

FAMILY CAREGIVER – A HIDDEN PATIENT: CRITICAL APPRAISAL.

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Abstract

Family caregivers are essential in the care of sick members of the family especially those with chronic medical conditions that require long –term care services. This article examines the various roles of the caregiver to sick relative and the impact of assuming these roles on caregivers' health and well-being. It describes the complex role of care giving and how it can affect both the health of the caregiver and the quality of care to the care recipient. Physicians and other members of the health team should see caregivers as hidden patients who should have access to high-quality, evidence-based interventions designed to mitigate or prevent the negative impact of care giving on their health.

Keywords: Caregiver, Care recipient, Informal Caregiver, Caregiver Burden.

Cite this article: Benson FN, Ndukwu GU. Family caregiver - A hidden patient: Critical appraisal. Yen Med J. 2019;1(1):15–27.

INTRODUCTION

Family caregivers play a major role in providing care and assistance to sick members of the family.¹ The influence of stressors on family members caring for an ill individual in the family has been mentioned as caregiver burden.¹ The burden of caring for relative with chronic medical conditions affects the patient and their families.

The change in family dynamics gradually reduce the level of family member's performance and their ability to be involved in other activities, destruction of emotional system and communication structures of family, ineffective relationships among members, emergence of financial and economic problems, reduce social interactions of the family, changes in roles, reduced life expectancy, emergence of symptoms

such as anger, feeling of guilt, grief, and even denial.² The caregivers are really the hidden patients here.³

To provide a high-quality level of care, caregivers have to attend to their own health care needs and their own physical and mental well-being so they can continue to provide care.³

THE CAREGIVERS

Main caregivers have been defined as the person belonging to the patient's informal support system who takes the care, and is responsible for the patient, and who commits most of his or her time to that task without receiving any economic retribution.⁴ Family care giving raises safety issues in ways that should concern healthcare professionals.⁵ Caregivers are sometimes referred to as "secondary patients" who needs and deserve protection and guidance.⁵ These unpaid volunteer

workers often need help to learn how to become competent, safe volunteer workers who can better protect their family member (care recipients) from harm.⁵

CAREGIVER POPULATION AND CHARACTERISTICS

All over the world, the family remains the cornerstone of care for members with chronic medical conditions. Family caregivers can be involved in providing “hands-on-care” or also a very significant role – in organizing care delivered by others, sometimes from a distance.⁶

A Nigerian study on the burden, health and quality of life of caregivers of stroke patients reports that caregivers are mostly females. Their relationships to the care recipients reveal they are either their spouses, children, grandchildren and children-in-laws.⁷ Caregivers' age cuts across teenagers, young adults, middle aged adults and the elderly. Young adults make up the highest population of caregivers by age(53.1%).⁷

In Europe, estimates suggest that as much as 80% of all long-term care is provided by informal caregivers. The available estimates of the number of informal caregivers ranges from 10% to 25% of the total population in Europe.⁸ The average varies between countries and the informal caregivers are often women.⁸

The US Centre for Disease Control and Prevention reported that 24.4% of adults aged 45 to 64 years are caregivers compared to 18.8% of adults aged 65 years and older.⁹

CAREGIVER RESPONSIBILITIES

As a society, we have always depended on families to provide emotional support, and to assist older parents, grandparents and other family members when they can no longer function independently.¹⁰ Family caregiving roles take on countless shapes and forms, usually intensive, complex and caregivers rarely receive adequate preparations for their roles.^{10,11}

Despite many common experiences, caregivers' roles are highly variable across the course of caregiving.¹⁰ The diversity of families, the timing of entry into the care giving role, the duration of the role in relation to the overall life course of the caregiver and transition in care experienced over time, all shape the nature of the care giving role.¹⁰

Care giving ranges from assistance with daily activities and providing direct care to the care recipients to navigating complex healthcare and social services systems.¹⁰ Caregivers' role cuts across a myriad of domains¹⁰. Each of these domains has multiple task and activities.¹⁰ The domain of care giving include assistance with household task, self-care tasks and mobility, provision of emotional and social support, health and medical care advocacy and care coordination, and surrogacy.¹⁰

ASSISTING WITH HOUSEHOLD TASK, SELF CARE, MOBILITY AND SUPERVISION.

