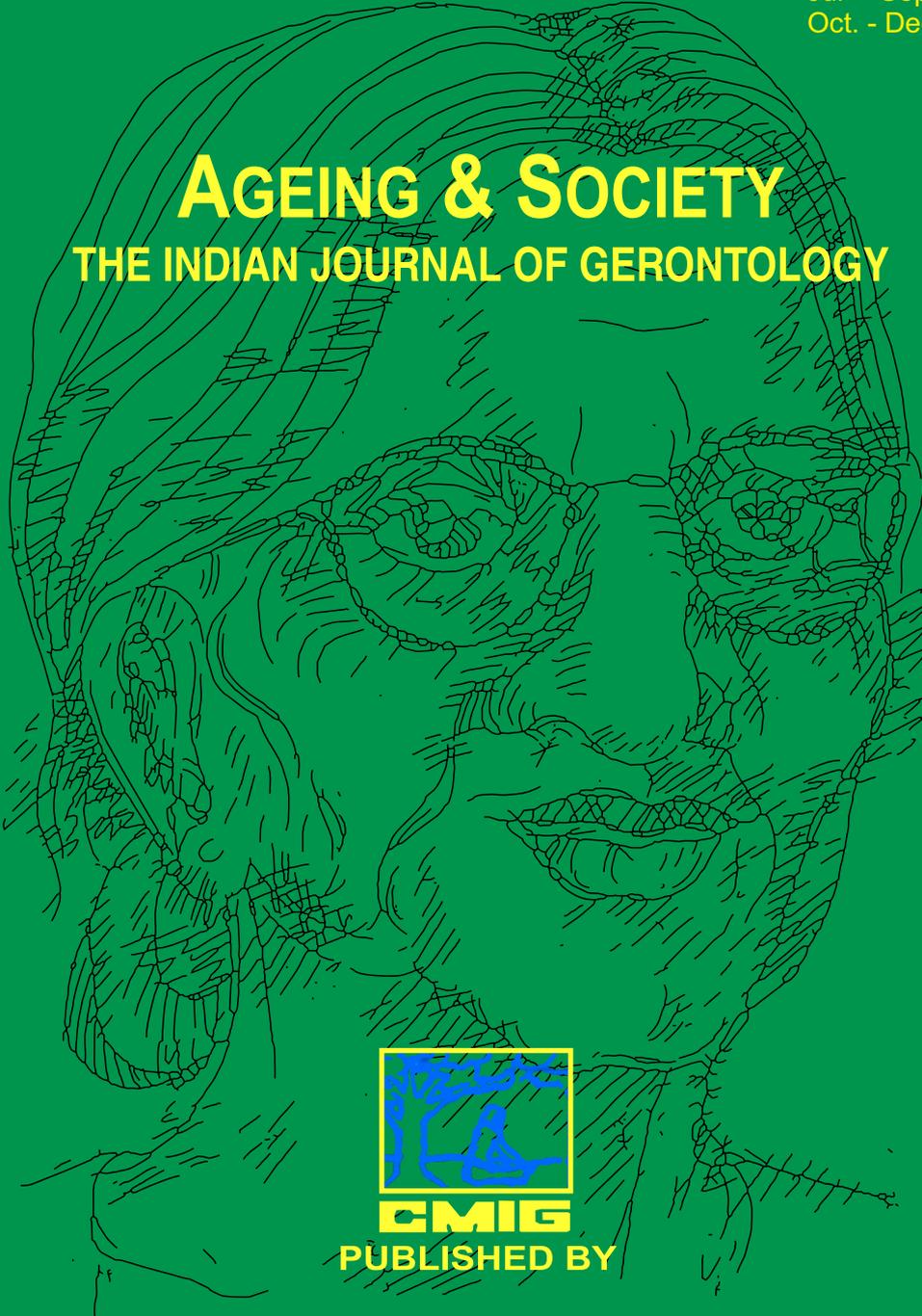


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CONTENTS

**ASSESSMENT OF QUALITY OF LIFE AMONG THE OLDEST
OLD 80+ LIVING IN OLD AGE HOMES IN
BANGALORE DISTRICT**

Roopa K. S.
Lakshmidevi S. 1

PRIMARY CAREGIVERS' STRESS IN DEMENTIA

Tashi Yangtso
Prabir Kumar Das 17

IMPACT OF ENVIRONMENT POLLUTION ON ELDERS

Savita Vermani
Abha Vermani
Jatesh
Reshmi 49

**MODELLING OF A SINGLE INDEX TO MEASURE THE
WELL-BEING OF THE ELDERLY**

S. K. Chakravarty 59

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ASSESSMENT OF QUALITY OF LIFE AMONG THE OLDEST OLD 80+ LIVING IN OLD AGE HOMES IN BANGALORE DISTRICT

Roopa K. S.*
Lakshmidhevi S.**

ABSTRACT

The present study was carried out with an objective to assess the QOL among the oldest old 80+ and also to compare the QOL among men and women living in old age homes in Bangalore district. Structured interview schedule developed by the researcher was used to assess the QOL. A total of 80 old age people of which 40 men and 40 women between the age range of 81 to 98 years residing in old age homes constituted the sample. Analysis of data obtained revealed that majority of men and women respondents were found to be suffering from hypertension, diabetes mellitus and arthritis. Cent percent of the women were found to be suffering from osteoporosis. Visual, hearing and movements disabilities were found among both men and women. In the area of physical functioning majority of men required help for walking as compared to women. However, majority of both men and women cannot climb the stairs without help. In the area of psychological and emotional functioning majority of men and women were found to be always experiencing of anxiety, depression, anger, tension, irritation and sorrow. They never experienced a sense of freedom, feeling of independence and self confidence. Majority of respondents felt lonely and isolated. The study concluded that oldest old are physically weak, psychologically insecure and socially isolated.

Key Words: Aging, Oldest old, Quality of Life

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Introduction

Aging of population and extension of life are significant by products of the demographic transition. Aging of population is primarily the result of reductions in fertility and mortality, while the prolongation of life has been mainly the outcome of reductions in morbidity. The aging of population first took place in the developed countries and has now become a worldwide phenomenon. Like many developed countries, India has a large population of the elderly in the population.

Aging is generally defined as a process of deterioration in the functional capacity of an individual that results from structural changes, with advancement of age or population above 60 years of age. Some demographers also distinguish young old 60-69 years, middle old 70-79 years, oldest old 80-89 years and the extreme old 90+ years.

Older people are heterogeneous i.e., extreme losses of physical, mental and social functions are often seen in old people yet many people continue to maintain high level of function. However, as "young old" move in to the "oldest-old" category, they tend to have more health complaints and diagnosed illness. The problems faced by them range from ill health, absence of social security, loss of social role and recognition and the non-availability of opportunities for their creative abilities.

Globalization, urbanization, industrialization, modernization have paved the way for many old age people being left alone by their families. As a result a large number of old age homes have come up like mushrooms all over the country. Today, the old age homes are indispensable as they are needed to take care of the lonely and forsaken elderly in the evening of their lives. The several consequences of such trends, one that causes serious concern is that of providing care to a large number of older persons to have better quality of life.

The world health organization defines the Quality of Life as "an individual's perception of his / her position in life in the context of the cultures and value systems in which he/she lives, and in relation to his / her goals expectations, standards and concerns. It is a broad ranging concept incorporating in a comparing way the person's physical health, psychological state, level of independence, social relationships and their relationship to salient features of their environment. Quality of Life is a sense of well-being and value of life of oldest old, which depends on how successfully or unsuccessfully the individual will adjust to the problems arising from the changed physical, mental and living status which comes from aging.

The present study was carried out with the aim and the objective to assess the quality of life of the oldest old 80+ living in old age homes in Bangalore District and also to compare the quality of life among men and women.

