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Caregiving and the Family

Olawunmi Olagundoye and Morenike Alugo

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Abstract

Caregiving is the routine rendering of care by a caregiver who has taken the sole responsibility for ensuring that the fundamental needs of the care recipient are met. With the population aging and the increasing trend of non-communicable diseases (NCDs), the need and the demand for home care will rise exponentially. Caregiving for most chronic illnesses has become a fastidious task requiring a combination of formal and informal caregivers to meet the needs of care recipients. The informal caregiving role falls squarely on the shoulders of the family, which remains the basic unit of every society connected biologically, legally or by choice, from which one expects a measure of physical, financial, and emotional support. This chapter discusses caregiving, home care, and the family against the backdrop of diverse world realities in beliefs and attitudes towards healthcare services and home care. It attests to the preferences for home care by some group of patients with chronic/terminal illnesses, especially the elderly, and it also expounds on reasons for this preference, the benefits to the patients and the family, including the family's need for support in dealing with the burden of caregiving for relatives with chronic illnesses.

Keywords: caregivers, healthcare financing, cross-cultural comparison, home care services, burden of care

1. Introduction

1.1. Caregiving: What, who, and why?

The term 'caregiving' as simply derived from the two separate words connotes the act of giving out care or extending care to an external body. The English Oxford Living dictionary describes it as the provision of the necessary and needful for the protection, welfare and total well being of an individual or a thing. Caregiving can simply be defined as the process or act of rendering care services to other people, who as a result of illness or disorder, have a deficit in or have lost the independent capabilities of carrying out certain fundamental activities on their own [1]. It

encompasses the provision of assistance to another who needs help in the carrying out the activities of daily living [2]. Rendering of care, assistance, support, aid, all connote the term 'caregiving' to individuals unable to function independently due to some certain form of impairments/disability or the other, often involving two groups of individuals: the caregiver and the care recipient [3]. The caregiver is the active person who renders the care to the passive care recipient who is on the receiving end [1]. It is usually an ongoing process, which involves execution of duties and routines by somebody who has taken the sole responsibility of ensuring the fundamental activities of the individual in need of care [1]. According to the work and family research networks, caregiving is generally rendered in three dimensions, which are instrumental, informational and emotional caring [4]. Instrumental caring involves performing tasks as household chores, errands, cleaning. Emotional caring involves emotional support and companionship, counseling, listening, and attending to psychological needs. Informational caring involves learning about the ailment and how to provide favorable conditions for the patient [4]. This term caregiving is rarely used in reference to the form daily care rendered by parents to their children as this is often referred to as parenting [5]. Caregiving according to Sociologists is often discussed in the light of unpaid workers who are usually relatives and friends although, all forms of caregiving are also rendered by paid workers who are usually trained professionals [4]. Caregiving is of optimal importance as it is an inevitable way of ensuring that the ill and disabled can thrive.

1.2. Types of caregiving

The act of caregiving can be categorized into two major types based on the source of care being rendered:

1.2.1. Informal caregiving

Informal caregiving signifies a form of caregiving that is less structured and in which the caregivers are not paid for the services rendered. According to the Los Angeles public health publication, informal caregiving is the daily support and help rendered by family members and friends to their temporarily or permanently ill relatives who are unable to function independently [6]. Often, informal caregiving occurs in a family setting involving parents, grandparents, siblings, children, cousins, spouses, in-laws, and other relatives. In some cases, it could involve friends, neighbors, and good Samaritans [1]. It is usually based on some form of social relationship between the caregiver and the care recipient and often evolves partly out of societal expectations of a family, as well as the inherent obligation of one family member to the other [1]. According to a publication by the international federation on aging, informal caregivers are those caregivers who receive no payment or payment below the market value where the caregiver might refuse to perform the same task at the same wage if it were outside their social circle [7]. This simply signifies that a major factor in informal care revolves around the form of relationship and social responsibility the caregiver has to the care recipient. For example, a son who was brought up by his parents, an uncle, an aunt, stepparents or even a family friend would feel the obligation and responsibility to care for these people peradventure they became ill at any point in time. The role of informal caregivers is of paramount importance being an essential resource to the care recipient and to the healthcare system in general [8].

