ISSUES FACED BY THE INFORMAL CAREGIVERS OF ELDERS

Abstract

The advancement in public health and medical technologies, during the twenty-first century, leads to an increase in the life expectancy. It leads to an overpopulation, especially of the aged. Increasing numbers of elders have been increasing in the number of people with disability, which happens due to old age. Hence, the elders require care assistance to fulfill their daily activities with the help of formal or informal caregivers. The ‘informal caregivers’ of elders refers to non-paid individuals, who are primarily responsible for providing and/or coordinating care of the elders in their house, such as a spouse, offspring, other relative and non-relative, they act as anticipatory, preventive, supervisory, instrumental and protective roles. With rapid changes of familial system, the caregivers of elder face psycho-social, physical, and financial problems. The researcher was motivated to undertake the perception, burden, strain, coping, well-being, and caring outcomes of BPL (Below Poverty Line) informal caregivers of elders at Coimbatore city with the objectives: to assess the personal background of the selected respondents, to find out the different levels of perception, burden, strain, coping, well-being, and outcome of the respondents and to identify the significant relationship among the respondents’ personal variables verses dependent variables. The researcher adopted descriptive research design, census method of selecting the caregivers, and interview schedule was used as the tool for data collection. The strong filial-piety norms, traditional values, community respect, and elders’ earlier contributions were the motivating factors making the informal caregivers to take care of the elders with a positive attitude. Their strain and burden were caused by financial problems, tediousness of the caring job, and the
difficulty in fulfilling the elders’ basic needs. The traditional cultural beliefs and practices, family members’ continuous support are the main reasons for the caregivers to adopt positive coping pattern. With the continuous elder caring the informal caregivers are not able to concentrate on their own health, which leads to their poor level of well-being. Lack of basic knowledge about aging leads to negative outcomes for the caregivers. In general, the caregivers felt that elder caring is a meritorious part and not just a duty, and expressed that it is the family members’ responsibility to care the elders till the end of their life.

**Key words**

Informal caregiver, BPL (Below Poverty Line), perception, burden, strain, coping, well-being, caring outcomes
CHAPTER – I
INTRODUCTION

Modernization and advancement in public health and medical technologies during the last few decades has led to increase in life expectancy and decreased fertility rates. The number of elderly population is accounting for an increasing proportion of the world population (Lowenstein, 2005). By 2030, it is estimated that elders will make up 13 percent of the total population in the world (National Institute on Aging, 2007). The elder population will increase four times in the world (324 million in 2050) by the middle of the 21st century. According to a report of the UN, approximately 60 percent of the elder persons were residing the developing regions (UN, 2001).

Elder Population in India

In India, 60 years of age can be taken as the beginning of old age (IGNOAPS, 2001 and MWPSCA, 2007). Worldwide, India is the second largest elderly populated country (UN, 2007). The elderly population is projected to grow from 76 million in 2001 to 137 million in 2021 (Census of India, 2001; Paliwal, 2007). Increasing number of elders has been increasing in the number of elders with disability. Such elders require the palliative care and assistance to fulfill their daily activities with the help of caregivers (Gavrilov and Heuveline, 2003).

Care Receiver (CR)

Care receiver (elder) is a person who requires day to day assistance due to an illness, disability or accident (Jamuna, D. 2006). The care receivers worldwide are classified as: 1) elders who are physically fit, mentally alert, self-sufficient, capable and competent do not bother about care from others, 2) elders are living in a hostile environment, 3) elders who are gerons like wearied, care-worn and almost consumed and 4) widows, widowers, divorced, abandoned, unmarried, issueless, ousted, bed-bound are mostly left alone in their old age (Hari Shankar Lalvidyarthi, 1995). However in India the elders are classified into four broad categories. There are: 1) elders
who deserve care as understood beforehand a reality of worldly life, 2) elderly who command
care or purchase care, 3) elderly who demand care such as poor planners or who have been
unlawfully deprived of their own constitute this group and 4) elderly who cry for care like
financially crippled, seriously sick from fatal diseases, gerons, socially isolated, widows,
destitute, dwellers in loneliness (Jamuna and Ramamurti, 2001).

