblings</td>
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<tr>
<td>Mother</td>
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<td>Other relatives</td>
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<td>Non-relatives</td>
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<tr>
<td>Students</td>
<td>3</td>
<td>9.4</td>
</tr>
</tbody>
</table>
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From the table, majority of these caregivers are between ages 30-39 and 50-59 as they constitute 50% of the participants. These people are also mature and energetic enough to assist in performing certain physical needs for the sick. Two children aged 13 and 15 were also found caring for their parents.

In terms of relation of caregivers to patients, most caregivers were found to be family members or close relatives. The high number of relatives or family members confirms the findings of Blum & Sherman, (2010); Oliver et al., (2013); and Wacharasin & Homchampa, (2008) that informal caregivers are mostly family members and caregiving is also seen as work for the female. This study also discovered high number of female (27 out of 32) participation. Majority (19) of whom are spouses and children (sons and daughters) confirms other studies that caregivers are often spouses and children (Pratt, C. C. et al 1985)

Twumasi (1988) indicates that the socioeconomic condition such as the occupation of the caregiver affects the condition of health of the family members. This implies that, if a caregiver’s occupation is so demanding that it takes him or her away from the home, that caregiver will not pay much attention for the sick. From the table, a majority of about 28 caregivers are in the informal sector most of whom are the owners of their own businesses hence, their availability to care for the sick.

Challenges Facing Family Caregivers in the Hospital Environment

The challenges facing family caregivers as identified in the data are numerous. These challenges are the difficulties they go through while caring for their patients. These difficulties are the conditions either present or absent in the environment and interfere negatively in their daily activities. Kasuya, Polgar-Bailey and Takeuchi (2000) indicate that, caregiver burden is a multidimensional response to physical, psychological, emotional, social and financial stressors associated with the caregiving experience. Two main types of challenges were identified in this study. These are the institutional and home cause challenges.

The institutional challenges are those conditions which are either present in or absent from the hospital environment which make caregiving very difficult for the family caregivers. The following were some of the institutional challenges: inadequate accommodation, lack of access to information, poor environmental hygiene, inhuman treatment among others. The main home challenge is inadequate finance. These challenges confronting family caregivers however, are multi-dimensional in the sense that some family caregivers were confronted with multiple institutional factors in addition to the home factor which is mainly financial.

INSTITUTIONAL CHALLENGES

The most institutional factors hindering care giving were inadequate accommodation or place of rest, inhuman treatment, lack of access to information and poor environmental hygiene.

In the quest to address the accommodation challenge of the caregivers, the hospital authority has put up a Visitors’ Hostel (mothers inn) built purposely to house lay caregivers. This five (5) unit mothers inn can accommodate only 28 caregivers at a time. The spaces are inadequate to meet the accommodation needs of the large number of caregivers who live in the hospital from time to time. Attached to the hostel are two summer huts to shelter the caregivers during the day but some have turned the place into a sleeping place during both day and night. The cost of using the hostel during the first data collection was two Ghana cedis (Gh¢2) but now its five Ghana cedis (Gh¢5) a day, an amount which is equivalent to two cedis in value at the time the first data was collected. The rooms are however too few to meet the needs of the large number of caregivers who patronise the facility hence most of them use the Out-Patient Department (OPD) seats and any available space as their beds since it is free sleeping there. One caregiver intimated:

“The accommodation is my greatest headache because we came with a sick person. However, in the night we do not get any place to sleep. They come to sack us from the room and do not think about our safety or provide any place for us. When you find a piece of wood; you lay your head on it and pray that the day will come quickly. It is one of the major causes of our poor health condition.

We wake up with bodily pains. We need to be in good health in order to take care of the sick but we do not have anywhere to sleep. We sleep on benches and wake up with bodily pains. They should get us accommodation at a price affordable to everybody for us to be healthy so that by the time the sick is discharged, the caregiver will also be in good health. Sometimes, the sick may get well and later you the caregiver also become sick due to the challenges we go through. Have you seen? They have to work on the toilet for us. The place must be kept clean. The toilets are only two while the patients are many. Sometimes, you want to go there while someone is already on it. People come to the hospital with different health conditions and someone goes to spend so much time on it and by the time you realise; another might have soiled herself so it is not good for such a big number to be using only two toilets. The bathrooms are also not sufficient.”