Methodology

The study was carried out in V phases viz;

Phase – I - **Survey of old age homes in urban Bangalore District**

Phase – II - **Development of Structured Interview Schedule (SIS) to assess the Quality of Life (QOL) of oldest old.**

SIS classified under seven broad domains namely:

- Demographic details
- Diseases and Disabilities
- Physical functioning
- Psychological functioning
- Emotional functioning

- Social functioning
- Healthcare

Phase – III - Selection of Sample

The cross section of the society with 80 old age people residing in old age homes between the age range of 81-98 years constituted the sample. A sample of 40 men and 40 women were selected from ten old age homes in Bangalore District.

Phase – IV- Interview using SIS

The respondents were interviewed fixing the date and time of their convenience using the SIS to study the Quality of Life

Phase – V- Analysis of the data obtained

Results and Discussion

Figure – 1 : Classification of Respondents by Age Group

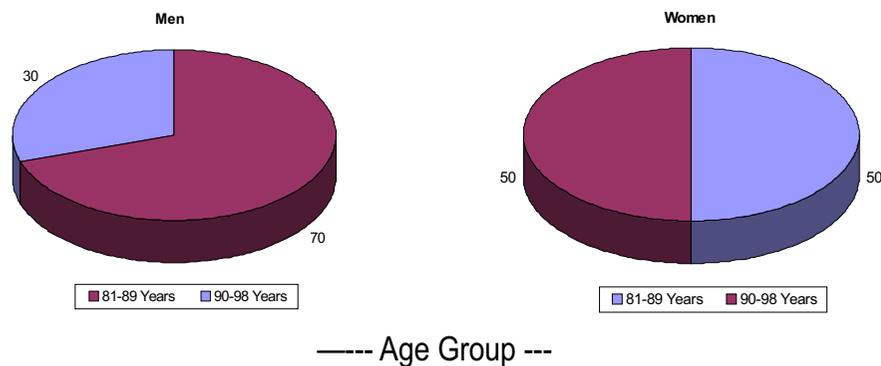


Figure – 1 shows the age of respondents. It was found that majority of men respondents (70%) belonged to the age group of 81-89 years, the other 30 percent of men respondents belonged to 90-98 years. Whereas in the women's category, equal percentage of respondents (50%) belonged to the age group of 81-89 and 90 to 98

years. The life expectancy for males is less than the life expectancy of the females. Hence, there are more old women and widows than old men in the population.

Figure – 2 : Educational Qualification of Men and Women Respondents

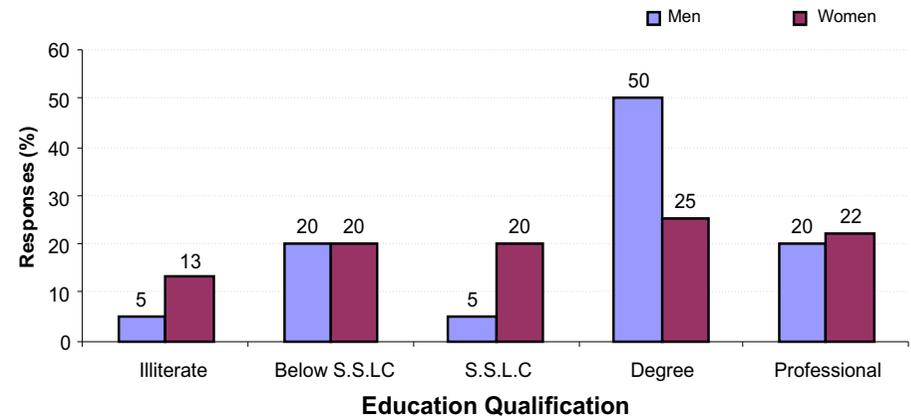


Figure – 2 indicates the educational qualification of respondents. Majority of men respondents (50%) studied upto degree level. 20 percent of men respondents studied upto professional level and only 5 percent of the respondents were illiterate. In women respondents 25 percent of them studied upto degree level followed by 22 percent professional and only 13 percent of them were illiterate. It is evident from the above results that majority of the women are literate but when compared to men, the illiterate women are still more in number.

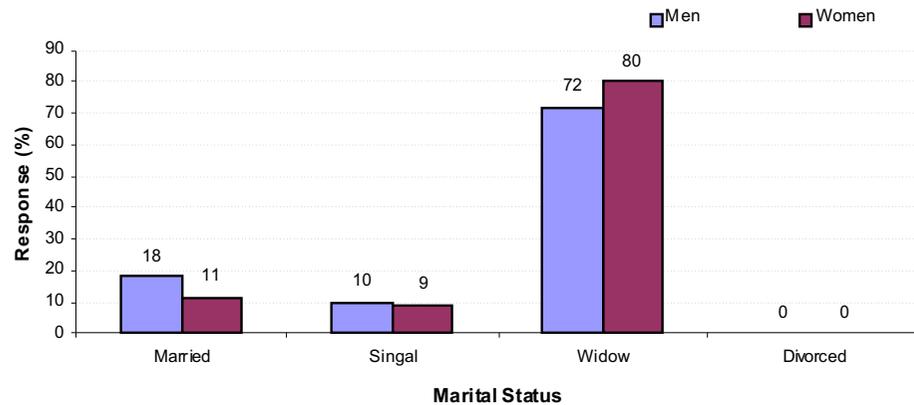
Figure – 3 : Marital Status of Men and Women Respondents

Figure-3 shows the marital status of respondents. Majority of the respondents men (72%) women (80%) were widow / widower. None of the respondents were divorced. 10 percent of men and 9 percent of women respondents never got married.

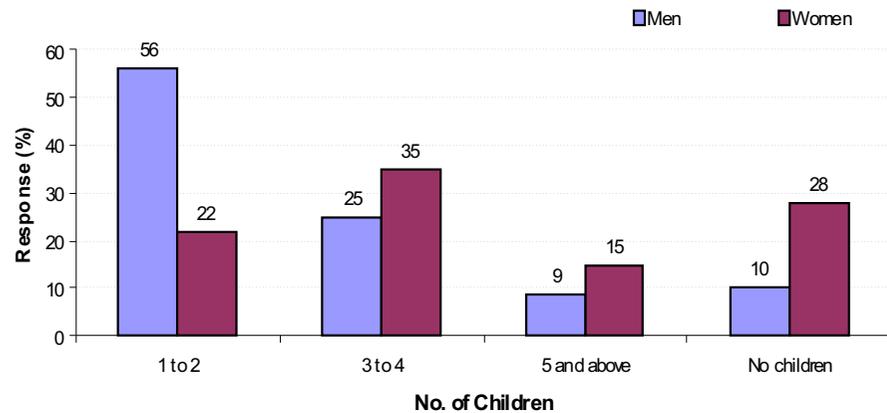
Figure – 4 : Classification of Respondents by Number of Children

Figure – 4 indicates the classification of respondents by number of children. Majority of men respondents (56%) had 1 to 2 children and

25 percent of them had 3 to 4 children. Only 10 percent of them did not have children. In women category 35 percent of them had 3 to 4 children, 22 percent of them had 1 to 2 children and 28 percent of women did not have children.

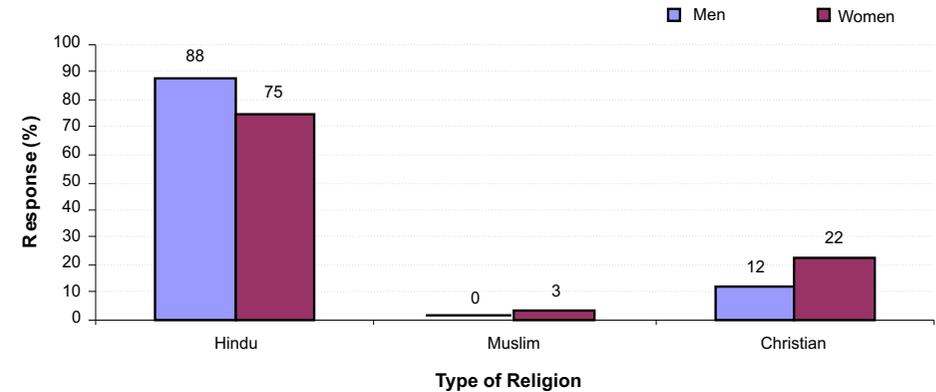
Figure – 5 : Classification of Respondents by Religion

Figure – 5 shows the classification of respondents by religion. Majority of the respondents 88 percent men and 75 percent women were Hindus, 12 percent of men and 22 percent of women were Christian and only 3 percent of women were Muslims.