**Elder Requesting Care and Support**
The elders require care from their caregivers in the time of 1) physical or chronic illnesses such
as visual, auditory, memory loss, hypertension, coronary heart disease, respiratory disease,
neurological disorders, cancer, urological disease, internal organs failure, diabetics etc., 2) social
problems like retirement from economic life, generation gap, family role loss, 3) psychological
problems such as depression, anxiety, stress, burden and tension and 4) task of daily living such
as eating, bathing, dressing, toilet using, they require care and assistance from their caregivers

**Elder Care in India**
Indian family system is an umbrella that acts as safety net. The family members are taking care
of children, destitu tes, disabled and elders of the family. The caring has qualitative and
quantitative aspects. Qualitative care refers to nature of care giving like love, affection, support,
mutable relationship, etc., while quantitative refers to amount of time and effort spent on the care
giving. Psychological interdependence, motivation, attachment, obligation, altruistic behavior
and desire to extend care determine the dyadic interactions (Jamuna, 1996, 1997a, 1997b;
Jamuna and Ramamurti, 1999). As far as the elder care is concerned, family is the primary
source to provide personal, socio-economic and emotional supports to fulfilling the elder’s needs
(Prakash, 1999), which is provided by their kith and kin or co-residing spouse of the care
**Elder Care Service in India**

Elderly care is the fulfillment of the special needs and requirements that are unique to senior citizens (UDAAS, 1965). Worldwide, a variety of elder care services are practiced. However it differs based on cultural perspectives. In India, the following elder care services are available: 1) Commercial care such as old age homes, hotels, hostels, banks, insurance companies, manufacturers of geriatric medicines, 2) Professional care like geriatric care, geriatric treatment, geriatric wards, geriatric nursing and geriatric psychiatry, 3) Social care such as care by breaking families (e.g., mother lives with one son and the father with another), 4) Religious and cultural care (all religions and cultures have made provisions to provide care and comfort to the elders), 5) State and Voluntary organization care such as finical assistance to elders, widows, destitute and disabled, 6) Legal care: the needy elders who have no source of income may get legal care from the court and 7) Philanthropic care: philanthropists believe that service of mankind is the service of god and a great good (Hari Shankar Lalvidyarthi, 1995).

**Status of Caregivers of Elders in India**

Traditionally in India demands, values, honor and respect of the elders were viewed with very high regard. Elder parents are typically cared by their own male child because of strong filial-piety norms (Jamuna, 2003). Indian constitution provides special preference and safeguards to the elders through social policy (social security, social assistance and social insurance), social legislation (Acts and bills) and five year plans (See Annexure – II). Majority of the caregivers of elders are living with poor socio-economic and health conditions, poor educational status and economically inactive groups (60th NSSR, 2008). They also expect assistance from the government and NGOs, but still the government and NGOs have not recognized elder caring as a problem and no one has generated any realistic statistical data base, policies and schemes relating to caregivers of elders in India.
Classification of Caregivers
The care giving to elders is the most common form of assistance worldwide (Stoltz, Udén and Willman, 2004; Paoletti, 2007). The caregivers are classified as 1) formal caregiver such as doctors, nurse, social worker etc., 2) informal caregiver like wife, son, daughters, in-laws, grandchildren, relatives and friends and 3) community caregiver means community is responsible to provide care to the filial elders (Cantore, 1991; Ramamurti and Jamuna 1999; Bhatla, 1998; Sivakumar, 1999; Varadharajan, 1995). In this study the researcher has focused on informal caregivers.

Informal Caregivers
The informal caregivers of elders refers to non-paid individuals, who are primarily responsible for providing and/or coordinating care of the lay elder in their house, such as a spouse, offspring, other relative and non-relative (USA-HHC, 2007). The informal caregivers are responsible persons to fulfill the elder needs with their optimal level of independence (Miller and Keane, 1992) and spend a substantial amount of time to interact with their elders. While providing care, the informal caregiver assist with Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs) such as: house cleaning, cooking, shopping, paying bills, giving medicine, bathing, using the toilet, dressing, eating (Anderssons, 1995 and Nayar. P.K., 2009).