1.2.2. Formal caregiving

As the name implies, formal caregiving is a planned and structured form of caregiving where the caregivers are employed and get paid for the services they render. These caregivers are mostly professionals such as nurses, doctors and other professional health workers who are trained to carry out services. Due to this nature of formal caregiving, there exists the possibility of them rendering services that informal caregivers cannot render. Depending on the severity and specialty of the illness, formal caregivers are usually in demand alongside informal caregivers for home care services [9]. Formal caregiving is often times the last resort for families who face challenges in providing the necessary care for their ill relatives [7].

Informal caregiving can be categorized into primary caregiving and secondary caregiving.

In primary caregiving, the primary caregiver lives with the individual in need of the care and substitutes for the deficient activities or tasks such as bathing and feeding. They bear most of the recipient's burden of care in terms of emotional, financial and physical support [10].

In secondary caregiving, on the other hand, the secondary caregiver usually does not live with the care receiver but gives support and assistance in form of finances, visits, and transportation to and from the hospital [10]. In cases where family members are unable to provide the necessary attention and care needed by the ill relative, secondary caregiving is usually the form of care rendered by the family members in which they might, in turn, employ a formal caregiver who can be paid to render optimal care around the activities of daily living required for the subsistence of the ill relative.

A larger percentage of caregivers often fall under informal caregiving. According to the Utah coalition for caregiver support, there are more than 22.4 million persons who serve as informal caregivers rendering unpaid services to the elderly in the community [2]. Despite countering factors, family caregivers i.e. informal caregivers are the ones who produce up to 80-90% of both personal and medical related care of older relatives, and one in four American citizens' falls under the caregiver position [2].

2. Caregiving in diverse climes and at different times

The act of caregiving and the need for it are universal. However, caregiving varies in different contexts from the developing world to the developed world. The differing health systems, norms, values and beliefs in different parts of the world play significant roles in caregiving. A study carried out to explore the influence of culture on family caregiver experience revealed that among African American, Asian American, Hispanic American, and European American, there were commonalities in the experience of caregiving and the challenges that come with. However, significant distinctions appeared in the cultural norms, beliefs and values that shaped the caregiving experience of the people [11]. Cultural diversity across nations has resulted in the differences observed in the employment of informal caregiving or formal caregiving. Studies have revealed that minority caregivers are less likely to employ formal caregiving services in contrast with white caregivers who more often utilize formal support services [12]. There is consistency in the lower level of employment of formal caregiving services by minority groups and the findings,

which show that minority caregivers provided more to their ill relatives in comparison to the whites [13]. The diversity in caregiving may also be assessed on the basis of the social orientation of the society. A society's orientation towards collectivism and individualism and the resulting values that guide their social behavior have been discovered to influence the caregiving role, in particular, the question of who takes the responsibility of rendering care [14, 15]. The informal form of caregiving predominates in most developing countries, which are collectivist in orientation. In these societies, family members play major roles in the care of their ill relatives. The role of caregivers in collectivist societies is usually culturally determined based on a set of hierarchy determining who is to render care and a traditional gender ideology that portrays care as a feminine role [14]. The national health systems are also a cogent factor that determines access to and uptake of health care services in general. Health infrastructure and the health care financing are influenced by the economic and political milieu. In many low and middle-income countries (LMIC), there appears to be poor access to health care services, which are grossly disproportionate to the population sizes. Access and equity are further impeded by the nature of health care financing where out-of-pocket payment still exceeds health insurance schemes. In the earlier century, there were few choices for family members who had ill relatives and care often fell on the family members, but in more recent times, there is easier access to information, more support and more resources available for both the caregivers and the care recipients [2]. The issue of health care financing has always posed a challenge, particularly in LMIC. Unlike the earlier times, health insurance schemes are evolving in LMIC, in addition to aids from nongovernmental organizations, welfare packages from local co-operative societies and other projects established to aid health financing. In Nigeria for instance, there is the National Health Insurance Scheme (NHIS), which was established to promote financial access to equitable health care for enrollees. Unfortunately, only about 10% of the population is currently covered by the NHIS [15]. The majority of the citizens finance their health care out-of-pocket.