Table – 1 : Classification of Respondents by Type of Diseases and Disabilities

Types of Disease and Disabilities	Men (Response in %)	Women (Response in %)
Hypertension	80	63
Osteoporosis	0	100
Arthritis	50	50
Diabetes Mellitus	87	75
Cardio vascular Diseases	15	25
Gastro intestinal Diseases	20	30
Respiratory Diseases	40	50
Psychiatric Disorders	12	9
Cerebral vascular Diseases	25	10
Cancer	0	0
Disabilities		
1. Visual	80	78
2. Hearing	63	80
3. Movements	90	60

Table – 1 depicts the classification of respondents according to the type of diseases and disabilities. Majority of the old age people were suffering from diabetes mellitus and hypertension, cent percent of the women respondents were suffering from osteoporosis. Equal percentage (50%) of both men and women respondents had the problem of Arthritis. Fifty percent of women respondents and 40 percent of men respondents suffered from respiratory diseases.

Majority of the respondents had visual, hearing and movement disabilities. Eyes and ears are affected greatly in old age. Changes in the nerve centre in the brain and retina affect vision. Most old people suffer from far sightedness because of the diminishing capacity of the eye lens. Most of the disabilities are caused by weakening of the circulatory system. Other problems that geriatrics takes into consideration are gastrointestinal disturbances, cerebral vascular diseases and psychiatric disorders.

Geriatric studies have shown that old age problems may also be due to alterations in the functioning of the thyroid gland. Progressive diseases tend to become more severe in oldest old. Chronic diseases cause medical, social and psychological problems that limit the activities of old people and decrease their quality of life. The occurrence of osteoporosis in cent percent of the sample of women respondents could be due to ignorance of not taking calcium during their pre and post menopausal years.

Table – 2: Physical Functioning of Men and Women Respondents

Physical Activities		Men (Frequency in %)					Women (Frequency in %)				
		A	S	O	N	T	A	S	O	N	T
Walking	Self	0	0	0	5	100	15	0	0	50	100
	With Help	95	0	0	0		35	0	0	0	
Climbing	Self	0	0	0	0	100	5	0	0	0	100
	With Help	100	0	0	0		0	0	0	95	
Feeding	Self	80	0	0	0	100	63	0	0	0	100
	With Help	20	0	0	0		37	0	0	0	
Dressing	Self	80	0	0	0	100	63	0	0	0	100
	With Help	20	0	0	0		37	0	0	0	
Bathing	Self	80	0	0	0	100	63	0	0	0	100
	With Help	20	0	0	0		37	0	0	0	
Toilet	Self	80	0	0	0	100	63	0	0	0	100
	With Help	20	0	0	0		37	0	0	0	

Legend:

A : Always S : Sometimes O : Occasionally N : Never T : Total

Table – 2 shows the physical activities of the respondents. Majority of the men respondents (95%) walk only with help and cent percent of them need help for climbing the stairs. Majority of them (80%) can feed, dress, bathe by self and only 20 percent of them need help.

In women respondents, majority of them do not need help for walking, climbing, feeding, dressing, bathing and toileting. Compared to men, women were independent in physical functioning. Old age is a period of physical decline. The physical condition depends partly upon hereditary constitution, temperament, the manner of living and environmental factors. Vicissitudes of living, faulty diet, inadequate rest, emotional stresses, endocrine disorder are some of the common causes of physical decline.

Table - 3: Psychological and Emotional Functioning of Men and Women Respondents

Psychological and Emotional Functioning	Men (Frequency in %)					Women (Frequency in %)				
	A	S	O	N	T	A	S	O	N	T
Anxiety	50	20	30	0	100	50	20	0	30	100
Depression	30	20	30	20	100	50	0	0	50	100
Anger	64	23	13	0	100	60	0	20	20	100
Tension	50	30	20	0	100	50	20	20	10	100
Irritation	75	25	0	0	100	60	40	0	0	100
Fear	80	20	0	0	100	50	0	0	50	100
Jealousy	50	0	0	50	100	60	0	0	40	100
Inferiority complex	25	35	40	0	100	75	0	0	25	100
Frustration	50	40	10	0	100	50	0	0	50	100
Sorrow	60	0	0	40	100	70	0	0	30	100
Love & Affection	40	30	0	30	100	80	0	0	20	100
lack of surety of life	45	0	5	50	100	50	0	0	50	100
Joy	0	0	10	90	100	50	0	0	50	100
Satisfaction	40	0	0	60	100	40	0	0	60	100
Understanding others	50	0	30	20	100	50	0	30	20	100
Sense of freedom	20	0	0	80	100	0	0	0	100	100
Feeling of independence	20	0	0	80	100	40	0	0	60	100
Self confidence	0	10	0	90	100	0	40	0	60	100
Dependency	90	0	0	10	100	100	0	0	0	100
Lack of memory	100	0	0	0	100	80	0	0	20	100

Legend:

A : Always S : Sometimes O : Occasionally N : Never T : Total

Table – 3 shows the psychological and emotional functioning of respondents. Majority of both men and women responded expressed that they have always fear, irritation, anger, sorrow, frustration, tension expressed and anxiety. Majority of them expressed that they do not have joy and satisfaction in life. Majority of old age people reported that they do not have sense of freedom nor feeling of independence. They never had self confidence and satisfaction in life.

Life satisfaction refers to a person's general happiness, freedom, less tension in life. It is concerned with physical, psychological and social well-being. The study shows the lower level of life satisfaction of the old age people living in old age homes. Cent percent of men respondent and 80 percent of women respondent reported that they lack memory. It is common with ageing there is slowing down of memory and mental abilities.

Table – 4: Social Functioning of Men and Women Respondents

Social Functioning	Men (Frequency in %)					Women (Frequency in %)				
	A	S	O	N	T	A	S	O	N	T
Visit to places of worship	0	0	0	100	100	20	0	0	80	100
Attending religious functions	3	0	0	97	100	20	0	0	80	100
Visit to friends' and relatives'	37	0	13	50	100	63	0	12	25	100
Visit parks	0	0	0	100	100	0	0	0	100	100

Legend:

A : Always S : Sometimes O : Occasionally N : Never T : Total

Table – 4 shows the social functioning of respondents. Majority of the respondents living in old age homes responded that they never visited to places of worship nor attended religious functions. Sixty three percent of the women respondents and 37 percent of the men respondents expressed that they always visited friends and relatives houses.

Cent percent of both the group of respondents reported that they never visited to parks. Older people increasingly suffer from social losses with age. Their social life is narrowed by loss of work associates, death of relatives, friends and spouse and poor health which restricts their participation in social activities.

Table – 5: Health Care of Men and Women Respondents

Health Care and Habits	Respondents Living in Old age homes (Frequency in %)					Respondents Living in Residences (Frequency in %)				
	A	S	O	N	T	A	S	O	N	T
General check-up	100	0	0	0	100	100	0	0	0	100
Weight check	100	0	0	0	100	100	0	0	0	100
Regular exercise	5	0	0	95	100	0	0	0	100	100
Take medicines regularly	75	25	0	0	100	89	0	0	11	100
Regular lab-test as advised by the doctor	63	0	0	37	100	100	0	0	0	100
Take medicines after consulting the doctor	100	0	0	0	100	63	8	0	37	100
Take medicines by myself/advice from friends	0	0	0	100	100	0	0	0	100	100
Stop taking medicines once health improves	100	0	0	0	100	100	0	0	0	100
Stop medicines when there are side effects	100	0	0	100	100	100	0	0	0	100
Try home remedies	40	0	0	60	100	50	0	0	50	100

Legend:

A : Always S : Sometimes O : Occasionally N : Never T : Total

Table – 5 shows the health care of respondents. Cent percent of both men and women respondents reported that general check up and weight check up is done in the old age home regularly. Majority of them reported that they take medicines regularly after consulting doctor and also lab test is done regularly as advised by the doctor. They do not take medicines by themselves nor as advised by their friends.