About 15% of caregivers provide direct hands-on-care with intensive personal needs such as bathing, toileting and dressing.¹² Nearly all caregivers help older adults in need of care with household task.¹⁰ Ninety-eight per cent of caregivers assist their care recipients with at least one instrumental activity of daily living (IADL) and eighty one percent assist with three or more IADLs.¹² One in three caregivers (31.3%) provides twenty or more hours per week of care and over half (53.8%) have given care or assistance for twenty-four months or more.⁹ Caregivers providing care to high need older adults – those who have at least two self-care needs or dementia are more likely to help with a wide variety of task.¹⁰ Care recipients with cognitive impairments or older adults with dementia may also require constant supervision and hands-on-assistance.¹⁰

PROVIDING EMOTIONAL AND SOCIAL SUPPORT

Social support has been studied in several context, one of which is informal caregiving.¹³ Care recipients need emotional and social support that

are different from the usual exchange among family members.¹⁰ People who are socially integrated and have strong social ties live happier, longer lives.¹⁴ The link between social connection and well being is commonly explained in terms of the benefit of receiving care and support from others.¹⁴ There are both theoretical and empirical reasons to hypothesize that giving support may promote longevity.^{14,15} Social relationships are believed to enhance the feelings of self-worth, self-esteem and the sense of well-being that comes from meaningful others and to aid in the resolutions of designated problems or losses.¹⁶

HEALTH AND MEDICAL CARE

Family involvement in health and medical task is not new, but it has become more common, and is often far more complex than in the past.¹⁰ Complex healthcare task often requires nuanced understanding of a health condition and its treatment as well as the ability to manage symptoms, detect complications, provide hands-on-care, offer emotional support and communicate effectively with healthcare providers to participate in decisions and manage logistical aspects of health care.¹⁷ Today, medication prescribed for home use are delivered not only by mouth but also via patches, injections, and intravenously.¹⁰ The caregivers may also be managing technical procedures and equipment such as feeding, drainage tubes, catheters, tracheostomies, as well as managing symptoms and monitoring the care recipients condition.¹⁰

ADVOCACY AND CARE CO-ORDINATION

Family caregivers often serve as advocates and care coordinators.¹⁰ As advocates, they identify and help the care recipient obtain needed community and healthcare resources.¹⁰ This may involve determining the care recipient eligibility for specific services and potential cost.¹⁰ In addition, informal caregivers must interact in varying degrees with physicians and other healthcare professionals about care recipients' status and care needed, hire nurses and aids, communicate and

negotiate with other family members about care decisions and provide companionship and emotional support to recipients.¹⁷

Informal caregivers are also called on to coordinate services from various health and human service agencies and make decisions about service needed and how to access them.¹⁷ Caregivers must navigate these multiple, evolving and increasing complex system often without assistance.¹⁰ The role of a family caregiver as coordinator, is to patch together services needed and serve as primary communication link among all.¹⁰

More than seventy-seven per cent reported helping with health system interaction¹⁰. Many with making appointment (67%);¹⁰ speaking to doctors (60%), ordering medications (55%).¹⁰ The task for coordinating care is logistical in nature¹⁷. This requires skills for gathering resources, organizing health care task and communicating effectively with other people involved.^{10,17}

DECISION-MAKING AND SURROGACY

In most cases, caregivers are often involved in decision making.¹⁰ The various decision-making roles of a caregiver varies.¹⁰ The type of decision-making roles includes directive;¹⁷ participating;¹⁸ supportive or guiding;¹⁷ advisory; and advocacy.¹⁸ Caregivers and care recipients may confront different kinds of decisions spanning from decision about treatment choices, location of care to end-of-life care.^{10,18} Decision-making may also involve religious considerations, family dynamics, finances and feasibility.¹⁰ There is the need to respect the right of the care recipient in decision-making, making sure his or her opinion primary.¹⁰ Communicating about care preferences can improve the well-being of caregivers and care recipients.¹⁹

Surrogate decision-making may be required for care recipients with cognitive impairment.¹⁰ Many individuals (care recipients) with advanced illnesses lack decision-making capacity and therefore rely on surrogate.¹⁰ Family caregivers may step into the role of surrogate formally by being appointed under advanced directive or power

of attorney or by a court or in a guardianship.¹⁰ However, most individuals prefer to involve family members in medical decisions and have family members serve as surrogate decision makers.¹⁰ Family surrogate also face surrogate decision-making tasks far beyond health decision.¹⁰

