"For better for worse is not easy", Challenges and Needs of Family Caregivers of Dementia Patients Seeking Care in Kumasi: A qualitative study

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Abstract

Background: The challenges and needs of family caregivers of dementia patients usually go unnoticed which could worsen the condition of both the caregivers and recipients in Ghana. The purpose of this qualitative study is to explore the challenges and needs of family caregivers of dementia patients who seek care at the Komfo Anokye Teaching Hospital in Kumasi Metropolis of Ghana.

Methods: With no predetermined sample size, 18 participants took part in the study. The study employed a phenomenological and an in-depth interview guide. The data were analysed using interpretive phenomenological framework.

Results: Three main challenges of family caregivers were identified: economic challenges (inability to buy drugs, limited income, high healthcare use charges, inability to work and lack of financial support), social challenges (lack of social participation, mockery and societal victimisation), and psychological challenges (stress, emotional trauma and inability to sleep). Three main needs of family caregivers were reported: physical needs (personal assistance, transportation assistance, physical attachment from spouse and inability to eat), societal needs (social gathering involvement and societal concerns) and psychological needs (free time to relax and faith assurance).

Conclusion: The authors argue that there should be a rethinking of how caregiving is constructed in Ghana. We further add that the health and well-being of caregivers should be a paramount aspect of patient well-being in Ghana in line with the Ghana Mental Health Act. It is therefore essential for clinician to institute caregivers needs in their medical plan for mental patient's recovery process.

Introduction

Most recently, there has been a growing research interest in the rewards and satisfactions associated with family caregiving [1]; [2]. The “invisible second patients”, often referred to as the family caregivers of people with dementia, play a critical role to the quality of life of care recipients [3]. Caregivers are the pivotal support system of care for individuals with dementia at home [4]. However, studies have reported adverse effects of caring for a relative especially dementia patients. Family caregivers of dementia patients experience depression at least once in their life cycle and are reported to be diagnosed with either depression or anxiety disorder at a rate 2-3 times higher than the public [5]. Specifically, family caregivers of dementia patients who experience depression have high vulnerability to stress, experience decreased self-esteem and increased despair, and in severe cases, contemplate suicide [6]. Reportedly, taking care of elderly dementia patients decreased life satisfaction and increased depression, therefore reducing quality of life [7]. Caring for a dementia patient as compared to caring for other sickness can have huge higher levels of psychological distress and lower levels of confidence [8].

In Ghana, the 2010 Population and Housing Census revealed that ageing population has increased up to 87% from 1960 to 2010 [9]. This, therefore, indicates higher possibility of an increased in dementia in Ghana as the disease is strongly linked to ageing. For instance, two studies independently put the

populations of dementia patients in Ghana around 39,916 and 45,302 in 2007 and 2010 respectively [10]; [11]. Meanwhile the cost of dementia treatment in Ghana is around \$87.9 million [11].

However, as caregiving specifically caring for dementia patients appears to be an emerging scholarly field in Ghana, much is not known on experiences particularly challenges and needs of family caregivers in the country. Though, some empirical studies have been conducted in this research area, none focused specifically on family caregivers of dementia patients. For example, a study by [12] generally explored the role of women and challenges faced as caregivers in rural and urban settings in Ghana. Again, studies in Ghana [13]; [14]; [15]; [16] focused on dementia but little emphasis was on the caregiver's experiences. Thus, there is a gap in the literature concerning family caregivers of dementia patients' challenges and needs. This study attempts to fill this gap by exploring the experiences of family caregivers of dementia patients in terms of their challenges and needs in Ghana. A comprehensive understanding of these experiences would offer valuable information for policymaking and implementation concerning ongoing discussions and efforts toward integrating family caregiving into the formal care system in Ghana.