Cent percent of both men and women respondents reported that they stop taking medicines once their health improves or when they have side effects. The results show that forty percent of men respondents and 50 percent of women respondents always try home remedies though they are staying in old age homes.

Conclusion

To conclude, oldest old are physically weak, psychologically insecure and socially isolated. Majority of old people were found to be suffering from hypertension, diabetes mellitus and arthritis. Centpercent of women were found to be suffering from osteop- orosis. The evaluation of the Quality of Life in the elderly has become extremely important due to the longevity brought to human life. Living longer may result in a life marked with dependence and disabilities. The epidemiologic changes resulting from this demographic transition have led to a greater prevalence of chronic degenerative conditions and complications producing impairments, dependence and the need for long-term care.

Welfare services must be provided to the oldest old by the institutions as in the west. The abilities and capabilities of the oldest of old should be encouraged and appreciated. A well planned programme catering to Nutritious diet, mental stimulation, positive coping skills, good social relationships and good support systems should be developed. If we are to celebrate longevity it must be accompanied by improvements in the QOL and the development of efficient support systems that turn the oldest old 80+ into a period of rest, comparative security and contentment in life

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PRIMARY CAREGIVERS' STRESS IN DEMENTIA

Tashi Yangtso*
Prabir Kumar Das *

ABSTRACT

Stress in dementia care is a widely known fact. The chances of primary care-givers' stress seems higher in developing countries like India, due to lack of awareness about dementia, care management directories and absence of professional help. This study is an attempt to have a closer look at primary care-givers' stress in dementia. Caregiver's Strain Index (Robinson, 1983/5) and self framed questions (which focuses on personal details, roles, support system and coping) are administered to understand how care-giving shapes the life of a primary caregiver; subjective challenges of care giving and also to explore what all contribute in coping with challenges of this labour-intensive job which ultimately define the quality of care for a person with dementia.

Key words: dementia, care-giving, care-giver's stress, coping strategies

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INTRODUCTION

According to Alzheimer's Disease International; globally, 35.6 million are suffering from dementia, 14 million from Asia Pacific region and according to WHO, India has 3.7 million recorded cases of dementia and by 2050 it is expected to cross 16.3 million. Public awareness about dementia in India is very limited and there are many stigmas attached to this brain disease which further blocks gathering of proper information about the condition. Due to lack of awareness and understanding, an early diagnosis is almost unheard of in India. Since the early symptoms of dementia are usually a little forgetfulness and mistakes; which overlaps with, what is considered as normal part of aging. The public awareness is increasing, although gradually.

Since medical intervention on dementia is very limited due to yet-to-be found cause, the focus is entirely shifted toward providing a quality care without compromising the five fundamental rights of senior citizens; right to participation, independence, care, self-fulfillment and dignity, wherever possible. No proper dementia care management is available in India due to lack awareness and understanding. Out of convenience or will one member of the family becomes the primary caregiver, without enough knowledge about dementia care giving which only increases the chances of stress and other psycho-social implications.

Although persons with dementia have been identified as the first victim of the disease, family caregivers of these persons are the second category of hidden victims (Zarit et al. 1985; Zarit 1990). In India, the little awareness that is already there is out of a close personal association with someone who is diagnosed with dementia; a family member or a relative. Family forms the main pillar stone of dementia care and this is especially true in developing countries like India where institutional care and social services are almost non-existent in dementia. With increasing life expectancy and declining birth rates, the global phenomenon of demographic

ageing has also surfaced in India (Pattanayak, et al., 2011). The chances of dementia doubles in every five years after the age of 65.

Many families try to hide and even deny about the diagnosis of the disease which prevents the person with dementia to receive medical aid and more importantly proper dementia care. But one or more family members have to assume the role of caregiving without knowing about the condition. Diagnosis of dementia changes the general peace and role of every individual in the family and sometimes the quality of ties between them both positively and also negatively. Another reason is challenges of dementia care, which is not half easy as, nor quarter as reciprocated as caring for any other physically impaired older person. The way dementia impact behavior makes the care giving challenging. And there is a constant need for change from the care-giver's part because what works today may not work tomorrow, due to deterioration; changes that the person with dementia doesn't feel comfortable with and his or her inability to communicate. So, intention of this study is to have a closer look at dementia care giving in India, and to see how it shapes the life of the primary caregiver, subjective challenges of care giving and also to explore what all contribute in coping with challenges of this labour-intensive job which ultimately define the quality of care for person with dementia.

CAREGIVING: A definition

Care is used to indicate an attitude, feeling, concern, support and commitment to the well-being of a person. Elderly care or simply elder care is the fulfillment of the special needs and requirements that are unique to senior citizens. This broad term encompasses such service as assisted living, adult day care, long term care, nursing homes, hospice care and in home care. According to WHO, 2000 care giving is defined as "The system of activities undertaken by informal and formal caregivers (family, friends, neighbours, professional) to ensure that a person who is not fully capable of self-

care can maintain the highest possible quality of life, according to his/her individual preferences with the greatest possible degree of independence, autonomy, participation, personal fulfillment and human dignity". Caregiver (US and Canadian usage) or carer (UK, NZ and Australian usage) is anyone who provides assistance to someone who is physically or psychologically impaired and dependent on others (answers.com, accessed 30th October).

TYPES OF CARE

Care giving can be broadly categorized as formal and informal depending upon the nature of relationship with the care receiver. Formal caregivers are generally paid professionals who are either part of a service organization, or independent and provide care for an ill or impaired person. Volunteers who are associated with an organization are also considered as formal caregivers. Informal caregivers are unpaid family members like spouse, adult children, siblings, friends and even neighbors.

Another way of categorizing caregivers is amount of responsibility, namely primary, secondary and tertiary caregiver. The person most responsible for the care of an impaired person is referred to as primary caregiver (Morgan & Kunkel, 2001). And those who provide support to the primary care-givers are secondary and tertiary caregivers. When a family member falls ill or requires some form of assistance, families are forced to bring changes in their routine lifestyle. Frequently, one family member, either by choice or due to convenience, becomes the primary care-giver (Emmathy, 2009). The quality of rendering care for elderly family member is generally governed by socio-economic, physical and most importantly cultural factor, which was an unasked privilege of elderly in culture-based countries like Japan, India and China.

But modernization, breaking down of joint family system, urbanization, population migration, revolution in technology and emancipation of women have brought along a drastic change in this tradition.

Medical revolution has only increased the longevity but not quality of life. Hence the demand for care is on a sharp rise due to population ageing and rise of age-related chronic diseases, in which dementia is one which requires the maximum care. But care provider is so much less in number, resulting into a huge disparity. And there is also inequality of intra-family resource distribution; more for children and less for older adults; inter-generation gap; patronising attitude towards the aged people. These factors and many others contribute to the poor quality of elder care, which is a long time commitment.

According to National Alliance for Care giving and AARD (2005), 34 million individuals are providing care to an adult over age of 50, who is in need of care.

HETEROGENEITY OF CAREGIVING

Decision about family care-giving is influenced by factors like geographic proximity to care receiver, gender of the care giver, availability of time, work schedule flexibility, physical health, and emotional closeness with the care receiver. On top of that most families follow a gendered family pattern called the care giving hierarchy which determines the care giving responsibility. According to this hierarchy, first on the list is the spouse followed by an adult children usually daughter or daughter-inlaw and last by fictive kins; frequently women (sisters, nieces, grand-daughters, neighbors) step in to provide care (Uhleenberg & Cheuk, 2008). This pattern is visible across the globe.

The motivation to provide quality care is what sets family care giving apart from assistance supplied by more formal source. Family members provide care out of feeling of love and affection, feeling of filial responsibility (Silversterp, Gans & Yang, 2006), inter-generationalised solidarity (Roberts, Richards, Bengtson, 1991) or derive to reciprocate for earlier support, which is like paying for an earlier debt. Taking on a caring role is mostly not a conscious

decision, as would be expected, particularly with a spouse carer, is a continuation of a long term established relationship; where the level of dependency had not just grown but also shifted progressively. The transition from a spouse or child to a carer can be subtle and is usually neither planned nor adequately anticipated (Gillies, 2011).