CARE GIVER BURDEN

Family caregivers are essential partners in the delivery of complex healthcare services.²⁰ Caring for loved ones has several benefits, including personal fulfilment and satisfaction from helping to relieve another's suffering.²¹ However, more and more evidence suggest that care giving is deleterious to one's health.²⁰ Stressors associated with care giving situation are often persistent, uncontrollable and unpredictable with one-third of all care givers describing a high burden of care.²¹

WHAT IS CAREGIVER BURDEN?

Caregiver burden has been defined as the type of stress or strain that caregivers experience related to the problems and challenges they face as a result of the status of the care recipient.²² It is the state resulting from necessary caring task restriction that cause discomfort for caregivers.²² It has also been defined as the strain or load borne by a person who cares for a chronically ill, disabled or elderly family member.²³ The care giving experience comes with multidimensional response to physical, psychological, emotional, social, and financial stressors.²²

Caregiver burden is the all-encompassing challenges felt by caregivers with respect to their physical and emotional well-being, family relations, work and financial status.²⁴ Zarit and colleagues defined caregiver burden as the extent to which caregiver perceive the adverse effect that care giving has on their emotional, social, financial and physical functioning.²⁵ Caregivers strain and caregiver's role strain are also terms describing caregiver burden.²⁵

Despite the fact that caregiver burden is predominantly used as an indicator of the care giving experience, much disagreement remains on

what the term entails and how it should be utilized.²⁶ Caregivers' burden can be subjective or objective burdens²².

SUBJECTIVE BURDEN

This burden refers to the perceived costs such as the extent to which the caregiver is bothered by performing these tasks and the positive or negative feelings experienced while giving care.²² It is the psychological reactions to the caregivers' experience - that is, feeling of loss, sadness, guilt, embarrassment in social situations, the stress of coping with disturbing behaviour and the frustration caused by altering relationships.¹ Subjective burden and lack of positive aspects of care giving were associated with poorer physical and mental health.²⁷

OBJECTIVE BURDEN

Objective burden is an observable, concrete, and tangible cost to the caregiver for taking care of the recipient.²² It refers to outwardly measurable demands placed on family members.¹ These include financial difficulties, strain on interpersonal relationships, a reduction in social support, physical violence, and disruption of routines in care and in households of relatives as well as leisure time.¹

Overall, caregiver burden as a subjective state reflecting the individual caregiver's perception is a widely accepted feature of many caregiving studies that measures the effect of caregiver stressors and emotional symptoms.²⁵ The caregiver's perception of the burden, rather than the perception of other family members or healthcare providers, determine the impact on his or her life.²⁸ Identifying and managing the caregiver burden require a greater understanding of the caregiver population and their needs.²⁹ In the United States, population level approach to characterize the family caregiver burden especially as it relates to activity participation and health, suggest that there is a substantial burden associated with family care giving, which affects physical, mental, and economic components of the caregiver's daily life.²⁹ In addition, the caregiver burden may also impact

the quality of care provided to the recipient, resulting in a broader societal burden.²⁹

THE BURDENS OF CAREGIVERS

The impact of care giving on the caregiver are numerous and highly individualized.^{10,21} Caregivers are potentially at increased risk of adverse effects on their well-being in virtually every aspects of their lives, ranging from their health and quality of life to their relationships and economic security.¹⁰

The diverse responsibilities of care giving are physically and psychologically demanding, which affects the health of the caregiver, as well as the quality care to the recipients.²⁹ However, the burden of caregivers depends on a host of individual and contextual characteristics.¹⁰

In the United States, the National Study of Caregiving (NSOC) data reports that more than 20 per cent of caregivers have financial and physical difficulty,¹⁰ and 44 per cent report it is emotionally difficult.¹⁰

PHYSICAL HEALTH EFFECTS

Caregivers tend to rate their health as poorer than non-caregivers.¹⁰ Caregivers of older care recipients consistently report poorer subjective health status than non-caregivers.¹⁰ One in five caregivers describe his or her health as fair or poor, and 17 per cent believe that their health has deteriorated as a result of providing care, particularly those who have been providing care for five or more years or who have shifted from light to heavy duty.²¹