Classification of Informal Caregivers
The informal caregivers are falling under two categories. There are primary and secondary. The primary caregivers are those who are mainly responsible for providing care to the sick elder. Those who support the primary caregivers in their caring activities as called secondary caregivers (Jamuna, 2002b; Contor, 1976; Horowitz, 1985a). The informal caring of elder is an intergenerational exchange that transmitted one generation to another generation. Depending on
the quality of family relationships and elder disability conditions, some elders adjust with their
caregivers and some are dominated by their caregivers (Ramamurti, P.V., 2008).

**Role of Informal Caregivers**
The informal caregivers caring role is an unscheduled one (Bowers, 1987). It is generally
categorized as: anticipatory, preventive, supervisory, instrumental and protective roles
(Archbold, 1982). The roles have different dimensions such as: a) the nature of the tasks, b) the
frequency with which tasks are performed, c) the hours of care provided each day, d) the skills,
knowledge and abilities of caregivers to perform tasks, e) the extent to which tasks can be made
routine and thus incorporated into daily schedules, f) the support received from other family
members. The caregivers provide direct care, performing complex monitoring tasks (blood
sugar, titrating narcotic dosages for pain), interpreting elder symptoms, decision-making and
providing emotional support to their elder (Cohen, 1998; Leibing and Cohen, 2006).

**Informal Caregivers Requirement**
The informal caregivers of elders require 1) knowledge of physical and behavioral symptoms of
elder such as daily living function and positive attitudes, 2) caregiver qualities like insight,
commitment, honesty with themselves, creativity, flexibility, persistence, patience, sense of
humor, ability to reframe experiences or circumstances, ability to make decisions, and analytical
abilities, 3) caregiver relationships such as past and current relationship between the caregiver
and impaired family member and other family members also viewed as prerequisites to care
giving the effectiveness and 4) general approaches towards ability to handle the day to day tasks
required in care giving (Clark and Diamond, 2010).

**Categories of Informal Caring**
Caring the elder has been divided into five categories: a) routine help which regular
assistance to the parent is incorporated their caregiver ongoing schedule or activities; b) backup
help like a sibling routinely involved in care; c) circumscribed help, in which the help provided to the parent is carefully limited by amount or type; d) sporadic help are occasional assistance to the elder provided caregiver own convenience and e) dissociation as the adult child abdicates any responsibility to help the elder (Matthews and Rosner, 1988).

**Problems Faced by Informal Caregivers**
The rapid social changes, breakdown of the traditional family system, increasing financial constraints, heavy work load, rapid growth of elder population, involvement of women in labor force (Velkoff and Lawson, 1998; Hoffmann and Rodriguies, 2010), increasing inter-generational distance and decreasing family cohesiveness have made that the caregivers of elders are facing different kinds of problems (Desai, 1982; Jamma et.al., 1991). They are listed below.

1) **Physical Problems**
With continuous elder caring, the caregivers of elders face different kinds of physical problems like fatigue, lack sleep, high risk of illness, injuries, lack of periodic exercise, lack of nutritious meals, neck, back and shoulder stiffness of muscle, joint pain, lower back pain, lost weight, loss their grip strength and musculoskeletal symptoms, high strain, blood pressure, lack of caring their own health, lack of rest and physical discomfort.

b) **Psychological Problems**
The care recipient’s behavior, cognitive impairment and functional disabilities are influencing the informal caregivers and renders psychological problems. They are: burden, higher levels of stress, anxiety, depression, guilt, sadness, dread, worry, ambivalence about care, higher level of frustration, angry, drained, guilty and feeling of helpless.

c) **Emotional Problems**
The emotional problems concern with strains, relationship stress, loss of time for self-care, reduced quality of life, conflict about care, behavioral issues, interpersonal conflicts, emotional turmoil, coping problems, apathy, fear and hopelessness.
**d) Social Problems**
The informal caregivers are facing different kinds of social problems such as lack of housing, problem of accommodation, lack of space in their house, poor level of community service, lack of respect, loss of self-identity, lower levels of self-esteem, constant worry, feelings of uncertainty, frequent social isolation, lack of cooperation by care receiver, poor level of cooperation, coordination and collaboration with caregiver co-partner, family members and relatives, lack of preparedness for their role which leads to little or no support, poor level of relatives and family members’ support and lack of relaxation.