CAREGIVERS' STRESS OR BURDEN

The care giving relationship can also be influenced by a variety of other factors, including the history of relationship between family members, geographic proximity, degree of disability and availability of support resource. As a result of this multiplicity, it is difficult to generalise care giving experience and stress associated with family care giving. In fact researches have explored the prevalence of care giver burden, and tried to measure the effects on psychology and physical health compared to burdening amount on non-caregiver has often remitted in inconsistent findings (Pinquart & Sorensen, 2003). Providing care to aging family member is not a simple or easy task. Caregivers often face demands on their time as well as difficulties that test their physical and mental endurance. Emotions commonly associated with caregivers burden includes depression, loneliness, anger and even guilt. Caregivers frequently exhibit higher levels of depression, physical fatigue and social isolation (Johnson, 2008). According to ABC-X Model of Family Crisis (Boss, 1988; Patts, 1988) how caregivers and their family cope with stress associated with care giving depends on the types of stress (Whether the event is dichotomous or not, major life event or daily hassle and whether it is an ambiguous loss) they encounter, availability of resource (traits, characteristics or abilities of a member of family, the family system and community resource) and perception of the situation; an individual's cognitive appraisal of life event strongly influences the response (Lazarus & Launier, 1998). And caring for dementia patient is much more different proposition than caring a normal aged patient.

DEMENTIA: The Disease

Dementia implies loss, and it is characterised by a decline from a previously attained level of functioning. The word 'dementia' is derived from the Latin word '*dement*' which literally means being 'out of one's mind'. However, the World Health Organization defines dementia as " a syndrome due to the disease of the brain, usually of a chronic nature, in which there is disturbance of many of its functions, such as calculation, learning capacity, language and judgment.. Consciousness is not clouded. Impairment in cognitive functions are commonly accompanied, and occasionally preceded by deterioration in emotional control, social behavior or motivation."

According to the causes, dementia is categorised as:

1. Treatable cause, where dementia is due to one or more of the underlying causes; medications, vitamin B12 deficiency, metabolic imbalances (including thyroid, kidney or liver disorder), chronic alcoholism, acute depression, blood clots pressing on the brain, certain tumour or infections (normal pressure or simple hydrocephalus, poor oxygenation and any other) of the brain. Or any other cause which can be treated, hence reverse the disease.
2. Irreversible dementia, which is a progressive, degenerative and irreversible in nature and hence can't be treated but retard the deterioration with functional support system, stimulating activities, medication and other therapies. The irreversible causes are Alzheimer's disease, vascular dementia, fronto-temporal dementia, lewy body dementia and parkinson's associate.

CARING DEMENTIA PATIENTS:

In the field of ageing and care giving, dementia has occupied a prominent place. Dementia is one of the most chronic old age disease which requires the maximum care and support. When a family member receives a diagnosis of Alzheimer's disease, usually

one or several relatives assume the role of nonprofessional caregiver. The transition places the relative in highly demanding situation which requires learning new skills, has no fixed time schedule, take a lot of time and has an uncertain concluding date (Hornillos Carlos et .al, 2011). It is therefore what is referred to as 'care-giver's'burden (Zarit, Reever, & Bach-Peterson, 1980) and caring for dependent elder at home has been one of the main paradigm to study chronic stress (Crespo, Lopez, 2007; Pearlin, Mullan, Semple & Skaff, 1990). And caring for someone with dementia has a higher chances of stress due to poor communication between the caregiver and care-receiver, challenging behaviors of the patient and lack of reciprocity from the patient and accepting ambiguous loss which are very subjective in dementia care giving. Hence the chances of care-giver's stress is very high. A wife care-giver, in her own words "There is nothing as lonely as fixing three meals a day to a person who can no longer talk to you."(Alzheimer's Disease Education and Referral; ADEAR Centre, 2009)

CONSEQUENCES OF CARE RENDERING IN DEMENTIA

Living with dementia patients is very different from living with normal older persons, because of the way dementia impact behaviour. The advancement of cognitive impairment will increase the care load on the caregiver. So those caring for loved ones with dementia experience the most severe stress because of challenges specific to cognitive progressive deterioration and lack of reciprocal expression of affection and gratitude (Pinquant & Sorensen, 2003). Another unique challenge for dementia caregiver is facing the reality of ambiguous loss (Boss, 1999). Persons who experiences this type of dementia gradually lose their ability to communicate, reason and even remembering the names and faces of loved ones. For their care-givers and family, persons with dementia eventually become psychologically absent even though physically present(Boss,1998/9). This type of partial loss can become very

difficult especially to family caregivers who witness slow deterioration on a daily basis. However, even though the person with dementia can't remember anyone's name, the perception of a continuing connection helps to maintain the care-giver's involvement with their care-receiver (Carbonneau et al., 2010). Dementia caregivers need to understand and prepare for the care giving role. They have to plan for care related activities, and adjust the home to make it suitable for the patient. Several care giving skills are required-to communicate with dementia patients, to help them, to cope with their challenging behaviours (example; anyone or more, such as wandering, sleep problem; insomnia or hypersomnia, restlessness, paranoia, agitation, aggression, hiding things and inappropriate behaviours) and to support them right through till the last stage of dementia, when patients are fully dependent. Coordination is required across various stakeholders. Caregivers may get tired and stressed, and may need help. Care is a full term charge on the caregiver since the patient can not be relied for his or her own care.

OBJECTIVES

To find out the level of stress among some primary dementia caregivers and to explore the detail of their care giving experience, with four major parameters on focus;personal details, roles, support system and coping. Also to asses the caregivers' burdenusing the -se parameters on a Caregivers Strain Index(Robinson B, 1983 / 85).

BACKDROP

Books and Journals

'No Aging in India' is a detailed investigation of mind and body in old age in four neighborhoods of the Indian city of Varanasi (Banaras) with events and processes around India and around the world. (Cohen, 2000).

'The Insight into Dementia Care in India' is a personal observation done in and around Kerala and it explores the care giving practices in India, coping among the caregivers and support system. The need of training to those who are already in health care field and importance of impartment of gerontology and dementia care training to increase the workforce were also suggested (Emmathy, 2009) 'In The Line of Alzhiemer's- mission continues', is a book written by a husband about prediagnostic signs shown by his spouse who is an Alzhiemer patient and detail of his care giving experience at each stage of disease. This book is on of first its kind in India (Brig: Bhattacharyya, 2009).

'Coping with Emotions and Stress in Alzhiemer's Caregivers; a resource list, is a small booklet published by National Institute on Ageing, 2004-2005. The book relates to number of advises for caregivers dealing with Alzhimier's disease patients (Clarkburg, 2005).

Caregiver's Stress Relief Advise for ALS is a book that deals with caregiver's stress. The major point is partnership between patients and caregivers, unless there is a good partnership on the part of the patient, caregiver will face much strain. The family members must understand this to give a good support in building a partnership between a caregiver and the patient (Mitsumoto, 2009).

Caregiver's Stress and Staff Support in Illnesses, Dying and Bereavement is a comprehensive, almost encyclopaedic in identifying the multitude of stresses that can affect the ability to maintain compassionate involvement (Renzenbrunk, 2011).

Taking Time for Me: How caregivers can effectively deal with stress, also deals with wholesomely how a caregiver can keep his/her stress free, cheerful, in good health and imaginative. This is a kind of book that helps the caregiver independently in a peaceful mind (Karr, 1992).

Stress Effect: a family caregiver's of Alzhiemer's disease, is a research work on the impact that family caregivers for a dementia patient has on the physical and mental health of the caregivers (Light, 1994).

Life with Clare: one caregiver's journey, is a story of one caregiver that started off with desire to help a loved one through a very trying time. The emerging emotions, very conflicting at times, made the journey difficult at times, very rewarding and satisfying at other times (Batamini, 2010).

Stress Reduction for Caregivers, is a book that deals with stress reduction particularly who are looking after dementia patients for a long time (Katz et al., 1999).

