Journal of Public Health: From Theory to Practice (2019) 27:321–327
https://doi.org/10.1007/s10389-018-0953-1

ORIGINAL ARTICLE

Informal health care: examining the role of women and challenges faced as caregivers in rural and urban settings in Ghana

Williams Agyemang-Duah[1] · Charlotte Monica Mensah[2] · Prince Peprah[2] · Francis Arthur[3] · Bright Addai[2] · Emmanuel Mawuli Abalo[2]

Received: 4 March 2018 / Accepted: 26 June 2018 / Published online: 5 July 2018
© Springer-Verlag GmbH Germany, part of Springer Nature 2018

Abstract

Objective Globally, the informal health sector is continuing to experience increasing growth despite the parallel development of the formal health care sector over the years. However, studies in Ghana concerning caregiving are limited since little attention has been given to the informal health care sector. This study therefore explores the role of women as caregivers and the challenges they face in the Kumasi Metropolis and Ejisu Juaben Municipality in Ashanti Region of Ghana.

Methods In-depth interviews were conducted with 20 caregivers from the two study areas. Data were analyzed and presented based on a content and thematic analysis approach.

Results Findings from the study showed that caregivers perform key roles including those of a domestic, health care, economic, social and spiritual nature. However, caregivers were confronted with many challenges, including inadequate funds, inability to work effectively, prolonged stress, limited time for socialization and emotional trauma.

Conclusion For caregivers to perform their roles efficiently and effectively, government and health care authorities must provide them with immediate financial support and training. Also, in the near future policy makers should put a comprehensive policy in place to bolster caregiving in general.

Keywords Informal health care · Caregivers · Caregiving · Challenges · Rural · Urban · Ghana

Introduction

Caregiving has become an issue of increasing importance over the past 3 decades and an integral component of the world health care system (Nordmeyer 2002). In countries all over the world, about three-fifths of older adults with poor health status are cared for by their family members. In the US, the majority of caregivers are women (National Alliance for Caregiving and American Association of Retired Persons 2009). These figures show that more women are involved in caregiving than men. As of 2015, approximately 16 million people comprising family and friends provided many hours of unpaid care to their relatives suffering from some form of chronic illness such as dementia or Alzheimer's disease (National Alliance for Caregiving 2009). In sub-Saharan Africa, for instance, nearly three-fifths of health care delivery is provided by caregivers (Sudhinaraset et al. 2013). Despite its importance, caregiving does not have much recognition because it is generally considered voluntary and unpaid. Hence, it is difficult to account for it in the national income measurement. However, a report by the Family Caregivers Alliance (2009) estimated that the services provided by family caregivers are worth $375 billion annually.

Aside from the unpaid and unacknowledged nature of caregiving across the globe, and particularly sub-Saharan Africa, most caregivers are faced with some form of additional difficulty such as financial insecurity, depression and stress (Taylor et al. 1996). According to Kiecolt-Glaser et al. (2003), caregiving also has an effect on the health status of the caregiver after providing care for some years. This, they say, is due to the difficult nature of the roles they perform and clearly shows that caregiving comes with multiple challenges.

✉ Williams Agyemang-Duah
agyemangduahwilliams@yahoo.com

[1] Department of Planning, Kwame Nkrumah University of Science and Technology, Kumasi, Ghana

[2] Department of Geography and Rural Development, Kwame Nkrumah University of Science and Technology, Kumasi, Ghana

[3] Oxford Department of International Development, University of Oxford, Oxford, UK

In Ghana, the percentage of people aged 65 and over represents 4.6% of the population (Ghana Statistical Service 2012a). Moreover, there are 737,743 persons with some form of disability, representing 3% of the total population, and people living with the human immune virus (HIV) and acquired immune deficiency syndrome (AIDS) number around 235,800 (Ghana Statistical Service 2012b). These statistics show that caregiving is an issue that is certainly on the rise in the country and therefore needs urgent attention.