**d) Financial Problems**
Due to caring the informal caregivers are compelled to resign their job and also lose their income. It can affect their total family income and result in heavy medical expenditure, loss their savings and increase the family debt. Sometimes they sell their movable or immovable properties, minimize the purchasing clothing, basic home maintenance and utilization of transportations and reduce or stop saving for children's future.

**e) Recreational Problems**
The informal caregivers are not able to participate in relatives’ religious and social functions. They cut back on vacations or travel, avoid the spending for hobbies. They have no leisure activities. They use sick or vacation hours to care. It arises from complex care giving situations and caring for frail or disabled family members (American Psychological Association, 2010).

**Caregiver Perception**
Elder care is a unique combination of assistance and supervision conditioned by characteristics of older persons who are receiving care from his/her caregiver (Jamuna, 1998, 1999b; Ramamurti, 2000). The informal caregivers’ caring perception is some kind of soul searching, common feelings and thoughts; it will reflect the caregiver as well as their family life (Jamuna,
Care receiver physical, memory and behavior problems, caregivers' health conditions, personal and social restrictions, social support, cost of expenses, caring situation, caregiver and care receivers relationship are influencing factors of caregiver caring perception (Jamuna, 1997b). The caregivers’ age, gender, culture, total family size, burden, strain, well-being and caregiver attitudes are playing important role in caregivers’ positive as well as negative perception (Kim, 2001).

The positive qualities of caregivers include helping nature, favorable life outlook, positive attitudes towards helping relationships, capacity to get insight into needs of another person (empathy), absence of irritability, tolerance to frustration, capacity to withstand stress, understanding and appreciative nature of others behavior and possession of flectional ties, optimum levels of tolerance, feeling sufficient care and involvement of elder life, spend enough time to providing care, asking for help from others and feeling responsible for the happiness of elder (Ramamurti and Jamuna, 1984).

The negative side of caregiving include inability to meet own needs, interference in personal life, guilty feeling, inability to spend enough time to their personal needs, elder expecting more than other family members, feeling anxious, sad, easily get angry, lack of contact with their friends and not able to utilized the enjoyable and recreation activities, poor level of caregiver and care receiver relationship, feeling insufficiency of care involvement, spending enough time for caring the elder, feel guilty, feeling powerless, no place to turn and suffering personal well-being (Jamuna, 1992, 1996, 1997b). The caregivers face the physical and psychological problems like loss of appetite, restlessness, frequent headaches, anxiety, short temper, worry, depression, sleeplessness, feelings of disgust and excessive irritability always expecting help from others, feel powerless to help, unanswered questions about the medical conditions and prognosis of
elder, health relief of elder health conditions and uncomfortable treatment (Stevone, 1996; Jamuna, 1996, 1997b; Jamuna and Ramamurti, 2000).

When the care services cross the optimum levels of tolerance and the caregivers are overwhelmed, it will lead to depersonalization, a dazed feeling and helplessness (Jamuna and Ramamurti, 2000). The competent and confident providers are important to ensure caregivers’ safe and effective care (Deborah Gold, 2009).

**Caregiver Strain**

The strain of care giving reverberates throughout families. It is a kind of feeling which focuses on informal caregivers’ caring role. The caregiver optimism is a strong predictor of reactions to the strain of caring (Kurtz, Kurtz, Given, 1995). Higher level of tension, depression, confusion, bodily pain, less social activity, poor mental ability, health perceived impacts and daily schedules are resulting in caregiver strain (Given et al., 1993).

The caregiver strain reveals three dimensions. They are: 1) role strain which find it hard to perform their roles or feel strained by situations such as financial burden, increased responsibility, role change, social withdrawal, loss of interest in hobbies, excessive anger, lack of sleeping, extremely irritability, change in appetite, trouble concentrating, feeling worthless and guilty, 2) personal and emotional strains include potential source of stress, disruptions to family functioning can have deleterious, effects for individual family members who have demanding care responsibilities and elder with mental impairments (Miaskowski, Zimmer, Barrett, Dibble, and Wallhagen, 1997) and 3) demographic characteristic wise the caregiver strain as gender, age, financial status, education level, health status. Steps to minimize strain should include: utilizing all available services and resource to share the responsibility of care giving (Given et al., 1993).
Caregiver Burden