The 36 Hours Day, is a periodic print which has been widely circulated and read. It carries all questions regarding dementia and tries to answer them as far as practicable. It is a very handy for caregivers to explain the situations of dementia patients in a family that never have had a such a patient.

Alzhimier's Caregivers' Guide and Sourcebook, a book that deals with Alzhimier's disease, cures, symptoms and treatment. There are also advises to cope with stress (Grutezne, 2001).

Support Groups for Caregivers of Alzhimier's Patients: a historical view, aims to make a historical review of the use and study of support groups for family caregivers of Alzhiemer's patient, describing their main features, variations with special emphasis on data about their efficacy (Hornillos and Crespo, 2011).

Growing and Gaining through caring a loved one with dementia, is a journal which aims to investigate the gains experienced by family dementia caregivers. All caregivers interviewed reported of gain from care giving. The most common gain was personal growth, then relationship followed by spiritual gain, this research has shifted

from the conventional focus to more holistic approach (Netto, Jenny and Philips, 2009).

'The experience of burden in India, is which deals with caregivers' burdens of people living with dementia were interviewed to understand the caregivers' experience of burden using Clinical Dementia Rating Scale (CDRC), Burden Interviews and open ended questions, at National Institute of Mental Health and Neuroscience (NIMHN), Bangaluru. But no correlation between quality of relationship and low burden was observed. At the end the need to create more awareness about dementia in general public is discussed (Emmathy, Bhatti, Mukalel, 2006).

Continuity and loss: the caregiver's journey through dementia is a journal which focuses to understand the complexity of relationship in dementia care giving and how continuity and loss are subjective and how that relationship is maintained through shifting progressive of the disease (Gillies, 2011).

Coping and its relationship with quality of life with dementia caregivers, is a study done in Delhi, which focuses to understand the coping strategies and quality of life of the caregiver. They have found that both variables depend on characteristics of the caregiver and not on the severity of the patient's dementia (Pattanayak et al., 2011).

Coping with caring: profiles of caregiving by informal carers living with a loved one who has dementia. The study was done in Netherlands. The aim was to find out the care-giving experience, and the finding contributed to development of interventions to support informal caregivers (Kraijo et al., 2011).

Dignity work in dementia care-sketching a micro-ethical analysis is a study done in Sweden. The study is concerned with dignity in dementia care when staffs handle potential or actual challenging behaviour. Micro-ethical analysis is used (Nikku and Oruly, 2007).

Making progress in psychosocial research in dementia, is an article that describes the importance of greater research funding in dementia. It also focuses on issues of ethics, consent, research fatigue and pressure for the result (Steve Iliffe et al., 2008).

Development of a conceptual framework of positive aspects of care-giving in dementia, is a study done in Canada. It focuses on positive aspects of care giving and attempt to create innovative ways to support dementia caregivers (Carbonneau, Caron and Desrosiers., 2010).

Spousal dementia care-giving in the context of late-life remarriage is a study done in USA. The decision to take care of one's spouse, which is a late-life marriage was explored. It has more challenges due to ambiguous approach from adult children and other complexities (Sherman and Boss, 2007).

METHODOLOGY

The method applied is basically anthropological, 8/10 dementia care givers have been purposively selected using random sampling method. Thereafter case study method have been applied to find out how they are faring while care-giving. The eight (cases) caregivers'; five children (4 daughters, 1 daughter-in-law), three spouses (2 wives and 1 husband), whose loved one are clinically diagnosed with dementia. Most of them have engaged in care-giving for more than eight years. The purposively selected candidates have been interviewed one-to-one with 'Caregiver's Strain Index' along with thirteen open ended questions, except for one caregiver, who had chose to give the interview with a family member. The method of data collection was face-to-face interviews and participatory observation. The unit of observation was respective family and the unit of study was the primary care-giver of the patient.

There are various blocks of information of caregivers collected, in addition to that 13 questions in the Caregiver Strain Index, (Robinson, 1983/5); Identity (most of the care-givers want to remain anonymous to keep their loved one unknown) gender, age, marital status, educational qualification, his/her medical conditions(if any), family composition, relationship to the care-receiver, number of years involved in care giving and the type of difficulties (both physical and psychological) suffered by the caregivers.

The nature of relationship between carers and the care-receiver is explored in much detail as far as possible by using the self-framed questions, which focus to explore the four parameters; personal details of the primary care-giver, roles, support system and coping strategies while rendering care to a loved one with dementia.

TABLES AND ANALYSIS

It is already defined at the outset the meaning of care-giving, the types of dementia and the stress factor in dementia care-giving. Family forms the main pillar stone of dementia care and this is especially true in developing countries like India where institutional care and social services are almost non-existent in dementia care (Pattanayak et al., 2011). To understand the nature of stress suffered by such caregivers is very difficult to locate primarily, the families do not want to reveal their problems, secondly the caregivers within the family always feel shy of exposing their problems and the nature of strains, which is of course changing. The present worker however have managed to enlist 8 caregivers, seven females and one male to express their difficulties and analysed it in a systematic manner.

Table I (see annexure) shows the sociodemographic profile of the primary caregivers and it may be seen that majority are females along with one male belonging to different age groups. All of these caregivers are also from the family orbit; four of which are

daughters, one daughter-in-law, two wives and one husband. Predominance of females is quite compatible with national and global trend. Informal caregivers are mostly female and close family members on the whole.

Most of them have been delivering care for more than 8 years, among which the longest duration of care rendering is 17 years followed by 12, then 11, 9, 8, 7 and 6 years, respectively.

Six female caregivers (CG-2,3,4,5,6,8) are married and looking after their loved one with dementia within the family surrounding, in which two care-givers (CG-2 and 8) have regular family life and their corresponding husbands are patients; three caregivers (CG-3,4,5) are daughters and one (CG-o) is a daughter-in-law; One(CG-7) female caregiver is single and was looking after her mother, who expired recently and one(CG-l) male of 87 is taking care of his wife who is an Alzheimer's patient. Thus 5 caregivers are retired among which two(CG-4 and CG-6) had to leave their respective job to engage in care-giving, where as remaining five had reached their retirement age before they were involved in care-giving or they worked during the first few years when the care load was less. All caregivers are well educated and were good job holders. According to (Emmathy et al., 2006; Rammohan et al.,2002) education contributes to the well-being of the caregiver, because greater educated caregivers can obtain outside assistance and access community resource. They seem to have more diverse support network. But then education is one variable among so many others. Therefore)worker likes to keep education and financial status as controlled variables in the study. All of the caregivers are well educated and belong to the affluent section of the society.

Table 2(see annexure) shows the socio demographic profile of persons with dementia. Among the patients 5 are males and 3 are females. They fall within the age group of 67-86 years age; 4 are married and other 4 are widowed. All the persons with dementia are well educated and led a socially engaging and intellectual life.

Patients in the present frame of work are suffering from different types of dementia, ranging from Alzheimer's disease to Binswanger's disease. Most of the patients are in late middle or more advanced stage of the disease and need very a close supervision and care-giving. Their current level of functioning is as follows; One patient has expired recently after 7 years into dementia, one is in semi-coma stage, 2 are bedridden, 2 are in poor mobile stage, one can do ADL with assistance and one can do ADL with supervision. As per diagnosis PwD-1 is 17 years into Alzheimer, PwD-4 is 12 years and PwD-8 is 6 years into dementia. Few of them have other medical conditions like hypertension, arthritis and blood sugar.

DISCUSSIONS

Table 3(see annexure) shows the stress indicators of the caregivers. Among the 13 parameters, the highest strain; was confinement, 7 care-givers reported of that and the least reported strain were inconvenience and financial strain, which was reported by 4 care-giver each.

As per Robinson's 'Caregiver's Strain Index', there are 13 parameters with Yes and No option. Each Yes is equivalent to one score and score range from 0-13. All Primary caregivers dwell with the loved one with dementia under the same rooftop. Two of the caregivers(CG-5 and CG-6) have scored 13 out of 13 and CG-2 with 11 which indicates a very high level of stress. CG-5 is a daughter and CG-6 is a daughter-in-law, who have their own family and CG-2 is a wife, they scored 11 each. CG-4 has scored 8 and other three (CG-1, 7 and 8) have scored 6 each.