Materials And Methods

Study design and context

The study employed a phenomenological design because the authors aimed at gaining a deeper understanding of family caregiving and its associated challenges [17]. Phenomenological research is well suited in situations where the goal is to understand people's "common or shared" experiences [18]. Thus, by understanding family caregiver's experiences through phenomenological study, our appreciation of their experiences will be better valued. The study was conducted at the Komfo Anokye Teaching Hospital (KATH). KATH is the main referral point for all hospitals and clinics from the northern part of Ghana, that is about six (6) regions refer patients to the hospital. The hospital has 1200-bed capacity and roads linking to the hospital is accessible.

Participants and recruitment procedure

Participants of this study were carers of dementia patients who were with their respective care receivers at the Psychiatric Unit of the Komfo Anokye Teaching Hospital from the period between (November 2018 to January 2019). Purposive sampling procedure was used to recruit the participants, as the sample was chosen deliberately on the basis that those selected can provide the necessary data for the study [19]. The specific characteristics that warranted a purposive sampling are captured under the heading eligibility criteria. This technique allowed the researchers to pick a selected group of individuals most appropriate to answer the questions and select the specific information sources required to gain insight into the research study. A total of 18 participants were used for the study, that is, 13 females and 5 males.

Eligibility criteria

In selecting the participants for the study, the research set the following criteria for inclusion:

1. The family caregiver should be able to express him or herself either in Twi (the local dialect of the area), English language or both.
2. Family caregivers must have been involved in caregiving for at least a year to provide detailed responses for the research.
3. Participants should be 18 years or over, to constitutionally be matured to answer question.

Data saturation

With no predetermined sample size, 18 participants took part in the study because this was the point when a saturation point was reached, and that new information were not coming from respondents but rather repetition of information. The general principles and concepts of no new data, no new themes, no new coding, and ability to replicate the study were encountered [20]. At this point, the researchers valued variation over quantity [21] and were confident that the categories were saturated, with the descriptions of these categories being sufficiently rich to allow for analysis to be undertaken.

Data generation tool and procedure

Since the study employed a phenomenological approach in examining the experience of family care givers of dementia patients, an in-depth interview guide was employed. The main issues covered in the interview guide included the needs of family caregivers of dementia patients, and the challenges they do through in providing care to the care recipient. Between December 2018 and January 2019, the study interviews were conducted at the waiting places at Komfo Anokye Teaching Hospital (KATH); Psychiatric Unit after approval from the Research and Development unit of KATH was granted. All the interviews were conducted were conducted in Twi (the local dialect or the preferred local dialect of the study participants) by the first author and each lasted for approximately 30-45 minutes. Some of the key questions asked included, "Tell me how you maintain the patient 's activities of daily living like oral care, physical cleanliness, nutrition and elimination", "Is there anything else you would want to add? E.g. Problems, stigma, negative reaction from people, etc", "Please tell me how the patient participate / influence in the care, Probes: Resist to grooming? React violently? Threatens to harm himself, you or others?" "What difficulties do you face while in the course of providing care and afterwards?" " Do you have joy providing care to your recipient" "What daily needs do you want as a caregiver" With the consent of the participants, all responses were audio recorded and ensured that all discussions were devoid of third party interferences.

Data analysis

The data were analysed by screening and reviewing all the interview for understanding and predominant themes were collated and then analysed using interpretive phenomenological analysis. Interpretative phenomenological analysis (IPA) recognizes that different people perceive the world in very different ways, dependent on their personalities, prior life experiences and motivations. It attempts to explore/understand/make sense of the subjective meanings of events/ experiences/states of the individual participants themselves [22]. The analysis constitutes transcribing, reading, reflective writing,

and interpreting rigorously [23]. The transcription was done verbatim, that is they were no omission of any part of the original recording when transcribing. Each reading and listening helped to get a new insight into the data. The themes were derived directly from the experiences obtained from interacting with the respondents rather than the prior theoretical standpoint of the researchers. These themes were compared to the responses to identify common trends, similarities and differences. The interpretive phenomenological analysis provided the opportunity to identify, analyse and report patterns within the data and help to organize and describe the data in rich detail. The study results were presented under several themes and key subjective views of the participants were discussed using quotations.