One significant observation is that caregiving is stereotyped as a woman's duty owing to the emphasis on care and nurturing; these gender roles in turn increase women's susceptibility to the stress of being a caregiver (Miller and Cafasso 1992). Women, to a large extent, are charged with the duty of caring for the young, sick and elderly in the home (Kabeer 1992). Caregiving is gradually becoming a major alternative for people who cannot afford high hospital bills or because of inadequate health facilities and lack of personnel (Taylor et al. 1996).

Despite some research done on caregiving, relatively little attention has been devoted to the exact roles played by female caregivers and the challenges they encounter while doing so (Saban and Hogan 2012). Considering this deficit, studies are needed to address the knowledge gap that has arisen.

Methods

Design and context

Dealing directly with real-life episodes and narratives of experiences provided by caregivers, we conducted a descriptive qualitative study to provide evidence on the role female caregivers play in the urban areas of Bantama and Tafo within the Kumasi Metropolis and the rural settings of Kwaso and Deduako in Ejisu Juaben Municipality.

Sample and procedure

This study was conducted among 20 female caregivers with 5 each recruited from the 4 study sites. Purposive and snowball sampling methods were used. The first purposively selected caregiver interviewed was asked to direct us to other people acting as caregivers. Following Babbie (2005), members of an identified target group provided interviewers with information about how other members could be located.

Data generation tool and procedure

An in-depth, face-to-face interview was the instrument for data collection for this study. This allowed participants the freedom to provide information that may not have crossed the researcher's mind (Hesse-Biber and Leavy 2011). The interviews were conducted in "Twi" (local dialect of the study participants) and translated into English for further analysis. The interview questions were centered on three areas: first, the relationship of the caregivers to the care recipients; second, the roles of caregivers in caregiving; finally the challenges faced by caregivers in caregiving. Each interview was audio-recorded and lasted for approximately 50 min. All participants were assured of strict anonymity and confidentiality. Also, participation in the study was voluntary.

Data analysis

Data were analyzed using thematic and content analysis (Braun and Clark 2006). The findings or results were categorized and grouped under identified themes. Transcribed data were reviewed to identify topics and content relevant to the research objective. Passages and quotations were used to give more insights.

Results

Background characteristics of participants

Table 1 provides the background characteristics of the 20 study participants. Most were aged 60 years and above (8) and married (16) with no formal education (11). Most were from the Akan ethnic group (19) and engaged in farming (11). All participants were Christians (Table 1).

Caregiver's relationship with care recipients

Most of the caregivers were related to the care recipient, which had led to the establishment of some form of bond and helped to develop a high level of commitment. Caregivers explained that they had no other choice than to support and assist their relatives, despite all the difficulties they faced. This was because the care recipients had in the past also often supported and raised them. For this reason, they could not abandon them at this stage in their life when they needed them the most:

> "She is my mother who gave birth to me and breastfed me right from infanthood, gave me all the support I needed. How can I neglect her at this stage in her life when she cannot do anything on her own? I cannot do that, I have to do for her like she did for me when she was strong and active." (Caregiver, Kwaso-rural)

Because of the love and affection they had for their relatives, the caregivers could not leave them on their own and decided to help them. Most of them did not have money to hire people

Table 1 Background characteristics of the study participants

Variable	Category	Frequency
Age (years)	20–29	2
	30–39	3
	40–49	2
	50–59	5
	60 and above	8
Marital status	Single	2
	Married	16
	Divorced	1
	Widowed	1
Educational background	None	11
	Junior high school	7
	Senior high school	2
Ethnicity	Akan	19
	Ewe	1
	Other	–
Religion	Christian	20
	Moslem	–
	Traditionalist	–
Occupation	Farming	11
	Trading	5
	Not working	4

to provide care on their behalf and had to do it under their own steam:

> "She is my mother and I cannot sit and watch her just because she is not strong as she used to be, I have to be with her and help her. Nobody will do it better than me because she is my mother and I know how she wants something to be done. My sisters and I decided I should be the one to care for her, I could not say no to that decision because she is my mother." (Caregiver, Deduako-rural)

Roles of female caregivers

From the discussions, several roles were identified such as cooking, washing, bathing, household cleaning, assisting care recipients in toileting, booking appointments and escorting them to hospitals, praying on their behalf, helping them to adhere to doctor's prescriptions, paying medical bills, visiting and sometimes accompanying care recipients to funerals. For the purpose of this study, these roles were broadly classified into five thematic areas: domestic, economic, health care, social and spiritual. These are further explained in the subsequent sections.