Informal home caregiving may be the economically realistic alternative in these resource-constrained settings. In high-income countries, however, health insurance is a widely accepted practice. There are cross-cultural differences in the beliefs and attitude of the people towards healthcare and utilization of health insurance in the developing and developed worlds.

3. Home care: An inevitable part of chronic care

3.1. What is home care?

Home care is a form of caregiving rendered in the home of individuals in need of healthcare services. It includes a wide range of healthcare services that can be rendered within the home [16]. Rather than being present for healthcare services at the hospital, the individual receives care at home. An in-depth definition of home care was given in 2007 by the African Medical Research Foundation (AMREF) with respect to home and community-based care of people living with HIV/AIDs. Home care was defined as the form of care directed towards individuals with chronic/terminal illnesses, which is being extended from the hospital to the homes of the patients through a combination of both family and community involvement, within the available resources and in cooperation with other healthcare workers [17].

These health care services rendered in home care are usually as effective as hospital care, as the goal still remains to manage and treat the illness [18]. Literarily, with the term 'home care' it becomes apparent that the family plays a great role in this decision; it is either the home care is carried out by family members, by medical practitioners or by a combination of the two in the home. Often, home care involves four major components of care services, namely: clinical care, nursing care, counseling/psycho-spiritual care and social support [19]. With the inherent components of home care, it can be said to constitute a combination of formal and informal care carried out within the home. Depending on geographical, socio-cultural, and economic factors, one of the two, i.e., formal or informal care may predominate in the rendering of home care services. Informal home care services can be explained as the services rendered by the family members and other community members within the confines of the home whilst formal home care services are rendered by medical practitioners and experts who receive payment for their services.

3.2. Why home care?

Home care often times appears to be an inevitable part of chronic care. In cases where people are faced with a range of chronic illnesses, which are usually long lasting and demanding of effective treatment/management to avoid further disability, home care becomes a necessity as it ensures that patients do not have to be kept within the confines of the hospital before healthcare can be accessed [19]. Patients with chronic diseases are often recommended for home care as they cannot be restricted to the hospital for as long as the illness lasts. Home care allows for more flexibility because it allows for patients to go on with their lives without having to be limited by hospital time schedules [20]. Home care is a major form of care for the elderly who have become too frail and weak to function and live independently. Also, in cases of mental illnesses, treatment, and monitoring often result in the demand for effective home care services so as to improve function and prevent relapse [20].

3.3. Benefits of home care

Home care has numerous benefits. Studies have revealed the positive impacts of home care in the physical, psychological, social, and economic well-being of the patients, the family, community, and the healthcare system [19]. One is the fact that patients do not have to be kept in the hospital environment indefinitely. This reduces the risk of hospital-acquired infection in individuals who were on admission for other non-communicable diseases (NCDs). Being nursed at home provides an increased sense of recovery. Although home care might initially be perceived to be less efficient in comparison to care in the hospital where the facilities are at the beck and call of the physicians, the truth remains that it is as effective as the care received in the hospital. Home care comes with numerous benefits for the patients, the family, and the community. Starting with the patient, home care provides a sense of comfort and belonging as they receive treatment at the home, which is a familiar environment where other supportive family members may be present [21]. It helps to maintain independence [22], allowing the patients to go on with their normal lives and remain in contact with family members. For example, patients who are head of their homes continue doing so and are able to fully getting in family matters and decision making [19]. In most cases, home care appears to be more affordable as it costs less than hospitalizing patients