Credibility and trustworthiness of the data

A consolidated criterion for reporting qualitative research (COREQ): a 32-item checklist for interviews developed by Tong et al. [24] was adapted as a checklist to underpin all interviews and the qualitative procedure. This checklist assesses the credibility and trustworthiness of the data and is a strong and scientific analysis of credibility and trustworthiness in data collection.

Ethics consideration

Ethical clearance for fieldwork was, therefore, obtained from the Committee on Human Research Publication and Ethics, with the Clearance number: CHRPE/AP/070/19, School of Medical Sciences at the Kwame Nkrumah University Science and Technology (KNUST) and Komfo Anokye Teaching Hospital (KATH), Kumasi with the Clearance number: RD/CR19/005. The purpose, potential benefits and risks of the study, was explained to the participants and they were well informed that they have the right not to join or to partake of the study. Again, respondents were assured of strict confidentiality of the data provided. Finally, participation in the study were declared as voluntary and as matter of fact, study participants were free to opt out of the survey anytime they deem fit [25].

Results

Background of Participants

A total of eighteen (18) participants who were all family caregivers and play various roles as mothers, fathers and siblings to dementia patients were interviewed. Most of the participants (12) were married with children and even those who were single, co-habituating and separated had children and other relatives to fend for. Also concerning caregivers' relationship to patients, it was identified that more mothers were caregivers. Other relationships found were, father, brother, sister, uncle and paid person to do the caregiving job.

Table 1: Demography of Participants

Demographic Variables	Frequency (n=18)	Percentage (%)
Gender		
Female	13	72
Male	5	28
Age		
30-40	4	22
41-50	5	28
51-60	4	22
61-70	3	17
71-80	2	11
Education		
School dropout	2	11
Primary school	3	17
Junior high school	3	17
Tertiary education	2	11
No formal education	8	44
Occupation		
Farmers	1	6
Traders	1	6
Civil servants	1	6
Private workers	6	32
No Occupation	9	50
Religion		
Christian	13	72
Muslims	3	17
Other religions denominations	2	11
Marital Status		
Married	12	67

Single	2	11
Co-habituating	2	11
Separated	2	11
No of Years spent giving care		
1-5 years	10	56
6-10 years	6	33
11-15 years	2	11

Challenges of family caregivers of dementia patients

The challenges of family caregivers of dementia patients faced were grouped into three main themes; social challenges, psychological challenges and economic challenges. See Figure 1

Social challenges of family caregivers

In this paper we examined social challenges family caregivers of dementia patients face and they different on various societal levels.

Mockery

Pertaining to the social challenges, there are many vulnerabilities that caregivers face in executing their duties. These put a dangerous impediment to their health and makes them prone to various health conditions. Mockery can create a burden and stress on their life and makes them shield from community activities, with little faith of disbelief in themselves.

Some participants view of the society mocking them were expressed as:

" the town people were calling her witch, so we had to vacate the village and settle in Kumasi, because of her condition" (Participant 13)

"We had to take her away from our hometown because she talks randomly, and it was same with my grandmother. The town people were insinuating our family has been cursed with randomly talking in old age." (Participant 7)

Social victimization

Socially, understanding of dementia has not gone down well with the community members. Some talk negative about the disease and even perceived it to be linked with sorcery. Some participants expressed the alienation and rejection from friends as a result of the patient's condition.