Domestic roles

In interviews with the study participants, it soon became clear that cooking, washing, cleaning and bathing were the main domestic roles performed by caregivers. The following excerpts throw more light on these roles:

> "I cook for her (three times daily), I wash her clothes every weekend, bathe her at least twice a day, I clean the house. I also help her when she wants to attend to the call of nature. I do all these activities daily and they are very important to her. She cannot live without eating and bathing and so it is my core duty to meet these needs every day. They are very crucial." (Caregiver, Deduako-rural)

Another respondent also stated:

> "I bathe him and cook for him every blessed day. He cannot walk on his own, cook for himself, bathe on his own, or go to the toilet on his own, so I have to do it for him on a daily basis. These are the most important things I do for him." (Caregiver, Tafo-urban)

Economic roles

Among the participants, most of them mentioned that one of the roles they played was an economic one. They worked on a daily basis for money to provide for the needs of the care recipients in addition to supporting their own family. Most of them were farmers or traders; others were street sellers. Most of the respondents were providing money and paying electricity and water bills, and these earnings were generated from various economic activities that they were pursuing. One participant commented:

> "I always go to the farm to work and bring home food, some of which I sell and some of which I keep for our own consumption. I pay water and electricity bills and this has become part of what I do for her aside from the cooking and washing." (Caregiver, Tafo-urban)

Another caregiver stated:

> "I am the one that provides money for her daily upkeep. I am a trader at the Bantama market, and I have to do that in order to support her and my family. I am the one that pays the electricity and water bills." (Caregiver, Bantama-urban)

Health care roles

Aside from these domestic and economic activities, caregivers also perform health care roles. They book appointments on behalf of the care recipients as well as accompany them to health care centers on a daily or weekly basis to seek medical attention or for doctors' reviews. They also help the care recipients to adhere to doctors' prescriptions as well as to pay medical bills. This role contributes effectively to the well-being of the care recipients. For instance, one study participant indicated that:

> "I take her to see the herbalist every three weeks for new medicinal herbs. By the third week, the herbs will have all been used since I do not buy them in large quantities. I go alone because the place is far away and she cannot sit for that long. At times too, the herbalist wants to see her, so I take her with me but most of the time I go alone." (Caregiver, Kwaso-rural)

Another respondent also explained:

> "I take her to the hospital every weekend to see the doctor. He runs tests on her to check her blood pressure, check her sugar level among others. It is mandatory for me to take her there every weekend. Her children told me to do so." (Hired caregiver, Tafo-urban)

Social roles

Caregivers also revealed that they performed social roles, including accompanying the care recipients to funerals, weddings and other social gatherings. They also sometimes represented them at these gatherings. One participant said:

> "I always go to funerals and weddings with her; sometimes I go alone and represent her, especially when it is someone who is related to us. In some situations, I only send monies to them in her name." (Caregiver, Deduako-rural)

Spiritual roles

Visiting churches and praying on behalf of care recipients to seek divine healing and protection for them were other roles performed by the caregivers. Most disclosed that they go to prayer camps and churches to pray so that God will heal the care recipients. Some believed the diseases that the care recipients were suffering from were purely psychological and that only God's intervention could make them feel well again. One of them stated:

> "Every weekend I go and pray on his behalf so that God will have mercy on him and heal him. We have been taking him to the hospital for years and there has not been any improvement, they are unable to establish what exactly is wrong with him so I have decided to always pray for divine intervention on his behalf because I know this disease is psychological." (Caregiver, Tafo-urban)

Challenges facing female caregivers

Through the discussions and interviews conducted, it became clear that participants face many challenges, including inadequate funds, prolonged stress, limited time for socialization, inability to work effectively and emotional trauma.