Several studies on physical health effects of family care giving suggest that a broad range of outcome measures has been examined including cellular and organ-based physiologic measures, global physical and psychiatric health status indicators, and self-reports on health habits.³⁰ These outcomes have been linked to primary stressors, such as the duration and type of care provided and the functional and cognitive disabilities of the care recipients as well as to secondary stressors such as finances and family conflicts.³⁰ As a result of these stressors, the caregivers may experience effects

such as psychological distress, impaired health habits, physiologic responses, psychiatric illness, physical illness and even death.³⁰

Studies have shown that illness of a close relative causes and compromises the caregiver's health to a greater extent.³¹ A widely cited landmark population-based study of care giving reported that a spouse caregiver who reported strain were at risk for premature mortality.³² Population based studies show that many caregivers do not report levels of strain, they cope successfully with caregiving.³³

PSYCHOLOGICAL EFFECTS

Caregivers experience both positive and negative psychological effects from care giving,¹⁰ however, researchers focus more on the negative effects.¹⁰ The effects of care giving care are variable, depending on characteristics intrinsic and extrinsic to the individual.¹⁰

When the demands placed on caregivers exceed their resources, caregivers feel overwhelmed and report high level of stress.³⁴ The stress has a negative effect initially on the caregiver's psychological well-being.³⁴ The effect of stress on the psychological domain of the quality of life appear as increased emotional distress, anxiety, and depression, feelings of helplessness and loss of control and difficulty in coping with care giving roles.³⁴

High emotional distress reported by family caregivers is a significant problem that affects the quality of care, and difficulty providing optimal patient care, administration of medication and changes in their immune system that can lead to flare-ups in auto-immune diseases, worsened glucose control in the body and increased vulnerability to cardiovascular disease.³⁴

The prevalence of negative psychological effects among caregivers indicates that large segments of the care giving population experience adverse effects.¹⁰ Several systematic reviews report that African-American caregivers tended to report lower levels of caregiver burden and depression than white, non-Hispanic caregivers while

Hispanic and Asian-American caregiver reported more depression than white caregivers.¹⁰

SOCIAL EFFECTS

Caring for a loved one with chronic disease has multidimensional and synergistic implication influencing every aspect of the family's well-being and quality of life.³⁵ The social effects of care giving range from changes in family relationships, to changes in social activities and social support from a wider network.¹⁰ The time demands of care giving often limit the opportunity to engage in other activities that caregivers enjoy.¹⁰ Attention to the social well-being concerns of family care givers includes the impact of the burden of care on the social network, family roles, social support, communication, sexuality and intimacy, education, employment and leisure activities, as well as possible financial burden.³⁵

Anecdotal evidences in clinical and research context suggest that a small percentage of family caregivers experience severe conflicts related to care giving, resulting in abusive interactions with other family members and even divorce or other legal actions.¹⁰

ECONOMIC AND FINANCIAL EFFECTS

Family caregivers experience financial cost, which creates burden and financial consequences for family caregivers.³⁶ Economic and financial burden has implication on the economic welfare of individuals.³⁷ These include direct costs, indirect costs or productivity losses that result from absence from normal productive work.^{21,37} Others are out-of-pocket spending,¹⁰ loss of salary and benefits,^{10, 21} loss of promotional and training opportunities,^{10,21} and reduction in retirement savings and social security benefits.^{10,21} Cost of illness studies separate the cost of illness into three components; Direct, Indirect and Tangible costs.³⁸

DIRECT COST

This is the cost of medical care such as ambulances, in patient or out-patient care, rehabilitation and medications.^{37,38}

INDIRECT COST

This seek to measure the loss of human resources caused by morbidity.^{21,38} Some cost of illness studies consider the loss of future earnings.³⁸ Others use much broader willingness-to-pay method, which assesses what people are willing to pay for relatively small changes in the risk of death.³⁸

INTANGIBLE COST

This captures the psychological dimensions of illness including pain, bereavement, anxiety and suffering.³⁸ Financial issues emerged as a significant concern for families.³⁹ This economic burden can have a long-term impact on the financial security, quality of life and the future well-being of the entire family.³⁹