especially in cases of chronic and palliative care. Generally, for the patient, home care allows for a more stable emotional health, being surrounded by loved ones in the comfort of the home makes a lot of difference, being in a familiar environment makes the illness more tolerable [19]. The patients are able to get assistance in carrying out their daily activities. Home care is also very advantageous for one-on-one focus on the patient, it allows for the rendering of individualized services, which focuses on the recipient's health needs [23]. It has been reported that a patient who is being attended to by a clinician or medical personnel in the comfort of their home often displays levels of trust that the Physician places their needs first [24]. For the family and community, home care allows for a steady relationship between the family members and their ill loved ones [25]. It maintains the family bond without any form of separation due to illness [19]. It also alleviates stress for the family member as constant visits to the hospital to monitor the progress in the health of a sick relative might result in some degree of stress and increased financial cost. The additional expenses that might be incurred from bed charges, food items and the likes if the patients were in the hospital are eliminated through home care. It also enables the family members to be present during the time of death [19]. For the community, home care permits a more affordable provision of support for the ill and also ensures that there is existent cohesiveness in the community with regards to caring for others in need [26].

To the healthcare system, home care helps to reduce the exasperating demand of health care on the health system by eliminating overcrowding of in-patient facilities, and ensuring effectiveness. Healthcare practitioners' workload is also reduced and where structural resources are limited, the demand on the health facility is reduced [19].

3.4. Major role players in home care

Home care basically involves two key players without whom no form of care will take place. The caregivers themselves are the active players who render care to the passive players who are at the receiving end. The active players in relation to home care can vary depending on several factors, such as the nature of the illness and the demands of care, epidemiological, socio-cultural and socio-economic factors. They can either be informal caregivers or formal caregivers depending on these factors. According to the African medical research foundation, the key providers of home care were classified as the patient, the family, the health workers, the community, and the government [19]. This list presents a combination of both formal and informal caregivers. Formal caregivers involved in the provision of home care services are practitioners as doctors, Family Doctors, Community Nurses, Social workers, also specialized practitioners such as Oncologists, Pediatricians, Gynecologists, Palliative care providers, Psychologists, and others. The nature of the illness usually determines the type of healthcare practitioner to be involved. Friends, nuclear, and extended family members are involved in home care in an informal capacity. The structure and functionality of the home is also a cogent factor as the state/condition of the facilities in the home may influence the nature and the extent of caring that can be done.

There are volunteer workers who offer home care services, and they may be retired professionals or others with interest in healthcare or healthcare charity organization workers [7]. Community service in the form of home care services may be meted out to public offenders

through the legal system in some developed countries. The community and government cannot be left out of the equation as they also exert great influence on the wellbeing of the ill in the community. The government plays a significant role in creating a supportive environment by establishing policies, setting and maintaining standards to support caregiving [19].