Inadequate funds

The major challenge highlighted in the responses from the interview was inadequate money to pay for the expenses and medical bills of care recipients. This was because most of the caregivers were working less to take care of the care recipients and their income had fallen. This confirms the proposition that caregiving negatively affects the financial status of caregivers. As a participant said:

> "The charges are expensive and I cannot afford them. Therefore, I can only take her to the hospital when I get money, even though I am supposed to take her every week for medical check-ups. I also have to buy her drugs." (Caregiver, Kwaso-rural)

These charges also caused some of the caregivers to go to chemist's (drug stores) rather than the formal health centers to seek medical attention. One participant complained that although the care recipient was enrolled in the health insurance scheme, they were sometimes told the insurance did not cover some of the prescribed medications. This assertion was best reflected in this quote:

> "I took out national health insurance for my son before he got admitted to hospital. Initially, I paid nothing. Later, they prescribed a new medicine for my son and asked me to go and buy it because it was not covered under the insurance. Therefore, I bought the one that is less expensive, even though it is not as effective as the prescribed one." (Caregiver, Tafo-urban)

Prolonged stress

The roles performed by the caregivers are very demanding and stressful. Over time, this adversely affects their own state of health. A participant confirmed this by saying that:

> "I have to lift and carry her outside every morning to bathe her, and then take her back to the room to dress her. After that I feed her. I try to find someone to help me, but when no one is around I do it myself. By the time I am done with the roles, my whole body will be aching." (Caregiver, Bantama-urban)

Another participant also stated:

> "I was already sick before I started caregiving. The tiredness from providing care causes me back pain. This is because I lift her to clean and feed her, wash her clothes and the walk for a long distance to work on the farm. I carry the foodstuffs and firewood home myself." (Caregiver, Bantama-urban)

Caregivers not only attended to the needs of the recipients, but also had other roles to perform. Most of them were married with children. In addition to fulfilling the caretaking demands, they also have to ensure that the needs of their spouses and children are met. Some of them were also working and needed time for their businesses. One respondent had this to say:

> "I clean my house, wash my children's and husband's clothes, prepare their food for school and make sure they are ready for school daily before I go over to my mother's place. I clean her place too (not every day though), wash her clothes and prepare all the food she will eat for the day. I do all this before going to the market to sell." (Caregiver, Tafo-urban)

Another respondent also mentioned:

> "My children are very young so I have to bathe and dress them, feed and take them to school. Before that, I help mother to the bathhouse so that she baths and take her back to her room. When I return, I prepare her breakfast, wash the dirty clothes and then prepare lunch for her and my children so that they will have something to eat when they get back from school." (Caregiver, Bantama-urban)

Limited time for socialization

Socialization also becomes a problem for caregivers. They are not able to go out with their friends as they used to do before. It becomes difficult to attend social functions. Most of them complained of not having any meaningful association with colleagues and also not having time for themselves, even when there were events that were important to them:

> "I cannot go to funerals and weddings any more. This is because no one is around to take care of her when I am not around. I am unable to associate with friends and also do not have any meaningful conversations with them. And in situations where I do go out, I am not able to stay for long as I have to get back home." (Caregiver, Bantama-urban)

Another respondent also told us:

> "I cannot visit my school mates because I am either always home looking after my grandmother or taking her to the clinic for her reviews and drugs. I am only able to talk to them on the phone, but even that is not regularly." (Caregiver, Tafo-urban)

Inability to work effectively

Caregiving also contributes to low productivity. Some of the caregivers had to stop working, or reduce the number of hours they work, because it was impossible to combine their work with their caregiving activities. Most of them had to leave their shops, farms and other places of work to come and assist the care recipients. One participant explained:

> "My shop is in Obuasi and I cannot be coming from there every day, so I have locked up the shop to provide care." (Caregiver, Tafo-urban)

Emotional trauma

Another challenging issue for caregivers was emotional trauma. Caregivers felt traumatized, especially when they did not know what illness their recipients were suffering from. The lack of money was also a constant source of worry to caregivers. This meant that caregiving also had a negative effect on the mental health of caregivers. This is what one participant had to say:

> "My other siblings and I have taken him to several places, but we still do not know what is wrong with him. We took him to the hospital but after the doctors diagnosed him, they said nothing was wrong with him so we brought him home. And now I have been taking him from one church to the other because I think it

> might be a psychological problem." (Caregiver, Bantama-urban)

Another caregiver also pointed out:

> "Hmm…sometimes getting money to even eat becomes a problem. This is because I do no work for which I get an income. I have to wait until my children give me money. It is not like the old times when I did my own work and could buy everything that I needed. I am always thinking about this and worrying." (Caregiver, Tafo-urban)

It can be seen from the statements above that caregivers face many challenges. This is mostly because they do not get enough support and have to do everything on their own.