The above statement captured the accommodation challenges facing lay caregivers at the Eastern Regional Hospital (ERH). With the exception of two who lived in the visitors’ hostel, the rest (30) including the thirteen who participated in the two FGDs all found their own sources of accommodation. The search for alternative source of accommodation was not without challenges. These challenges come as a result of limited space at the hostel, harassment by the security men and the presence of mosquitoes in the environment.
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As indicated earlier, the mothers’ inn can accommodate only 28 caregivers at a time. However, the Eastern Regional Hospital is a referral point for almost all the hospitals and clinics in the region and admits over 100 patients from both immediate and remote areas of the region. This called for self-search for accommodation but unfortunately, local private property owners do not make accommodation available near the hospital for the caregivers. Through improvisation, any available space in the hospital could do the magic for them. The floors in the various wards, the benches at the main adult OPD and any other department OPDs are “meant for beds”. These caregivers use these places as sleeping places paying little or no attention to the negative health implications associated with the use of these unapproved places for accommodation.

The floor of the ward is used as bed by some of the lay caregivers. When asked whether they were permitted by the hospital authority to sleep on the floor in the ward, two responses were recorded. While some do so at the blind side of the nurses, some said they were asked to stay by their patients hence using the floor as a bed. It was found that while some spread pieces of cloth on the floor before sleeping others brought their own mattresses from the house. Anyina indicated:

“I don’t sleep at the hostel but I sleep in the ward. This is my mattress” (pointing at a folded mattress under the mother’s hospital bed)

When asked whether the nurses were aware of the presence of her own mattress in the hospital, she answered in the affirmative even though the sleeping in the ward is done at the blind side of the nurses. The caregiver intimated:

“The nurses have seen the mattress but have said nothing about it. When they come to clean this place in the morning, I normally fold it and put it under the bed… I do not sleep here in the day but after 9 pm when they (nurses) have finished with their rounds and gone to sleep. I spread the mattress and sleep. So there is no problem.”

Anyina’s story indicates the nurses have accepted her and the mattress into the ward. This should be of great concern to health policy makers because the mattress could be infected with germs in the hospital. This mattress, if sent back home without proper treatment will have health implication for other members of the family who may use it. However, Anyina has no other option than to put up with this condition. Similar stories were shared by other caregivers except that they slept on pieces of cloth spread on the floor and not on a mattress. This is the case of Hajia, a 72-year old mother who spread cloth on the floor by her daughter’s bed. In some cases such as that of this 72 year old mother, the health professionals did ask the caregivers to stay in the ward due to the conditions of their patients. These conditions mostly include agitating and or unconscious patients. This is done so that the caregivers will keep a constant eye on the patient as some patients attempt to remove the oxygen and infusions set on them. Also, since availability is the best resource, their presence in the ward aids the health professionals in attending to the patient’s needs on time.

Those who could not use the floor found rest in the plastic chairs meant for sitting. A 57-year old kenkey seller caring for her daughter and several others were confronted with this challenge. She complained bitterly:

“We have not had a place to lay our heads, since we came here. We have always been sleeping in the chair and can you imagine the pains in it? That is my problem”.

Majority of the participants who could not find their way inside the wards used the main OPD benches; benches at other departments and any open place as beds. Not only were they disturbed occasionally by the hospital security men (HSM) but they were constantly disturbed by mosquitoes as well. Caregivers complained they were driven away by the security men when seen at any other place apart from the visitors’ hostel. This practice is however common during the day. However, in the night, they were allowed to use the main adult OPD benches and no other place. At the OPD of the children’s department is the inscription “DO NOT SLEEP HERE, THIS PLACE IS NOT FOR SLEEPING”. This is typed and pasted on the wall. This inscription is visible and welcomes anyone who gets to the children’s department OPD. This act and similar others are done to restrict the caregivers from using any available space for rest. Despite these measures put in place by the hospital authority, caregivers continue to use any available space for sleep.

In an attempt to drive away the mosquitoes, caregivers meet opposition from the hospital security men. Most of the caregivers complained the security men prevent them from using the fan to drive away mosquitoes.

“We sleep at the OPD on benches which give us bodily pains. Even when we turn on the fans to drive away mosquitoes, they (the hospital security men) put them off. They even chained some of the benches so that we cannot sleep on them.”