Every patient is special, so is how each of them deal with their functional declining and hence the manifestation of each one's subjective dealing in their behaviour. That is also very same with the caregivers, because perception of stress depends on many factors.

According to Boss, 1987 Part, 1988, coping depends on type of stress, availability of resource, perception and finally the response. But then they are few things which can be generalised, as per the patients current level of function. For example if the loved one with dementia can do activities of daily living (ADL) with supervision, the respective caregiver will not face physical strain or if the caregiver is a financially sound spouse of a family where his or her respective spouse is the patient, the care-giver is less likely to have other demands on time, especially to earn money. Stage of the patient's disease, seem to give a general overall view of difficulties usually manifested at that particular stage, but subjective difference of individual need to be considered. Patients taken care by above caregivers range from early middle stage to semi-coma. Their care-giving experience; early stage is characterised by gathering information about the disease, facing ambiguity to accept the diagnosis by hoping things would be better due to the absence of any physical change, learning the care-giving skills, hard way. Few longitudinal studies have found that care-giving is most stressful when it is a new role. With longer duration of care there is greater potential for adaptation. Middle stage is usually handling the difficult behaviors of the patient, taking safety measure and being in vigilance all the time. The ability to tolerate problem-behaviour actually increases as the disease progresses. The care-givers establish a daily routine that is not excessively burdensome (Emmathy, 2009). Late stage is focused on making life more comfortable for the patient and preparing oneself for the inevitable. A study by Mokenko's study, (1989) revealed that the meaning of care-giving is more important to care-giver's well being than the amount of care provided.

Quality of previous and present relationship relationship has an impact on care-giver's stress (Cantor et al., 2003; Kramer, 1993; Lyonette & Yardley, 2003). for example if the previous relationship was very affectionate and protective on the part of the patient. There might occur a role reversal i.e the daughter might assume the role of

the father and vice-versa, which can be harder to accept. However, mostly the good old memories of the loved one helps the care-giver to differentiate the person and the disease, which does have a positive affect as reported by CG-2,5, and 6. CG-8 reported that she is very glad to give care to her husband who had always been so loving and caring to her daughters and her as well.

CASE STUDIES

Acceptance of Diagnosis and Emotional Adjustments

Care-giver-1, who had a wonderful bond with the patient reported that the acceptance of loved one's condition came gradually, who has been rendering care for last 17 years.

" When the diagnosis of Alzheimer's disease was confirmed, I was not aware of how disease could progress since there was no outward deterioration. I assumed that AD is just little memory loss and occasional loss of temper, because her language was very coherent and so were other social skills. "

Care-giver-4, who did not share a very loving relationship with her mother, who is suffering from dementia, reported less emotional adjustment although the acceptance of the disease was gradual, who have been rendering care for last 12 years. In her own words:

" Though when she started acting stubborn and repetitive because of dementia, and I did not know it was because of dementia, I assumed it was just another way of her showing her natural tendency to control me. Our acceptance of her condition was gradual; though we medically understood the atrophy of the brain, we did not comprehend the extent of how it was impacting her behavior, and it took us time to understand how much dementia would be impacting all of us. "

Care-giver-5 had very close and loving relationship with the

patient(father) said that diagnosis made everything clear to them, who was in early middle stage then. In her own words: *" My mother was the first to complain about his change of personality. His moodiness, anger, suspicion, and confusion affected us profoundly, but diagnosis made everything clear. "*

Whether you shared a good relationship or not, the acceptance of such diagnosis come slowly and also the adjustments required to provide the best possible care through trial and error method. More so when care management is not available particularly designed for Indian tradition and culture. Those caregivers who have access to care management information designed for Americans or Europeans, need modification and check its positive results. But, general aims remain the same which is firstly, the safety of the patient; secondly providing care as per his or her preferences in a stimulating environment by making necessary changes as disease deteriorates. Jame A, a son care-giver in his own words "I find that a hug makes my dad feel more secure, so I try to give lots of hugs. (ADEAR,2009)"

Roles and Social Support Network

Social support and roles impact care-giving experience. There are three daughters(CG-3,4 &5) and one daughter-in-law(CG-6), who have other roles like one's career apart from care-giving and obligations to carry parallel, whereas remaining 4 caregivers do not. Having other family members along can be positive if they provide practical assistance, emotional support, appreciate and motivate the caregiver and reduces the likelihood of misunderstandings; which seemed to the case in CG-3, 5 and 6's.

For example Care-giver-5 has a wonderful family and a sister, who provide her with both emotional and practical support whenever required. In her own words; *"My family understands my difficulty, my sister who lives abroad keeps in touch and comes down whenever*

possible to give the respite care and rest are sympathetic and dole out advises"

Other family members share her other roles, like her mother-in-law and her husband provide care to her father-in-law who also requires full-time care.

But Care-giver-4 reported that presence of other family members only increased her strain. They did not accept the diagnosis, criticise her care-giving skills and disrupted the routine of the patient. She did not get any spiritual strength from god. In her own words;

'I was never religious and found no help in spiritual practice during the difficult times; I opted for a deep study of meditation, which gave me a solid mental framework to handle changes and emotions. I also got tired of people who acted religious and did nothing other than adding to my problems.'

Even though the whole family is involved in care to some extent, the major brunt is borne by one key caregiver. Sometimes, he or she may not get enough help from the rest of the family and occasionally have to face criticism (Shaji, Smitha, Lal, & Prience, 2003), as in the above case.

Care-giver-1, who lived with his spouse since their children are settled a far, reported that not having other members made him rely solely on their house maid. Being retired and living alone allowed him to become a full-time caregiver. Presence of good network and support from his children, relatives and friends has helped him. In his own words; *" My children's daily calls, emotional support, gathering information about the disease, supplying medicines (which are not available in India), providing respite care and also relatives and friends for their understanding and support. The caregivers' meet organised by Alzheimer's and Related Disorders Society of India (ARDSI) has given me both emotional and practical help. I remember feeling rejuvenated after those meetings"*

So, at the end it comes down to functionality of members and more importantly how the support recipient evaluate the existing roles and supports provided. The appraisal of gain and the appraisal of strain in care-giving are independent and have different impacts on well-being (Rapp & Chao, 2000). But the important factor is the extent of social network and the kind of social support one expects from the networking (Emmathy, 2009).

Personal Characteristics of the Care-giver

Stress seems quite prominent in dementia care-giving. But how people cope with stress may be more important than the stress itself (Lazarus & Folkman, 1991). May be that is why the personal characteristics of the caregiver plays the most important role in coping with stress. The strain of above individuals differ in degree which not necessarily correlates with degree of difficulties they faced, rather on how they dealt with the situation. 2 caregivers (CG-1 and 4) had faced most severe form of difficulties during their long duration of care-giving, but both of them have lower stress score of 6 and 8 respectively, as compared to some other caregivers. This might be because, they have acquired the required skills and now settled with an organised routine.

It is also influenced by whether the respective care-giver use appropriate coping strategy as applicable for the situation. Sometimes both emotional-focused and problem-focused can work together at a time. Caregiver-1 used problem-focused coping strategies like home-grown therapies to save the patient from exhaustion and himself from stress; 'giving exposure to familiar people and environment', which had reduced her agitation and restlessness, 'Reminiscence therapy' like framing her favourite photos on the shelf facing her chair, which reduce her agitation, getting violence and later served as a diversion tool, 'music therapy' too made the patient happy and she would sing along the song and dance to the tunes as well. He also used emotional-focused coping,

by accepting her reality, enjoying every joy she could give and learning to agree with her by taking necessary precautions which concerns her safety. He was content and grateful to other's understanding and support.