Discussion

Caregiving has over the past 3 decades become an issue of increasing importance and is a significant aspect of health care delivery in the world nowadays as many people are sent home from public health facilities to continue recovery in their own homes (Nordmeyer 2002). It has been estimated that in sub-Saharan Africa, caregiving forms 48% of the health care system (Sudhinaraset et al. 2013). The present study expands on the literature by providing evidence on the roles caregivers play and the challenges they face in rural and urban Ghana. It reports and discusses the significance and implications of three main findings.

First, most of the caregivers were related to the care recipients. This is in consonance with a study conducted in the US, which reported that about three-fifths of caregivers were relatives of the care recipients. As a result of the relationship between the caregivers and the care recipients, most of the caregivers were not paid for the services they provided. Most caregivers deemed it morally and customarily incorrect to charge for the services they rendered to their relatives. This finding has been previously reported elsewhere (Australian Institute of Health and Welfare 2016; Sharma et al. 2016).

Second, as found by Hudson (2003), Sinha (2013), Steiner (2015) and Sharma et al. (2016), the present study identified the major roles played by caregivers for care recipients to include domestic, economic, health care, social and spiritual. This finding means that caregivers are committed individuals who seek to ensure the best possible service provision to their care recipients. However, to fulfil these roles, caregivers have to spend almost all their time providing care, which may effect their economic and other social functions and activities. The present findings also mirror the assertion that caregiving roles are dependent on several factors such as the physical, psychological and social needs of patients and the relationship between the caregiver and care recipient (Hudson 2003), type of disease and locational differences between the caregiver and recipient (National Alliance for Caregiving 2009).

Third, in line with previous studies, the present study reported that as women give their best in caring for their relatives, they encounter challenges in diverse ways which tend to affect their personal well-being. In this study, these included a lack of or inadequate financial resources stemming from the limited time for economic activity, enormous stress, low support from other family members, inability to work effectively, limited time for social activities, and other emotional and psychological trauma (Sharma et al. 2016; Steiner 2015; Kiecolt-Glaser et al. 2003; McGhan et al. 2013; Kuo et al. 2011). If not properly addressed, these pressures have the potential to further worsen the physical and mental health of both caregivers and care recipients. For instance, inadequate or non-existent income may hinder adequate drug adherence and compliance by the care recipient, which in the end worsens his or her condition. This suggests that female caregivers need both informal support from family members, relatives and friends and formal support from stakeholders such as governments and NGOs. Official support mechanisms should be set up to assist caregivers in Ghanaian societies.

This study has some strengths that need to be remarked upon. First, to the best of our knowledge, it is the first study that provides evidence on the role of women and the challenges faced by them as caregivers in rural and urban settings in Ghana. Second, the interpolation of data and incorporation of viewpoints and experiences of the actual people who are directly involved in the caregiving act make the current study unique. It therefore demonstrates a good depth of understanding from the views of a multicultural and multi-ethnic population and offers an important contribution to addressing the existing knowledge gap. Our findings could serve as a baseline for the government and other stakeholders for formulating their future policies to put in place support mechanisms for caregivers and informal health care as a whole.

While our study has many advantages, we also acknowledge a number of limitations, basically due to the methods used. Interpreting and using findings from this study must therefore be undertaken with caution. Owing to the use of non-probability sampling techniques including snowballing, our results should not be regarded as representative of the general population in Ghana. However, this study consciously prioritized the depth of participants' experiences rather than merely the breadth. Furthermore, the measures were derived from self-reporting, thereby exposing the findings to potential response and social desirability bias.