CAREGIVERS' BURDEN AND UNMET NEEDS / INADEQUATE PREPARATION

Family caregivers experience burden of care, various unmet needs and emotional pain.⁴⁰ The top unmet needs of caregivers include keeping care recipients safe at home, managing emotional and physical stress, finding easy activities to do with recipients and having enough time for themselves.²¹ A majority of caregivers feel inadequately trained for the skills that they perform, lack adequate information about support services and most likely use the internet or their doctors as primary sources of extra care giving information.^{1,21}

PREDICTORS OF CARE BURDEN

Caregivers burden affects the health of both caregivers and their care recipients.⁴¹ A study carried out in the United States, reported that disease-related factors were the most significant predictors, explaining 16 per cent of caregiver burden.⁴¹ In the same study, caregiver socio-demographic factors and care giving related factors were next in rank.⁴¹ There are correlations between caregiver socio-demographic factors, disease related factors, care giving-related factors and care burden.⁴¹

CAREGIVER ASSESSMENT

Family caregivers are the backbone of the long-term services and support system⁴². These

individuals provide the vast majority of the care and support for loved ones with chronic care needs and functional limitations. As a result, they need to be assessed.^{21,42}

Caregiver assessment is a systematic process of gathering information about a care giving situation to identify the specific problems, needs, strength, and resources of the family caregiver, as well as the ability of the care giver to contribute to the needs of the care recipients.⁴² It serves as a tool to help identify the many roles a particular caregiver plays, the challenges he or she faces, gaps in knowledge, skills and kinds of help that will be both useful and acceptable to this caregiver and to the older adult receiving care.⁴² It can be performed by the caregiver's physician, or by other health care team members, including a social worker or case manager.²¹

Physicians may only have time to identify caregivers during an office visit and may refer these persons for full assessments.²¹ Referral for assessment may be triggered by a diagnosis of a medical condition associated with high burden for care giving, change in functional status of caregiver or care recipients, or care transitions.²¹

Caregivers who have their needs assessed often feel acknowledged, valued and better understood by practitioners.⁴² When family caregivers are supported, they are better able to continue in this role, thereby reducing the cost of both public and private services.⁴² Research has shown that having a family caregiver can prevent unnecessary hospitalisations among care recipients.⁴² Thus, assessing and addressing a family care giver's need is an important component of public programme's overall approach to providing long-term services and support.⁴²

FUNDAMENTAL PRINCIPLES FOR CAREGIVERS ASSESSMENT

According to reports from a National Consensus Development Conference in the United States, leaders in health care and long-term services and support have developed. Seven basic principles to guide assessment in policy and practice.⁴² Family

caregivers are a core part of health care and long-term services and support, it is important to recognize, respect, assess and address their needs. A caregiver's assessment should embrace a family-centred perspective, inclusive of needs and preferences of both the care recipient and the family caregiver. Caregiver assessment should result in a plan of care (developed collaboratively with the caregiver) that indicates the provision of services and intended measurements outcomes. Caregiver assessment should be multidimensional in approach and periodically updated. It should reflect culturally competent practice.

Effective caregiver assessment requires assessors to have specialized knowledge and skills, practitioner's and service providers' education and training should equip them with an understanding of the care giving process and its impacts as well as the benefits and elements of an effective caregivers' assessment.

Government and other third-party payers should recognize and pay for caregiver assessment as part of care for older people and adult with disabilities.

TOOLS FOR ASSESSING CAREGIVER BURDEN

There are a number of well-validated tools to specifically assess caregiver burden, examples are the Caregiver Burden Inventory and the adapted Zarit interview.²¹ The tables below are guidelines and tools for assessing caregiver burden.