When asked why they do not sleep at the hostel provided by the hospital, three reasons came out. These are limited space, cost and any open place as beds. Not only were they disturbed occasionally by the hospital security men (HSM) but they were constantly disturbed by mosquitoes as well. Caregivers complained they were driven away by the security men when seen at any other place apart from the visitors’ hostel. This practice is however common during the day. However, in the night, they were allowed to use the main adult OPD benches and no other place. At the OPD of the children’s department is the inscription “DO NOT SLEEP HERE, THIS PLACE IS NOT FOR SLEEPING”. This is typed and pasted on the wall. This inscription is visible and welcomes anyone who gets to the children’s department OPD. This act and similar others are done to restrict the caregivers from using any available space for rest. Despite these measures put in place by the hospital authority, caregivers continue to use any available space for sleep.

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Those who do not use the hostel, pay one Ghana cedi when they bathe, fifty pesewas when they visit the toilet and buy water for other purposes, an amount which is equal to paying for the hostel. As a result of this, some caregivers use the washrooms and the bathrooms in the wards when they go to attend to their patients. Some of them justified their decision on the grounds of a genuine financial challenge. This was the case of a 60-year old woman and several others. In her disappointment, she complained: “Paying 2 cedis every day is too much. If you put it together for a week or two, you can use it to buy some drugs. It isn’t that I don’t want to sleep there but the money.”

Other caregivers also feel it is not right for them to pay for the use of the hostel since it was put up by government. They justified their reason on the ground that the services they provide help government from employing more health staffs. A discussant of one of the focus groups however justified their action for not using the hostel and said: “For me, it is not right for the government to put up a hostel and rent it to caregivers. We are helping the nurses to care for the sick. They must have a place for us so that when we are coming, we will only get some bedsheets and just come to stay.”

In relation to this complaint, the researcher sought the views of the health professionals on why they charge for the use of the place. One of the nurses finds it amazing for the caregivers to complain that the two Ghana cedis now five Ghana cedis charged was too much for them and exclaimed amidst laughter: “Two Ghana cedis! In a way, the room they are staying in is free. It is because of the utility bills that they are paying the 2 cedis. If they were to go to town to rent an apartment, it would have been more costly. The 2 cedis is just a token to pay electricity bills because some even use blenders, water heaters and water for flushing the toilet so I think the 2 cedis is not bad.”

This assertion was echoed by one of the Ward Matrons. Like the nurse, she explained amidst laughter that the two Ghana cedis is a token for paying utility bills of water and electricity.

The third category of LCs who did not use the hostel also complained of lack of knowledge on the existence of such a facility. The two who said this explained they were not told and did not also find out if there was a place like that. In a follow up question, participants were asked if they knew the health implications of either sleeping on the floor or the chair in the ward; on the benches at the OPD and any other places. The responses have shown that not even a single participant lacks knowledge on the negative effects of their actions on their health. However, they were doing this for the sake of the sick believing that nothing bad will happen to them because God will protect them. Maame Wakye represents the rest of the caregivers in this regard: “I know sleeping in the chair will bring some side effects but God is in control. I am thinking about the welfare of my child hence I have to do this.”

Caregivers, who use the hostel, were not without problems. They were also disturbed by mosquitoes. However, their solution to this problem is that they could turn on the ceiling fans to keep the mosquitoes away. They however feel more secured and protected as compared to those who do not use the hostel. Below is the picture of the visitors’ hostel and summer huts:

“The security men are also worrying us. I just picked up with one before coming to you. I was angry and told him it is not our wish to stay in this environment. They are impolite when talking to us. They sometimes push you and you may say something and later regret what you have said. They sack us like animals.”
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Some actions of the health professionals such as the one described in the above statement by Wofa is what the caregivers described as inhuman treatment. This complaint came second on the list of the challenges facing these caregivers in the professional health delivery environment. This treatment is meted out to them mostly by the hospital security men even though occasionally, some nurses also do it. What then constitutes the inhuman treatment these caregivers experience? For want of words to describe their experiences, they simply said “wɔn retettey en (they are worrying us), “wɔn reha yen, (they are disturbing us) wɔn rebuyen (they don’t respect us) and wɔn repam yen” (they are sacking us) were the most common vernacular expressions used. To majority of the participants, even though the security men have the duty to sack them after visiting hours or when they hang around, the way they go about it is very inhuman. One of them lamented: “Sometimes you may be in front of the ward to keep an eye on your patient, but the way they treat you does not show any respect. Look at me, last time, I leaned against a pole and the security man called me “hey hey hey” (derogatory) and when I turned, he asked me not to lean against the pole or else it will break. I asked whether I am a bulldozer to break a pole. Is this body (turning her body around for the researcher to view) heavy to pull down a pole? However, he sacked me and I came here” (visitor’s lodge).