3.5. Elderly patients with terminal/chronic illnesses and their care preferences

Terminal and chronic illnesses are medical situations that require constant medical attention. Chronic illnesses are long-lasting illnesses that progress gradually with time; these illnesses often affect the quality of life of the patients if they are not properly managed [19]. They include hypertension, bronchial asthma, diabetes mellitus, Parkinson's disease, and neuro-cognitive disorders/dementia, which majorly affect the elderly. These conditions often require continuous medical care so as to sustain functioning and prevent deterioration. The preference of patients with these chronic illnesses usually falls within home care, the case being that these patients cannot remain within the confines of the hospital for as long as their illness lasts. Once the major treatment has been received where the doctor does the necessary medical treatment, prescribes drugs, and does the necessary therapy and counseling, the patients and their relatives can make decisions to continue with home care. Some patients and their families favor home care services carried out by family members, in addition to home visits by medical practitioners as the situation demands [19]. Home care allows for more emotional support and a quick sense of recovery for these patients ensuring they go on with their daily lives [22]. Although there are several factors that may affect the decisions of these patients regarding home care; factors such as the availability of family members to take up the responsibility of acting as primary caregivers, providing support, and constant care. In the absence of these informal primary caregivers or in situations where the family desires to ease members of the physical burden of care, the tasks may be shifted to nursing homes. In the case of terminal illnesses where death is inevitable, the goal is to improve the quality of life, by relieving pain, discomfort and ensuring more emotional balance, support, and happiness for the patients. Palliative care is the form of care rendered to terminally ill patients to make pain and sorrow easier to bear though curing is unattainable and death inevitable [27]. Home care is usually more preferable for terminal illnesses as these patients need to feel more accepted and loved in their remaining days [19]. Although home care is a more preferred option for elderly and terminally ill patients, the society, and cultural beliefs also determines the choice of home care for terminally ill patients. In countries ruled by the idea of collectivism, the act of family members caring for their older relatives, their chronically/terminally ill relatives are common [11]. On the other hand, in individualistic societies, there is usually a shift away from informal care in the home for chronically/terminally ill relatives to a more formalized form of care [11]. Thus, a form of care, which is designed basically for patients nearing the end of life, i.e. the terminally ill, becomes more popular [25]. This care was designed to provide professional care to maximize comfort for terminally ill patients by looking into the psychological, physical, spiritual and physical needs of the patients. Hospice care is often the resort for terminally ill patients in most developed countries to ease relatives of some of the burden of care, and to prepare the patients and their families for the end [25]. In most African countries, family relatives hold the belief that their elderly relatives who are ill should preferably die at home. It is a custom in some African societies for older relatives to return home once they are

approaching death. The employment of hospice care is still at the evolutionary stage in most developing countries and where they currently exist; they may be elitist and out of the reach of the common man.

4. Family and care giving

The family is the basic unit of every society; it is defined as a social and intimate nurturing group of individuals connected biologically, legally or by choice from whom one expects a measure of support in form of food, shelter, clothing, finance, emotion and natural nurturing as well as sharing a past, present and future together [28]. The family forms the basic unit of care for every individual; it is in the family setting that every individual receives first-hand attention whenever an ailment is discovered. In cases of less severe illnesses, family members are mostly capable of bringing about recovery without the ill relative having to visit the hospital [8]. This makes the act of caregiving to fall majorly within the family. Informal caregiving appears to be the more predominating form of care. Consequently, the members of the family are regarded as critical partners in the care of the patients, and family functioning becomes a significant factor in determining the quality of care rendered by informal caregivers. Families play very significant roles in the treatment of their ill relatives [7]. The existence of an emotional bond and a sense of belonging explains the clear differences in the approach to care by families in comparison with the professional and mostly formal relationship that patients have with their healthcare providers.

Most patients find it very rewarding to have their loved ones around to care for them, and to accompany them through their healing process. However, this does not imply that family caregivers are adequately equipped to provide most of the care needs to hasten recovery. They are not professional caregivers, and they often have multiple roles and tasks to attend to [9]. These constitute some form of stress, both physical and emotional as they try to meet up with several demands [29]. Family members as caregivers are also not trained and are usually less skilled in rendering care for particular illnesses [9]. In view of the foregoing, it becomes expedient to combine both formal and informal caregiving services to guarantee effective outcomes.

5. Burden of care on informal (family) caregivers

The burden of care is a complex, multifactorial construct, which includes emotional, psychological, physical and economic impact as well as related distressing feelings such as shame, embarrassment, anger, feeling of guilt, and self-blame [29]. It is customary to describe burden as for either objective or subjective. A researcher differentiated between objective and subjective burden [30]. Objective burden is a disruption to family/household life, which is potentially verifiable and observable. It refers to changes in household routine, family or social relations, work, leisure, and physical health. Subjective burden consists of subjective distress