One participant explained;

"With the reaction from family, there is not any problem but most of my friends insist that I should take my wife to her family house, because I have done my part in caring for her. With all the pressure from friends I still do believe that is not right to do because it is not her fault for this condition. So, I always become sad of the way my friend behaves and say about my wife. So recently they do not come and visit me again, even with kotoko [A football team in Kumasi] meeting I mostly go alone as we went together always for years. " (Participant 4)

Lack of social participation

Involvement in societal gathering culturally, is seen as a responsibility and a mandate for every individual regardless of societal status. It there creates a burden when personally someone cannot function in them. The gathering are open spaces where friendship is mended back again and helps improve psychological health. Some also expressed how they had to withdraw from certain social gatherings due to caregiving duties;

"I am part of the men's church fellowship and a leader as well but since my wife had the condition, I am not given enough responsibility as earlier on, because most at times I have to ask permission and go see if she is ok, I remember going for men's fellowship only twice this year. (Participant 7)

"I am a vibrant member of the Ruling party's women's commission but due to my mother's condition, I cannot involve myself in the groups duties as I previously used to" (Participant 18)

"My twin sisters daughter was marrying and I had to be there but due to our mothers condition, I have to sacrifice and be with her at home."(participant 8)

Economic challenges

Here it was imperative to assess the economic demands of the caregivers and how it has been achieved.

Inability to work

Family caregivers managing patients with mild conditions expressed they can work within the day but those with patients whose conditions are severe made it emphatic they were not unable to work, and some stated they had meaningful employment until the conditions of their relatives started. The participants expressed their concerns as:

" she was diagnosed with dementia in 2003, I have not been employed since, but it was left with only two years for retirement. I took an early retirement and now we survive on my pension fund and the monthly monies from my children. " (Participant 3)

" I was a taxi driver but after my wife was diagnosed, I had to stop and take care of her"

Limited Income

The onset of the disease makes family members sacrifice some employment offers which cut down the income of the household. Some participants reported as;

"My mother's condition is not that serious, so I have a shop in front of our house, where I sell provisions. The shop fetches a little, as we can depend on it for our daily consumption but sometimes the drugs are expensive, but I manage" (Participant 17)

"For two years now, only my husband provides for us all, I was a trader and supported him. Currently, I am caring for my mother and our family is in serious hardship, since our children are all in tertiary schools and is expensive." (Participant 6)

High healthcare use charges

Participants also mentioned high expenditure involve in hospital evaluation visit, transportation, drugs, scan, laboratory and accommodation.

Some of the participants recounted:

“We have registered the national Health Insurance, consultation fee is free for 70years and above, but for scan, laboratory and Drugs we pay, which is the most expensive “ (Participant 4)

“I have spent almost all my pension funds on my wife’s condition. The condition has taken a heavy toll on my finances” (Participant 3)

Inability to buy drug

The cost of drug for dementia care is expensive and very difficult to buy since most of the inhabitants of the country are characterised as average income earners.

“Her condition is draining me, you can buy one drug for 350GHC (68 dollars) and is not the only cost. “ (Participant 18)

“I remember she could not sleep, so we had to buy a certain medicine for her, and it was roughly around 450GHC (79 dollars)

Lack of financial support

The study reported that most of the dementia patients could not access any social intervention policy programme to help them cut down cost.

Some of the participants expressed as:

“I went to the office of the social welfare at the hospital and wanted to register my mother for the Livelihood Empowerment Against Poverty Program (LEAP) and the Disability Common fund program, but they said she cannot enjoy of the policy, since they did not capture dementia patients in the beneficiaries”

Psychological challenges of family caregivers

Caring for the dementia patients may bring some psychological interruption for the caregiver and this anomaly normally goes unnoticed. Family caregivers experienced a lot of psychological stress and agony. Participants mentioned the following psychological challenges; stress as a result of finance, shock and sadness, emotional trauma, inability to sleep.