Another member of the group retreated and lamented bitterly on the disrespectful way they are treated by some of the hospital staff. She has a word of suggestion to those who could influence the life and decision of these workers and said: “One thing that workers of this hospital must be made to understand is that all the fingers are not equal. There are some that are short while others are long. Caregivers are not carpets or it isn’t that they don’t have any work to do. Take for example this elderly woman (pointing at a 75 year-old woman in the group), a nurse or security man who could be her grandchild can call her “hey” stand up from this place. When you complain, they will tell you “dwuma bia ni emu brofo” (every work has its “English language” meaning every profession has its rules). They shout at you “go go”. Even if they are bosses at their workplace, they could call the person with politeness and say it is not right to do these things here but the health professionals do not have any respect for anybody. For the security men, the least said about them, the better. They talk to people without showing respect. They should respect us for we are also human beings”.

Several of such complaints were brought forward during data collection. The actions of the workers were described as very bad and disheartening. Some advised that the health professionals including the hospital security men learn to be patient with the caregivers since they are also humans and need to be recognised as such. This need for recognition is what Maslow (1954) termed self-esteemed needs which is one of the basic needs of man.

The above notwithstanding, some caregivers indicated that when you treat the security men well, they will also treat you well. “Treating well” here means that, you motivate them by giving them something either in cash or in kind and also respect their office. To the caregivers, if you do any of these, you will be in their good books.

Other caregivers who lamented on how they are sacked from the wards when the doctors come on visitation feel such an act is wrong. They argue that they are with the patients and know what is wrong with them and will be in a better position to describe the condition of the patients to the doctor better than the nurses. The health professionals however expressed different view on this. According to the one of the nurses, it is true that the caregivers may have certain information about the patient that they (health professionals) may not know. However, since health issues are supposed to be confidential and the presence of these caregivers in the ward cannot guarantee this confidentiality, they are sent out. One of the Medical Officers also indicated that the presence of the caregivers will interfere negatively in their work because the caregivers may misinterpret their actions. The action of the health professionals finds support in the patient’s charter of Ghana. Clauses G and H of the patient’s right, talks on the privacy and confidentiality of the patient respectively. Clause G reads” the patient has right to privacy during consultation, examination and treatment. According to clause H “the patient is entitled to confidentiality of information obtained about him/her and such information shall not be disclosed to a third party without his/her consent... “. The nurse therefore suggested that if any caregiver has any special information about their patient, such information should be made known to the nurses on duty so that they will inform the doctors when they come on visitation. Further, they added that, caregivers also have the right to request or book an appointment to see the doctor attending to their patient and lodge any complain they have. Expressing her view on this issue, one of the Medical Officers added that when the patient is unconscious and they need certain information on him or her, they contact the person whose name is given to the hospital as caregiver.

A study carried out by Washington et al (2011) on information needs of informal caregivers of older adults with chronic health conditions report on lack of access to information as one of the challenges facing caregivers. In this study, caregivers show lack of access to information on the health condition of their patients, lack of knowledge on availability of accommodation and lack of knowledge on their basic right of access to information. As discussed earlier on, some caregivers lack knowledge on the actual problem of their patients (Hynes et al., 2012; Toscan et al., 2012). When asked why they did not ask the health professionals about the health condition of their patients, some said they were afraid to ask while others said they have planned to ask at a later date. Some however, stated that they did not know they could ask. For those who could not ask for explanations, the reason is purely on power relations. They feel the professional has power which should not be interfered with. This power is based on the level of formal education and the expertise of the health professionals. Also, caregivers believe that the healthcare institution has invested some
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authority in the health professionals which cannot be challenged. They also fear that doing so may create some hatred in the health professional towards their patient which may negatively affect the quality of care that will be given the patient.

Lack of knowledge on the availability of accommodation was discussed under accommodation difficulties. Regarding lack of knowledge on their basic right to information, all that they could say was that they did not know they could ask the doctor questions concerning the health conditions of their patients. Bee, Barnes and Luker (2009) also report on inadequate information exchange between health professionals and lay caregivers when a systematic review was done on informal caregivers needs.