Informal caregiver burden poses a health risk to both the caregiver and the care recipients (Hughes, Giobbe-Hurder, Weaver, Kubal and Henderson, 1999). The informal caregivers’ burden affects the caregiver physical, emotional, social and financial condition that can be experienced by family members caring for impaired elder (George and Gwyther, 1986), lack of adjustment, lack of relationship, role conflict, role overload, lack of coordination of the family members are influencing factors of caregivers’ burden (Chatterjee, Patnik and Chariar, 2008) and helping people with personal care, tasks violates norms of privacy becomes more difficult, anxiety, depression, leading to a negative impact on their capacity for social engagement, high medical costs, insufficient rest, sleep arising from their caregiver responsibilities, limited finances, limited knowledge of the elder situation and lack of supports are associated key factors of caregiver burden (Ramamurti, 2000).

The informal caregivers of elders burden categories as: 1) objective burden includes time spent on care giving, tasks performed, health problems, limitations on one's social life, 2) subjective burdens include caregiver's attitudes, emotional response to care giving (Brody, 1985; Cantor, 1982), 3) physical burdens include difficulties in performing specific care giving tasks, by deterioration in physical health (Poulshock and Deimling, 1984) and 4) emotional burdens include depression, demoralization, negative feelings, adverse effects in various spheres of personal or family life, feelings of embarrassment and overload (Horowitz, 1985).

In Indian situation, the caregiver burden is mainly focused on cultural values and normative reasons. The chief determinants of informal caregiver burden were referred to be: a) characteristics of the informal care givers, b) quality of family supports and c) severity of the care receivers’ condition (Coppel, 1985; Miller, 1987). The caregivers’ daily life occupies their time, energy and attention for providing care of elder, the caregiver facing fear or uncertainty,
shift in roles, financial pressure, isolation, little time alone, demands of constant care, guilt pain, increased weakness, altered breathing patterns and decreased levels of consciousness are some of the reasons the caregiver facing more burden.

Reducing the burden of the caregiver is primary concern for improving the quality of care of the elder. Care giving is a product of cultural expectations, duty, love and a positive attitude (Bhagat and Unisa, 2006; Gupta, 2000). Reciprocal relationship is carefully reduced the caregiver and care receivers burden (Gupta and Pillai, 2002).

Caregiver Coping

The informal caregivers of elder should have knowledge of coping to overcome the caregiver as well as care receiver condition. The caregiver should understand that there is no ideal way for caring the elder (Gonda and Ruark, 1984). The informal caregiver plays multiple roles for caring the elder, it has to bear with the behavioral disturbances and social functioning thoughts such as: denial, anger, fear, grief, depression, guilt, sadness, acceptance, confusion, frustration, fear, resentment, compassion, sympathy and love which refer to the set of cognitive, emotional, spiritual and social difficulties. Hence the caregiver should adopt the coping strategies to overcome their problem of elder caring (Gonda and Ruark, 1984; Kubler-Ross, 1969; Goy and Ganzini, 2003).

A trial and error coping pattern may be involved in caring the elder. The coping strategies can be broadly divided into emotion focused group and problem focused group. The emotion focused group aim to diminish the negative emotional impacts which includes; avoidance, denial, fatalism, and looking to religion. The problem focused group refers to direct actions, change the situation, solving or seeking social support to resolve the caregiver problems.

The role and demands are incorporated within the regular family responsibilities. The caregivers develop different kinds of coping strategies to deal with the elder caring. The caregivers were
using multiple coping strategies, which included positive emotions, compassion, hope for a better future, developing faith in God, positive reframing, emotional support, venting, behavioral disengagement, self-blame are playing the effective coping pattern of caregiver (De Spelder and Strickland, 1999). Good quality of care, respectful relationships, good communication and emotional support from their family, the community and caregiver support groups are playing important coping roles to reduce the caregivers’ problem.

**Caregiver Well-being**

The informal caregivers’ well-being is important to elder health, it consist of four dimensions such as physical health, mental health, financial resources and social participation (Stryker, 1980). The caregiver’s well-being is dependents on the elder condition as well as the individual characteristics of the caregiver (Weitzner and McMillan, 1999). The care giver’s poor health condition, lack of caring experiences, lack of role play, lack of effective coping styles, depression and lack of adjustments are the risk factors of caregivers’ well-being (Elliott and Pezent, 2008; Pearlin, Mullan, Semple and Skaff, 1990).