Emotional Trauma

Here it comes as a result of dishearten event that family caregivers faced as a result of their duties. Some participants recounted that:

“Emotionally, I am not off myself, without the sickness, he used to assist me by selling the farm goods we produce but now I must do everything by myself. When it is getting to farming day, I start to think of him and keeps mute the day before, because it is worrying to know he is here physically but not here in strength with me. ” (Participant 15)

‘Recently, he defecated and urinated immediately after cleaning him, which made me very angry and talked for hours. I checked my blood pressure on the next evaluation day and it was high, which I think he is the cause’ (Participant 3)

Stress

Events and happening that makes family caregivers feel frustrated and angry. Some of the participants reported as;

“The drugs are very expensive, even now the drug they gave us for her during our last visit, I haven’t bought them. I must come to the village and see if my cocoa has yielded and sold for money, it is frustrating to see no improvement but still we are buying drugs. ” (Participant 12)

‘He easily gets angry and it gets worse when he has not eaten. Such situation is very difficult to deal with as a caregiver, sometimes you become motionless. Personally, I have

been thinking a lot since he was diagnosed with dementia. ” (Participant 9)

Inability to Sleep

One helpful event for the body and mind is getting enough sleep. But this is not the case for family caregivers of dementia patients, since you must be on alert for any noise you hear in the house. Some participants expressed as:

“Personally, it is difficult to get sleep because he can wake up at any times and would like to involve you in a conversation but not meaningful”

“One night we did not close the main gate and around 2am when I woke up, she was not around, we must search the whole town and found her around 5am, we could not sleep again.

Needs of family caregivers

From the analysis the research identified various needs caregivers of dementia patients. The main needs of the family caregivers were categorised as Physical, Social and Psychological needs. These main themes also have sub-themes which the studies were captured under.

Physical needs of family caregivers

The research participants were asked some questions that made it possible to get a concise feel of their physical needs; some daily activities they perform as family caregivers.

The caregivers explained patients who had mild conditions assisted in the caregiving like their oral care, physical cleanliness of the patient and feeding but, patients with severe conditions made it tough for caregivers, as they must perform almost all the activities. The activities performed by caregivers were different depending on the patient's conditions and how severe or serious the condition of the patients. The attention given to the males is more than the females as most of the males were reported to be

aggressive because they become disoriented, having difficulty recognizing friends or family members, identifying what time or day it is, or even misplacing items and accusing others of theft whereas the females were antisocial due to the mood swings.

Personal Assistant

Some of the family caregivers expressed their major need in respect to the duties they perform daily would be a personal assistant. Some participants recounted:

"When she had dementia, she could not do anything. In terms of bathing, brushing and other things is done by me. She starts by talking to herself and difficult to talk to her. In terms of daily living is very difficult but my son take care of her also. Is not easy, we have been married for 43 years and I tell you that commitment of "for better for worse" is not easy." (Participant 6)

"We have a house help who is being paid to help us cook, bath and dress my wife. My wife cannot do anything for herself as she is totally incapacitated" (Participant 7)

"personally, for now I need someone who can assist me in taking care of her, is never easy being the only one" (Participants 17)

Transportation Assistance

Cost involve in taking the dementia patients to evaluation is very enormous and it is very important to get a vehicle to help ease the cost. These was a major need for some family caregivers. Some participants are expressed:

"for now, a car to convene us from here to the hospital, car fares are quite expensive, especially, I have to rent a car to and from the hospital on days of evaluation"

"because of transportation fare to and fro the hospital instead of two weeks visitation, we normally go on a one-month interval"

Physical attachment from Spouse

The married family caregivers lamented on the need to have physical touch from their spouse since they are depriving their partners their rights according to scriptures. Some had faith and prayed their spouse would not cheat due to these situations.

"I told you my physical needs is to get affection and attachment from my husband, is been long we had fun and I want that physical touch from my darling"

"I am keeping faith, my husband does not take any mistress and have fun with her, is been long I saw her, he lives in the norther part of Ghana 12 hours by bus"

"I cannot remember the last time, I had intimacy with my husband, I need that feeling as a woman, but caregiving duties would not give me the time to visit her."