ENVIRONMENTAL CHALLENGES

Environmental challenges were not left out on the list of lay caregivers. This has to do with the physical environment they live in. Some of these include the activities of the mosquitoes and inadequate washroom facilities which were discussed under accommodation problem. Those left to be discussed here are the unkempt nature of the washrooms and the weedy environment. Coupled with the inadequate number of washrooms is its unkempt nature. The male and the female wards are 23 and 44-bed capacity wards respectively. However, they have only two washrooms each for all these patients. This notwithstanding, some of these caregivers also share this limited spaces with them. This has resulted in pressure on the facility. Even though the Orderlies of the hospital are seen cleaning most of the time, complaints from caregivers revealed that the places are not kept in the best conditions exposing the users of the place to opportunistic infections. In response to this complaint, one of the Ward Matrons explained that even though they are working with limited number of staff, their staff are doing their best. However, some patients and caregivers use the washroom paying little or no attention to cleanliness. She did not hesitate to add that they will take a second look at the complaint. It must be put on record that towards the end of the study, both the male and female wards were renovated to give aesthetic improvement to the working environment. This however, did not come with any infrastructural additions.

Even though the ERH cannot be described as generally unkempt, much needs to be done especially on the lawn near the mothers’ inn. Caregivers complained bitterly about the weedy nature of the place which serves as a breeding ground for mosquitoes and some reptiles. Some said they fear passing there in the night for the fear of being bitten by snakes. It must be noted that towards the end of data collection, the place was cleared. Caregivers suggested the place should be sprayed with pesticides and insecticides to destroy the mosquito larvae as some of them go back home with malaria even though they come to the environment very healthy.

Seeing people die, absence of warm water in the wards, seeing patients with different and serious health conditions and lack of space for rest during the day are but a few of the other challenges confronting the caregivers. One of the caregivers lamented on how dead bodies are sometimes left on the bed without screens around them and the way they are handled by the mortuary attendants as very disturbing. This is what she has to say:

“Seeing people dead and left in the beds on the ward is a problem because when they come to pick them to the mortuary, they throw them “ghughum” (sound) onto the carrier in the presence of the other patients. I feel that since they have curtains in the rooms it would be better to cover the place with a screen so that those who are alive by the mercy of God will not see how the dead are treated. The way the dead are handled will make the living, to be thinking and imagining they will be treated like that when they also die...this is very disturbing.”

Most caregivers use warm water to bath their patients. The wards however, do not provide warm water for these patients. Caregivers have to look for hot water outside the ward and this they said cost them two Ghana cedis per bucket. When asked why they are not able to provide warm water for patients, one of the nurses in the female ward explained that when she started work there about four years ago, there was no water heater and when she enquired she was told that they used to have one but it is spoilt. However, the male ward has a kettle which they say is used to heat water for the patients.

The hospital is a place where people report with different forms of ailments. While some will come with mild conditions which will be treated under the out-patients’ department, others come with more serious conditions resulting in their hospitalisation. The ERH being a referral point in the region receives cases, especially the seriously ill patients on regular basis. This, some caregivers complained is very disturbing because seeing critically ill patients made some of them to become sick.

During the day, some caregivers wanted to be close to their patients so that in case of any emergency, they will quickly provide the needed service but they complained provision is not made for them in this regard. Meaningful as this idea may sound, the health professionals think that, the caregivers closeness to the ward is not necessary since the patients are in their (health professionals) care. The caregivers’ plea for space to be provided near the ward is therefore immaterial.

Some caregivers also complained of the unknown spirit world and a caregiver described the experience of another caregiver who did not participate in the study. This challenge was also mentioned by some participants except that they did not vividly describe it as in the case of the one stated below. She indicated:

“There are things in darkness. There was a sister who was sleeping near the gate because the mother was on admission and by the time she realised, there was a sister (stranger) sitting by her at around 12 mid-night. The things the stranger was saying frightened the caregiver and she started shouting and running and all the nurses and the patients were asking what was happening. She told
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them the stranger said she (the stranger) is a witch. The things that are happening in darkness…so this morning I was even telling her God has protected her a lot otherwise she might have fallen sick.”

The statement above indicates the belief in the supernatural. “There are things in darkness” simply means that darkness/night is pregnant with spirits. Supernatural beliefs are beliefs in things that are believed to exist or appear real in the mind’s eye of the believers but are not based on scientific knowledge. The Ghanaian believes that we have the natural (physical) world which are the things that we can feel or see around us and the spiritual world comprises spirit beings which cannot be seen but are believed to have power to bless or harm. Witchcraft, lesser gods, ghosts, ancestors and the supreme God are some examples of the components of the spiritual world. The beliefs in the existence of the components of the spirit world constitute supernatural beliefs. The major implication of the beliefs in the supernatural is the fear it creates in its adherents which can impact the individual negatively or positively. In the example above, it is the negative impact which made the lady shouted for help.