Table 1. Guidelines for Caregiver Assessment

| <i>Areas to assess</i> | <i>Possible questions</i> | <i>Examples of potential implications</i> |
|---|---|--|
| Context | | |
| Relationship to care recipient | What is the caregiver's relationship to the care recipient? | Provides information on dynamics of relationship between caregiver and care recipient |
| Quality of family relationships | How would the caregiver rate his or her quality of family relationships? | Self-identified poor quality of relationships may correlate with higher burden levels |
| Physical environment | Does the care recipient live in the same household with the caregiver? | Caregivers who live with recipients tend to provide more care |
| Duration of caregiving | How long has he or she been in the caregiving role? | Longer duration of care is associated with a higher likelihood of burden |
| Financial and employment status | Is the caregiver currently employed? Full-time or part-time? What is the caregiver's household income? What has been the financial strain, if any, on the caregiver because of his or her caregiving role? | Identifies financial burden |
| Household status | Is the caregiver married? Does the caregiver have children? How many persons live in the caregiver's household? Are other family members or friends involved in the care? | Identifies additional caregiving stressors and potential resources for support |
| Caregiver's perception of recipient's health and functional status | | |
| Activities of daily living | Can the care recipient carry out activities of daily living (e.g., bathing, dressing) without assistance? Instrumental activities of daily living (e.g., managing finances, shopping, taking medications)? | Assesses type and intensity of care needed Identifies need for supervision |
| Psychosocial needs Cognitive impairment Behavioral problems | Does the care recipient have any mental health diagnoses or emotional problems? Any memory loss or cognitive impairment? Does the care recipient have any behavioral problems? How frequently do they occur and how much do they bother or upset the caregiver when they happen? | Cognitive impairment and emotional and behavioral issues increase the likelihood of caregiver burden |
| Medical tests and procedures | What medical tests have been done or are needed? | Assesses type and intensity of care needed |

| | | |
|--|---|--|
| Caregiver's values and preferences | | |
| Caregiver and care recipient willingness to assume and accept care | Is the caregiver willing to assume the caregiver role? Is the care recipient willing to accept care? Does the caregiver feel he or she is obligated to provide care? | Burden levels are higher in caregivers who feel they had no choice in assuming the role |
| Perceived filial obligation to provide care | | |
| Culturally based norms | What types of care arrangements are considered culturally acceptable for this family? | Provides insight into additional support for the caregiver and recipient |
| Caregiver's well-being | | |
| Self-rated health | How does the caregiver rate his or her own health? Does the caregiver rate his or her own health as better than, about the same as, or worse than it was six months ago? | Caregivers who rate their own health as poor are at higher risk of serious medical complications, including increased mortality |
| Health conditions and symptoms | Does the caregiver have any health conditions or symptoms? How often in the past six months has the caregiver had a medical examination or received treatment for health problems from a primary care physician? How often does the caregiver get a full night's sleep? | Assesses need for the caregiver to focus on his or her own health Assesses effect of caregiving on sleep deficiency, which can contribute to increased morbidity and mortality |
| Depression or other emotional distress | How often does the caregiver feel anxious or angry when in the presence of the care recipient? | Anxiety or anger can lead to increased levels of burden |
| Life satisfaction, quality of life | How does the caregiver rate his or her life satisfaction and quality of life? | Caregivers who report lower satisfaction and poorer quality of life are at risk of increased morbidity and mortality |
| Caregiving consequences | | |
| Perceived challenges and benefits of caregiving | Does the caregiver have a social support network or is he or she isolated? Does caregiver have work-related, emotional, or health problems from caregiving? Does the caregiver feel satisfaction in helping a family member? Does the caregiver feel he or she has developed new skills and knowledge as a result of caregiving? Has there been an improvement in family relationships as a result of the caregiving situation? | Identifies additional support for caregiver Assesses work-related, emotional, and physical burdens Identifies perceived benefits from caregiving role that may lessen likelihood of burden |
| Caregiver's skills, abilities, and knowledge | | |
| Caregiving confidence and competence | How knowledgeable does the caregiver feel about the care recipient's condition? | Caregivers who do not feel adequately trained for caregiving roles report higher levels of burden |
| Knowledge of medical care tasks | What are the skills and abilities needed to provide care for the care recipient? How would the caregiver rate his or her confidence and competence in these areas? Does the caregiver have appropriate knowledge of medical care tasks (e.g., wound care, transfer techniques)? | Identifies unmet educational and informational needs |
| Potential resources for caregiver | | |
| Social support | Can the caregiver rely on his or her social support network for help? | Identifies caregiver support and coping strategies |
| Coping strategies | What are the caregiver's coping strategies? Are these constructive? | |
| Financial resources | Has caregiver accessed all financial benefits and entitlements for which the caregiver and care recipient are eligible? | Identifies need for additional resources |
| Community resources and services | What other community resources and services are the caregiver utilizing or aware of? | |

Adapted from Caregiver Care; Am Fam Physician. 2011;83(11):1309–1317.