Inability to eat

Due to the caregiving roles, many family caregivers engrossed themselves in the duties and cannot have enough food to eat. Some participant expressed as;

"Physically, for hours I haven't eaten or drank any water, I move from doing one thing to the other, I don't not intentionally deprive myself from food and water, but the duties are many, I think a helper would be ok"

Social Needs of Family Caregivers

The study examines the social needs of family caregivers, the social activities they engage in aside giving care and the social challenges they encounter as a result of giving care.

Social gatherings like funerals, engagements and weddings, church services, meetings, association meetings etc. were the social activities listed as caregivers used to attend. Conversely, almost all the participants expressed that, their participation in social activities have slowed down since they became family caregivers to their dementia relatives. Also, time was the major factor, family caregivers expressed as the force behind their inability to fully participate in social activities. Another session of the participants had a laid down

criterion of their schedule time as to when and where to attend the social gatherings and the time to return.

Social gathering involvement

Some caregivers expressed the need to be involved in societal gatherings since culturally it is a must to partake of such events like wedding and funerals. Some participants recounted:

“I can’t remember the last time I went to a funeral or wedding; I cannot leave her here by herself and is difficult.” (Participant 6)

“At first usually once a month I have drinks with my friends but for three years I cannot interact with anyone, because I cannot go and leave her indoors.” (Participant 11)

“When I want to go out, I leave her in the room locked so that he doesn’t go anywhere. Especially when I am going to the bank for money, our children usually send money to us. “ (Participant 10)

“ I want to get my social life back, going for occasions like wedding, funeral, parties, currently, all my clothes are locked indoors”

“I cannot remember the time I sow new clothes for a gathering, I don’t go out anymore, is hurting”

“Someone saw me and said, I thought you have travelled, I do not see you at our women’s fellowship anymore, I was speechless, because I didn’t want her to know my mother’s condition”

“You know seeing friends and people, makes the soul happy, socially am out of the game now, I want that freshness in my life again”

Societal Concerns

Some of the caregivers wanted people from their neighbors and family to visit them and even have a chat about their struggles with them. Some participants reported as:

"I think a good education about the condition should be given to us the caregivers and the society in general, because the society must understand the condition more."

"If people would visit me at home and at least let's chat for a while, I think will help me close that gap of being socially ideal"

Psychological Needs of Family Caregivers

The study examined the psychological needs family caregivers of dementia have in relation to providing their caregiving duties.

Free time to relax

Some participants expressed the need to find time within their duties to relax their mind and body, to leave any stressful events.

Some expressed as:

"Mentally, I think is very difficult, caring for him and his behavior, I have to deal with a lot and is stressful, I should be a free time from the care giving duties and resume later, I think my emotional state will improve massively"

"The duties are demanding and the only want to release some stress and trauma is having time to relax, which is sometimes difficult to get."

Faith assurance

"My faith is risen whenever our pastor comes around, I think is a good emotional state for me, but he comes only twice a month, think should be more, so I have good emotional balance"

Discussion

Social challenges of family caregivers

In line with other previous studies [26]; [27]; [28], this study found evidence to show that family caregivers are faced with diverse social challenges including health, public backlashes and community stigmatization.

Findings from the study indicates family caregivers, experience physical high blood pressure, inability to sleep, low participation in any physical activity, developing heart disease and weight reduction as reported. Family caregivers experiencing high blood pressure can be proven by a study of [26], where it was known active family caregivers suffer from disease like high blood pressure and many others. Some of the caregivers expressed their views that they believe they develop blood pressure as a result of over talking and thinking that their care recipients sometimes makes them do, especially cleaning the care recipient and the person urinating on him or herself the next moment. Contemporary documented evidence indicates that one serious physical health concern with caregiving is greater risk of developing cardiovascular disease [29]. The present study demonstrated also that family caregivers of dementia patient develop cardio issues as a result of their care giving duties. This study sums up the notion that caregivers suffer from depression and other negative mental health and physical health problems at higher rates than non-caregivers as documented in studies [30]; [8].