The caregiver’s well-being is to fulfill the caregiver’s basic needs and activities of life. The basic needs concern with enough money, eating a well-balanced diet, getting enough sleep, medical needs, having time for recreation, feeling loved, expressing love, laughter and joy, sadness, enjoying sexual intimacy, learning new skills, feeling worthwhile, appreciated by others, good about family and secure about the future, having close relationships, having a home making plans about the future and activities of life concern with preparing meals, getting the house clean, yard work, home maintenance, having adequate transportation, washing, caring for clothing, relaxing, exercising, enjoying a hobby, starting a new interest or hobby, attending social events, taking time for reflective thinking and having time for inspirational or spiritual interests (Moen, Demptster-McClain and Williams, 1989, 1992; Marks, 1977; Jamuna, 2001).
The caregiver roles and activities, behavioral and social initiatives are important to promote the health and quality of life, positive reappraisals, spiritual beliefs, adaptive coping mechanisms, managing the physical, emotional and mental health, a strong cultural norm are beneficial for caregiver self-rated health are important criteria for caregivers’ well-being (Haley, et al, 2003). The sound psychological, physiological and financial position of caregivers can contribute to their well-being (Chappell and Reid, 2002; Kramer, 1997; Lawton, Moss, Kleban, Glicksman and Rovine, 1991). The higher level of well-being is associated with caregiver experience and positive attitude while low level of well-being is associated with negative attitude (Beach et al., 2005; Williamson et al., 2001) in overall caregiver well-being, specifically caregiver’s positive experiences (Kramer, 1997b) or focus on the strength of the caregiver as opposed to quality of life (Berg-Weger, Rubio and Tebb, 2000).

**Caregivers’ Caring Outcome**

The informal caregivers; caring outcome influences the mental and physical status of caregivers of elder (Adams et al., 2008). The caregivers provide care to their elders and maintain good relationship and pre-existing interpersonal relationship between the caregiver and care-receiver. The elder caring outcome can affect different reasons such as relationships with other family members, work responsibilities and personal privacy.

The caregivers are able to identify positive aspects of their caring outcome as: a sense of giving back to someone who has cared for them, the satisfaction of knowing that their loved one is getting excellent care, personal growth and increased meaning and purpose in one’s life. Informal caregivers are facing a number of negative outcomes including emotional strain, financial losses, disruptions of plans and lifestyles and health declines (Schulz and Sherwood, 2008; Beach, et al., 2000; Connell, et al., 2001; Bookwala et al., 2002; Vitaliano, et al., 2004;
Family Caregiver Alliance, 2006). Some caregivers feel that they are passing on a tradition of care and other are modeling the care (Cohen, Colantonio and Vernich, 2002; Kramer, 1997).

Need and Importance of the Study
Elder care giving (end of the life care, frail caring, and palliative care) is a highly strained and burdened work. However, it is a responsible humanitarian task fulfilling the elders’ wishes and personal satisfaction in life. Some people accept it gracefully with a positive attitude, but many informal caregivers adopt negative attitude in their day to day life depending on elders’ physical and intellectual health condition. The informal caregivers in India normally adhere to the Indian cultural norm of dharma or moral duty to provide care for the elderly parent (Gupta and Pillai, 2002). The elders and their adult children live in the same household providing mutual care for all the members in the family. However, with modernization and development, high cost of living, technological development, elder population growth and poor economic condition, the caregivers of elders are facing physical, psychological and socio-cultural problems not only in rural areas and also in urban areas. In general about 40% percent of Indians are living in extreme poor condition (Statistics Report, 2011). In the present scenario, informal caring in urban area is classified as: 1) the upper class people recruit home caregiver (home nurse) and provide proper care for their elder parents or relatives, 2) middle class people among whom both husband and wife are employed, they provide neither informal care nor formal care (paid homes); it depends on their earning and place availability and 3) poor class people (Below Poverty Line) depend on informal elder care service. They are facing all kinds of problems. The researcher was motivated to undertake a study on informal caregivers’ perception, strain, burden, coping, well-being and caring outcome in an urban community.