Table 2. Assessing Caregiver Burden: The Adapted Zarit Interview

For each question, please circle the response that best describes your caregiving situation:

| Questions | Never | Rarely | Sometimes | Quite frequently | Nearly always | Score |
|---|-------|--------|-----------|------------------|---------------------------|-------|
| Do you feel that you don't have enough time for yourself because of the time you spend with the person for whom you are providing care? | 0 | 1 | 2 | 3 | 4 | |
| Do you feel stressed between caring for this person and trying to meet other responsibilities (work, family)? | 0 | 1 | 2 | 3 | 4 | |
| Do you feel angry when you are around this person? | 0 | 1 | 2 | 3 | 4 | |
| Do you feel that this person currently affects your relationships with family members or friends in a negative way? | 0 | 1 | 2 | 3 | 4 | |
| Do you feel strained when you are around this person? | 0 | 1 | 2 | 3 | 4 | |
| Do you feel that your health has suffered because of your involvement with this person? | 0 | 1 | 2 | 3 | 4 | |
| Do you feel that you don't have as much privacy as you would like because of this person? | 0 | 1 | 2 | 3 | 4 | |
| Do you feel that your social life has suffered because you are caring for this person? | 0 | 1 | 2 | 3 | 4 | |
| Do you feel that you have lost control of your life since this person's illness began? | 0 | 1 | 2 | 3 | 4 | |
| Do you feel uncertain about what to do about this person? | 0 | 1 | 2 | 3 | 4 | |
| Do you feel you should be doing more for this person? | 0 | 1 | 2 | 3 | 4 | |
| Do you feel you could do a better job in caring for this person? | 0 | 1 | 2 | 3 | 4 | |
| | | | | | Total score: _____ | |

Add together the scores given for each answer.

Total score ranges from 0 to 48; higher scores correlate with higher levels of burden.

Adapted from Caregiver Care; Am Fam Physician. 2011;83(11):1309–1317.

SUPPORTING CARE GIVERS

For centuries, family members have provided care and support to each other during times of illness.^{5,10,21} In a bid to provide help, they often neglect their own health care needs in order to assist their family members causing deterioration in the caregiver's health and well-being.^{5,10,21}

In supporting caregivers, we should encourage them to take breaks, care for their own health, maintain a healthy diet, exercise, seek preventive health care, join support group and locate respite care when needed.²¹

Caregivers who are burdened with unmet educational and informational needs should be

directed to appropriate resources and online tool kits.²¹

PUBLIC POLICY SUPPORT FOR CARE GIVERS

Caregivers make significant contributions to society.⁴³ In some countries, policy attention has shifted to finding ways to support and empower informal groups of helpers and caregivers as part of a strategy to avoid or delay the institutionalization of elders.^{43,44} The critical need for policies supportive of informal caregivers has been recognized.⁴⁴

Policy makers in many developed countries have introduced a range of measures to support informal caregivers.^{44,45,46} Some of these measures are provision of cash benefit, tax credit, legal protections for workers who are also caregivers, improving the integration of informal caregivers into formal system element such as hospitals, primary care teams, long-term care providers and professional associations.^{45,46} The growing interest of policy makers on caregivers has employed the innovative use of technology to support caregivers.⁴⁷ These policies would serve as support to improve informal caregivers and capacity to care.⁴⁸

In sub-Saharan Africa, the need for long-term care is large and growing. Already, 46 million elderly people live in the region, and this number is expected to more than triple (165 million) by 2050.⁴⁹ Provision of organized long-term care is patchy in sub-Saharan Africa. Within this region, national efforts to develop long-term care systems exist only in Mauritius, Seychelles and South Africa.⁴⁹

Nigeria has no functional policy on caregiver and care of the elderly.⁵⁰ Long-term care must be recognized both societally and politically as a public good.⁴⁹ Government should build understanding and commitment for long-term care systems, establish national coordination systems, develop indicators and map for long term-care, and foster cross-national learning and exchange.⁴⁹

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