Policy implications

Our findings show that caregiving is an important aspect of health care delivery, particularly among recipients who are

older adults. However, caregivers face multiple challenges that affect their ability to deliver their services effectively, adequately and in a timely manner. These circumstances require that policy makers in the health care sector pay maximum attention to this form of health care to ensure the provision of assistance, either in kind or cash, to the caregivers, as a means of support to help them perform their roles properly. Caregivers should also be trained by health care authorities to give them basic knowledge on how to provide certain services that are important to the well-being of the care recipients. To reduce the financial burden faced by caregivers, policy makers should also increase and ensure effective functioning of the National Health Insurance Scheme. This will, to a large extent, reduce the stress and difficulties caregivers are confronted with when attempting to access health care for care recipients.

Conclusion

This study examined the role of women as caregivers and the challenges they face in performing the associated tasks and constitutes a significant contribution to establishing empirical knowledge on the role women play in informal health care. Our findings give a valuable insight into the real situation of caregivers. They could serve as a basis for formal organizations, government and health care authorities, and NGOs to provide support to caregivers to facilitate better service provision to care recipients.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval All procedures performed in this study involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individual participants included in the study.

References

Babbie E (2005) The basics of social research. Thomson Wadsworth, Belmont

Braun V, Clark V (2006) Using thematic analysis in psychology. Qual Res Psyc. 3(2), 77–101

Ghana Statistical Service (2012a) 2010 Population and housing census. Summary report of final results, Author, Accra, Ghana

Ghana Statistical Service (2012b) 2010 Population and housing census. Final results. Author, Accra, Ghana

Hesse-Biber SN, Leavy P (2011) The practice of qualitative research, 2nd edn. Sage Publications, New York

Hudson P (2003) Home-based support for palliative health care families: challenges and recommendations. Palliat Care 179(1):35–37

Australian Institute of Health and Welfare (2016) Informal health care. Accessed at http://www.aihw.gov.au/informal-care-ageing/ on September 25, 2016

Kabeer N (1992) Triple roles, gender roles, social relations: The political subtext of gender training. Discussion Paper 313, Institute of development studies. Accessed at http://www.ids.ac.uk on September 20, 2016

Kiecolt-Glaser JK, Preacher KJ, MacCallum RC, Atkinson C, Malarkey WB, Glaser R (2003) Chronic stress and age related increases in the proinflammatory cytokine IL-6. Proc Natl Acad Sci 100(15):9090–9095

Kuo DZ, Cohen E, Agrawal R, Berry JG, Casey PH (2011) A national profile of caregiver challenges among more medically complex children with special health care needs. Arch Pediatr Adolesc Med J 165(11):1020–1026

McGhan G, Loeb SJ, Baney B, Penrod J (2013) End-of-life caregiving: challenges faced by older adult women. J Gerontol Nurs 39(6):45–54

Miller B, Cafasso L (1992) Gender differences in caregiving: fact or artifact? Gerontologist 32(4):498–507

National Alliance for Caregivers and American Association of Retired Persons (2009) Caregiving in the United States. Accessed at www.caregiving.org on October, 2016

Nordmeyer K (2002) Gender role perceptions and women's caregiving experiences. [MSC Thesis], University of Utah, Salt Lake

Saban KL, Hogan NS (2012) Female caregivers of stroke survivors: coping and adapting to a life that once was. J Neurosci Nurs 44(1):2–14

Sharma N, Charkrabati S, Grover S (2016) Gender differences in caregiving among family-caregivers of people with mental illnesses. World J Psychiatry 6(1):7–17

Sinha, M (2013) Spotlight on Canadians: Results from the general social survey. Portrait of caregivers (2012). *Statistics Canada* (catalogue no. 89-652-X). accessed at http://www.statcan.gc.ca>IPS>display. on February 24, 2017

Steiner A (2015) The lived experiences of sandwich generation women and their health behaviours. [MSC Thesis], Wilfrid Laurier Univerity, Ontario

Sudhinaraset M, Ingram M, Lofthouse HK, Montagu D (2013) What is the role of informal healthcare providers in developing countries? A systematic review. PLoS One 8(2):1–12

Taylor L, Seeley J, Kajura E (1996) Informal care for illness in rural Southwest Uganda: the central role that women play. Health Transit Rev 6(1):49–56