FINANCIAL CHALLENGES

Most participants reported financial difficulties as one of their biggest challenges. This finding gives support to a previous study carried out in Uganda (Emanuel et al. 2008). The financial challenge facing caregivers in this study is both home and institutional problem. Most of these caregivers are found in the informal sector of the economy where their source of income is generally low and irregular. This is considered as a home factor. Their already low income status is worsened by the ineffective functioning of the National Health Insurance Scheme (institutional factor). This difficulty, according to some of them resulted in trying other means of health care especially visiting prayer camps and some herbalists (Assimeng, 1995). They therefore resorted to the use of allopathic medicine where professional help was sought when they realised that the condition of their patients was getting worse. Due to this, some came to the hospital with advanced form of ailments resulting in their being hospitalised. These caregivers blame the Health Insurance Authority for their predicament. While some claimed that the scheme does not cover most of the treatment given to their patients, others feel it is rather not functional. Due to the high cost of treatment, some patients were even detained at the hospital for non-payment of bills. The case of Asem is an example as she was detained at the hospital and in the fourth day when I met her . According to one of the Ward Matrons, the minimum bill that any patient who comes to the ward with or without health insurance pays is one hundred Ghana cedis (GH₵100). Perhaps, the statement made by Maame Kanewu captures the views of all others on the status of Ghana’s National Health Insurance Scheme:

“The Health Insurance does not cover anything. We are just holding it. It is not working. The Health Insurance that we have done to help us is not working. Any time a medicine is prescribed and you go to collect it, you are told to pay first. Sometimes 1,200, and where can you get this? Some people came to sleep here and could not get money to pay and as a result they died. A lot have died. We want to appeal to them to do something about the health insurance because it is not serving the purpose for which it was introduced. We pay for virtually everything.”

The National Health Insurance is with several challenges rendering it ineffective as far as its operation is concerned. This however, calls for a thorough investigation to ascertain the truth or otherwise of it. During the study, it was only one patient who came to the hospital with the national health insurance card and another from a private company. She therefore had no problem as far as financing her treatment was concerned.

It must be noted that it is not only patients who suffer from the financial predicament of their caregivers, but the caregivers themselves. Even though eating three meals or better still a well-balanced meal is required for good health, some caregivers sacrificed their meals and fast because they do not have the money to buy food. Some eat once a day while some forgo their meals entirely. This however has its own health implication. Despite the many challenges that caregivers face, they are not ready to give up on their job.

OTHER COPING STRATEGIES

In response to the challenges faced by the lay caregivers, these family caregivers adopted some basic strategies in the caring environment. These are denying themselves some pleasures of life, developing faith in God through prayers, giving the identification card given them by the hospital authority to other relatives who are not recognised by the health professionals as caregivers and improvisation.

In order to meet the financial needs of their sick relatives, some caregivers denied themselves food and good sleeping place. Some caregivers eat only once a day or fasted some days in order to save money. Others also denied themselves good sleeping place (visitors’ hostel) and slept in the open at the OPD and any available space. Even though these actions may seem pragmatic, the associated health implications are very disastrous. To relief themselves from the care burden, some caregivers give the identification tag given them by the hospital to other family members in order to get entry into the wards to help. Taking solace in the divine working power of God through prayers is one of the commonest strategies adopted by almost all the caregivers. They therefore rely on prayers offered by the hospital ministers, pastors and the leaders of their various religious denominations.
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CONCLUSION AND RECOMMENDATION
This study and related literature reviewed have highlighted the complexities of the challenges facing caregivers in the hospital environment and the various coping strategies adopted to deal with the challenges. The study also highlighted the need to understand the psychosocial context for coping in a low-income country like Ghana. With this, human agency, resources and support systems available to the caregivers must be critically examined in the cultural context for an in-depth understanding of the problem.

Future research should consider recruiting participants from the Ministry of Health in order to find pragmatic solutions to the challenges confronting family caregivers in the hospital environment because the Ministry is directly involved in making policies for the health sector. The need for further studies in other public hospitals on caregiving burden and coping strategies in Ghana is highly recommended.

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