among relatives including the impact on mental health, personal feelings of carrying a burden, being unhappy or upset [30, 31]. It was also pointed out that one aspect of the objective burden is in fact based on a subjective experience {distress} whose presence or absence is logically assumed by the investigator [30]. Thus, the investigator is consistently considered a better judge of caregivers' feelings than the caregivers themselves. Family caregivers have been described as forgotten or hidden patients and it was suggested that caregivers' symptoms such as mood swings, headache, joint and muscle pain, marital and family conflicts, and financial problems may be a reflection of caregivers' stress in looking after a sick relative [32]. Most studies of family burden in severe mental illness have taken place in developed countries and they reported that family caregivers experience high levels of burden [33, 34]. There has been an emergence of self-help and advocacy groups of affected families and also a rising pressure towards involving consumer groups in service planning during the last two decades, which has helped in bringing the needs of the informal caregivers into increasing focus [35]. From the result of a study conducted in 2009, it was revealed that providing support that enhances the quality of life of patients with mental illness may indirectly help reduce the sense of burden felt by family members caring for them [36]. Caregivers have been described as hidden patients who also need attention so as to be protected from both physical and emotional harm. Interventions to reduce burden are important in directly curtailing caregiver distress and promoting overall well being whilst the care recipient also benefits secondarily from such interventions [27]. Intervention for caregivers can come in different forms to help increase the confidence and competence of caregivers in providing effective care for the care recipients which in turn help in eliminating the feelings of distress among caregivers [37]. Healthcare professionals have significant roles to play in alleviating the burden on informal caregivers. More involvement by health practitioners in the duties carried out by informal caregivers often proves effective. Counseling sessions carried out by healthcare practitioners to enlighten and educate caregivers often results in a significant reduction in burden [38].

The significance of support for informal caregivers cannot be overemphasized as it has also been suggested that burden of care indirectly affects medication adherence and by extension the course of illness [39]. This gives credence to the fact that family intervention is needful as part of the holistic care of the patient with a chronic illness. Gender, socio-economic, and cultural factors also influence the experience of caregiver burden by the family members. Most often, mothers take up the most of the physical responsibilities for caring for the patients, and women have been found to report poorer states of perceived health [40]. Fathers, on the other hand, take up the financial responsibilities and are more likely to experience burden in relation to their finances. A number of socio-demographic characteristics of the caregivers exert great influence on the levels of burden. A study in the province of Arica, Chile involving 41 relatives of patients with schizophrenia who were attending a public mental health outpatient service showed a very high degree of a burden especially in mothers, older relatives with low educational level, unemployed caregivers and those taking care of young patients and caregivers of patients with more hospitalization in the previous 3 years. Similar findings were made in an African context, where it was observed that those who cared for patients in the age range 21–45 years were the most burdened [40]. A more recent study in a similar context revealed a significant relationship between gender and the experience of caregiver

burden, with females accounting for 67.3% of those with a high burden [3]. A high level of burden was also found among mothers (35.1%) and spouses (33.9%). It was also revealed that level of income played a significant role as the majority of the participants who experienced low burden earned above $125 whilst those with high burden earned less than $62.50 [3]. Furthermore, living in rural areas, large family size, the severity of patients' illness, and caregivers' low level of education were associated with a high level of burden in Nigeria [41–43].

It has been shown that the incidence of depression in caregivers is high, ranging from 18 to 47% and caregivers who are depressed experience higher degrees of burden [44]. A landmark study of caregivers' health revealed that elderly spousal caregivers who experienced caregiver strain had a mortality risk that was 63% higher than that in control subjects [45]. The implications of this study make early identification of caregiver burden and appropriate intervention even more critical. The caregiver burden experience can be controlled by a process of family intervention. This is an essential plan for assessing the family functioning and establishing ways of managing the experience of burden. Emotional burden experienced by primary caregivers is a pressing factor that cannot be overlooked. This factor spells out the need to care for caregivers through therapy sessions and enlightenment on how they can manage their emotional health and wellbeing. Counseling and educating caregivers on how they can adopt coping strategies and deal with stress will go a long way. Adjustments in Government policies regarding health financing and insurance are also ways of improving access to healthcare and reducing the financial burden on middle and low-income families.

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