This study also revealed that most of caregivers do not have enough sleep and have limited time to rest, it becomes needful as a physical measure that family caregivers find time to sleep and relax. Participants noted that they needed to sleep and take breaks in their roles as family caregivers. This confirms the recommendation by the [31] that caregivers should be taking periodic breaks to do something that gives them enjoyment and peace, even if it is only a 10-minute break, can help recharge them for the rest of the day. Having enough sleep and rest is also an effective way of releasing stress, which [32] posit can lead to compromised functioning of the immune system and more specifically, increase the healing time for standardized wounds.

In consistent with previous research family caregivers of dementia people face several public backlashes [33]; [27]; [28]; [34]. The public backlashes include ridicule, mockery and social stigma family caregivers of dementia patient face as a result of caregiving duties. Many societies in Ghana regard dementia as an ageing related disease which is attributed to sorcerer or witchcraft and so those who are related to the patients are victimize and neglected by community members. Caregivers could not attend various social gatherings due to their role in caregiving for their dementia relatives. The study emphasized that caregiver's social life had suffered, as most of them were unable to go out, even to attend important functions like marriages. Ultimately, the fact that the time when caregiving duties are getting more demanding, is likely to coincide with less social support being readily accessible, is one of the most unfortunate social outcomes of the caregiving experience [35].

Psychological challenges of caregivers

From the findings of the study, family caregivers experience a lot of psychological challenges including stress and agony. This is as a result of overthinking about the relative's condition and finance about their hospital bills due to lack of social support and inadequate social intervention programmes. They are

mostly psychologically distressed as they have redrawn from societal gathering and shrink to their inner beings due to the caregiving duties. This finding mirrors the reports from [28] who reported that patients and their caregivers in Ghana expressed that the experiences of family caregivers of dementia patients face a lot of emotional trauma. The mental capacity that motivate people to achieve goals and perform certain activities defined the boundaries for was meant to be psychological needs.

Economic challenges

Many researchers have been specifically concerned with the contributions made by informal caregivers and how employment impinges on these contributions [36]; [37]; [38]; [39]; [40]. The findings from this study show that caregivers have a lot of financial constraints arising from unemployment. This is consistent with a study from [41], which indicates, finance was a matter of concern for carers, in terms of expenditure associated with travelling expenses, special diets, clothing, laundry, continence materials, holidays, and charges for services. At other times, it was expressed in terms of restrictions on income through reduced or lost employment and/or the interaction between benefit entitlements. According to [42], caregivers needed assistance for the financial burden of the illness and is very consistent with our findings as caregiver recounted the support they needed financially to cater for drugs and scans of their patients. Several studies have reported the cost of treatment and services as a major barrier to service use in dementia [43]; [44] and was in accordance with the findings of our study which indicated, caregivers cry a lot in providing basic medical cost for the treatment of the condition, like scan, laboratory and the high cost of drugs. The decision to undertake caregiving duties can result in substantial financial penalties to the primary caregiver and their family [45].

The Needs of Family Caregivers of Dementia Patients

The study found various needs of dementia caregivers including physical, social and psychological needs. These needs are in line with other previous studies [34]; [41]; [42]. The physical needs comprise of food, water, shelter and clothing as detailed in Abraham Maslow's hierarchy of needs. The social needs according to a study by [13], are the needs met through satisfactory relationships – relationships with family members, friends, peers, classmates, teachers, and other people with whom individual interact. Maslow categorized social needs as the need for friendship, family, intimacy, sense of connection, love and belongingness and the psychological needs comprises of mental capacity that motivate people to achieve goals and perform certain activities defined the boundaries for was meant to be psychological needs. The social needs family caregivers of dementia patients wanted included; reintegration back into the society and establishment of social pressure of the individual and emotional talk with spiritual leaders. These social needs could be meet by caregivers giving off duties to mingle with friends and family on social gatherings. Findings from this study indicated that, family caregivers need societal involvement in their caring duties and also the general public should have education about the condition. A need that is not satisfied dominates behavior and a need satisfied makes the individual aspire higher motivation to continue another activity with fulfillment. This is very applicable to a caregiver's aspiration of needs.

From the findings of the study, family caregivers have a lot of physical needs which includes food, transportation and physical affection from others. These needs are not met daily as a result of their full involvement in the care giving duties all day. This makes it very difficult physiologically to attain maximum health. Most family caregivers are deprived of food and other physiological needs like water and clothes not because they cannot afford but the care giving role or duty makes it difficult to even eat at home, since some patients can defecate on themselves or either mess up the environment to make it not conducive to eat. This study's findings are consistent with others which indicated deprivation of food, warm, and clothes for family caregivers [34].

A study of interest which shared some similarities with current findings is the study of [34] whose findings showed that societal conflict was commonly encountered during caregiving duties. Pertaining to interacting with the society, caregivers noted that knowledge about the condition from the society limit their participation in societal activities, that's is due to the societal stigma and mockery they retract themselves from societal activity. This is because people tend to ask more questions about the condition and sometimes associate it with societal and cultural interpretation which creates misrepresentation of the condition and social stigma for the caregivers. As caregivers gained more knowledge of the disease, they provide better quality of care and ensure quality social integration for them and this is in concordances with some previous studies [46]. Since we live in a social world and care giving exists in the societal arena, care givers and the society should be provided with quality social care, adequate knowledge about the condition, mental change and family support.

From the study, it was known that caregivers need includes, free time to relax their brain and be mentally fit, someone to talk to about their emotional behaviour and also someone to confide in especially the clergy to boost their emotional wellbeing and sort strength from the faith-based approach. They needed that sleep due to some psychological stress like grief, sadness, anxiety fear and embarrassment they face as a result of their caregiving duties. The findings from this study is consistent with a study by [34] which indicated, most caregivers reported psychological symptoms. This finding is consistent with the findings of [42] that caregivers reported of having psychological distress with some emotional responses including grief, sadness, anxiety, anger, guilt, blame, fear and embarrassment. These results also support previous research that has shown that emotional experiences are the biggest challenge faced by caregivers [47].

Conclusion

This study has demonstrated that family caregivers of dementia patients go through a lot of challenges and do not meet their daily needs that would make life and caring easy for them. The challenges reported were in forms of health, social, economic and psychological challenges. These challenges coupled with their needs made caregiving very difficult. It was recommended that there should be a rethinking of how caregiving is constructed in Ghana, their health and well-being of caregivers should be a paramount aspect of patient well-being as stipulated in the Ghana Mental Health Act. To the best of our knowledge, this is one of the first studies in Ghana investigating the challenges of family caregivers of dementia in

relation to assessing their needs. Further, the current study depicts a detailed analysis of the views of carers of different ages and social responsibilities from the study prefecture. It could contribute partly to the attainment of Sustainable Development Goal 3 in addition to helping policymakers design and formulate policies that aim to address the existing barriers to meet the needs of caregivers of dementia.

Declarations

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Availability of data and materials

The corresponding author will release all data set on reasonable request.

Competing interest: The authors state that there are no potential competing interest. Also, there was no financial support for the research, authorship and/or publication of this article.

Consent for publication

Not applicable

Ethical Statement

The research obliges to all ethical responsibility and was granted ethical clearance from the Committee on Human Research, Publication and ethics from School of Medical Sciences/Komfo Anokye Teaching Hospital and Kwame Nkrumah University of Science and technology. With the clearance number CHRPE/AP/070/19. The participants were assured of the confidentiality and anonymity of the data and informed consent was sorted from them before the study started.

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Author contributions

The first author drafted the paper, helped in the designed of the study, developing study tools, and participated in data analysis. The second to fifth authors helped design the study and participated in data collection. The rest of the authors helped with data analysis, proofreading and referencing.

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Figures

Figure 1

Framework for studying challenges of family caregiver's dementia patients face