Care-giver-4 made all necessary compromises and changes to make her loved one comfortable and safe. She did what she had to do, which included moving away from few people who had a negative affect on the patient's condition, leaving her career and accepting the reality. When asked the caregiver what she see ahead with respect to care-giving and beyond. She said, "*I am not sure what I will do after my mother passes away. All these years, in order to carefor her without resentment, I have made it a point not think about my future(future after her death), so I do not see her as someone who is standing in the way of what I am looking forward to.*"

Care-giver-5, who had a high stress as per the index even though with availability of good support system, and a very good relationship with her father prior to the diagnosis. This finding correlates with another recent study done in Delhi. According to that, both coping and quality of life of care-givers did not differ according to the severity of dementia (Pattanayak et al., 2011). But stress level could also be due to the stage of the dementia and may also be influenced by the state of care-giver's mind at the time of interview.

The care-giver-care-receiver's relationship takes a new form in dementia care-giving as per the stage. However, even though the person with dementia can not remember anyone's name, the perception of a continuing connection helps to maintain the caregiver's involvement with their care-receiver (Carbonneau et al., 2010). Which seem to be the case in all the 8 care-givers, that have been interviewed.

OBSERVATION AND CONCLUSION

Public awareness about dementia is very low in India. Most primary care-givers are females which is compatible with the global trend. All care givers' face strain at some point of care-giving. Some strains are subjective to the stage of dementia. Education and coping seem to have a positive correlation, because education gives more access to information and other available resources. Good social support and cordial relationship with the loved one prior to dementia act as a buffer. Finding meaning in care-giving and perception of continuity of the relationship is vital for the care-giver's

well- being and motivation. The overall stress is governed by combination of intensity, duration and perception of the stressful event, but primarily by the caregiver's adjustment and resilience.

From this micro study it can be said that primary care-givers' stress in dementia is prominent. Care-giving is a subjective experience, hence cannot be generalized. Finally every care-giver has to find his or her own coping strategy to deal with the difficulties at each stage.

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TABLE -1 SOCIODEMOGRAPHIC PROFILE OF THE CAREGIVERS

Caregiver's Identity	CG-1	CG-2	CG-3	CG-4	CG-5	CG-6	CG-7	CG-8
Gender	M	F	F	F	F	F	F	F
Age	87	64	46	54	46	50	42	66
Marital Status	Married	Married	Married	Married	Married	Married	Single	Married
Edu. Qualification	B. Engineer	M.A., B.Ed.	M.A.	B.Tech MBA	B.Sc, B.A. MBA	C.A.	M. Com	M. Sc, B.Ed
Other Profession	Retired	Retired	Govt. Employee	No	Runs a family Business	Retired	Accountant	Retired
Relationship with PwD	Husband	Wife	Daughter; Father	Daughter; Mother	Daughter; father	Daughter-n-law, mother-in-law	Daughter, Father	Wife
Years engaged in Care	17	11	9	12	8	8	7	6

Legends: CG: Caregiver, C-A Chartered Accountant

Table - 2 Sociodemographic profile of Persons with Dementia

Patient's Identity	PwD-1	PwD-2	PwD-3	PwD-4	PwD-5	PwD-6	PwD-7	PwD-8
Gender	F	M	M	F	M	F	M	M
Age	76	67	86	86	76	75	80	73
Marital Status	Married	Married	Married	Widow	Widower	Widow	Widow	Married
Edu. Qualification	M. A.	M. Eng	B. Com	Double M. A.	B.Sc.	B.A.	B.A. LLB	B. Eng
Type of Dementia	AD	Lewy Body	AD	Dementia	Fronto-temporal with AD	AD	Binswanger's diseases, VaD	AD
Current Status	Semi-coma	Poor mobile	ADL with little assistance	Bedridden	Poor mobility	Bedridden	Deceased	ADL with assistance
Other Medical conditions	None	None	Blood Sugar	Blood Sugar and Hypertension	None	Arthritis	Blood Pressure	Blood Sugar

Legends: PwD- Person with dementia, ADL - Activities of Daily Living, AD - Alzheimer's disease, VaD- Vascular dementia

Table - 3 shows the Stress indicators of the caregivers

	CG-1	CG-2	CG-3	CG-4	CG-5	CG-6	CG-7	CG-8
Sleep Disturbance	No	Yes	No	No	Yes	Yes	Yes	Yes
Inconvenience	No	Yes	No	Yes	Yes	Yes	No	No
Physical strain	Yes	No	No	Yes	Yes	Yes	Yes	Yes
Confinement	Yes	No						
Family Adjustment	No	Yes	No	Yes	Yes	Yes	Yes	No
Change in Personal plans	No	Yes	No	Yes	Yes	Yes	Yes	No
Other demands on time	Yes	No	Yes	No	Yes	Yes	No	Yes
Emotional Adjustments	Yes	Yes	Yes	No	Yes	Yes	No	Yes
Certain upsetting behaviours	No	Yes	Yes	No	Yes	Yes	No	Yes
Change of patient's peronality	No	Yes	Yes	Yes	Yes	Yes	No	No
Work Adjustments	No	Yes	No	Yes	Yes	Yes	Yes	Yes
Financial strain	No	Yes	Yes	No	Yes	Yes	No	No
Complete overwhelmment	Yes	Yes	No	Yes	Yes	Yes	No	No
Total score	6	11	6	8	13	13	6	6

Caregiver's Strain Index (Robinson, 1983/85)

Impact of Environment Pollution on Elders

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ABSTRACT

According to the United Nations Department of Economic and Social Affairs, one out of every ten people on the planet is now 60 years of age or older. If the current trend of lowering birth rates and lowering death rates continues, by the year 2050 one out of five people will be aged 60 years or older and by 2150, one out of every three people will be aged 60 years or older.

The environmental problems in India are growing rapidly. The increasing economic development and rapidly growing population is putting a strain on the environment, infrastructure and the country's natural resources. Similarly Industrial pollution, soil erosion, deforestation, rapid industrialization, urbanization land degradation and over exploitation of country's resources have been increasing the problem of environment pollution. India is now world's third biggest carbon dioxide emitting nation after China and the U.S. (2006). Empirical evidence showed that environmental pollutants trigger the production of an inflammatory enzyme that destabilizes cellular processes, causes cells to deteriorate prematurely. Environmental factors are also the cause of many diseases in old age. In other words pollution and ageing work together to make people live shorter, less healthy lives. Therefore attempt has been made to assess the effect of environment pollution on elders and to suggest suitable measure to check it.

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According to the United Nations Department of Economic and Social Affairs, one out of every ten people on the planet is now 60 years of age or older. If the current trend of lowering birth rates and lowering death rates continues, by the year 2050 one out of five people will be aged 60 years or older and by 2150, one out of every three people will be aged 60 years or older. Additionally, the oldest old are the most rapidly expanding segment of the elderly population. Currently, the oldest old make up 11 percent of the 60+ age group and will grow to 19 percent by 2050.

Indian population has approximately tripled during the last 50 years, but the number of elderly Indians has increased more than fourfold. The 2001 census has shown that the elderly population (60+) of India accounted for 77 million and census 2011 projections indicate that elderly population has crossed the 100 million mark. It took more than 100 years for the aged population to double in most of the countries in the world, but in India it has doubled in just 20 years. The life expectancy has also gone up to over 70 years today. Better medical facilities, care and liberal family planning policies made the elderly the fastest growing section of the society in India.

Ageing is an inevitable truth, a reality that has been a thorn in the flesh for mankind. Man has been trying to find out ways to avoid and prevent ageing and has tried many ways evil or good, 'to accomplish the same, the result has always been – defeat'. From sacrifices to lab research, it's all going on. (Garg, A.D., 2005).

The environmental problems in India are growing rapidly. The increasing economic development and rapidly growing population that has taken the country from 300 million people in 1947 to more than one billion i.e. 1.21 billion people today is putting a strain on the environment, infrastructure and the country's natural resources. Industrial pollution, soil erosion, deforestation, rapid

industrialization, urbanization and land degradation are all worsening problems. Overexploitation of country's resources be it land or water and the industrialization process has resulted environmental degradation of resources. Environmental pollution is one of the most serious problem facing humanity and other life forms on our planet today.

India is now world's third biggest carbondioxide emitting nation after China and the U.S. (2006).

Ageing and Environment

Ageing is a universal phenomenon referred to as slow, progressive, structural and functional change that takes place at cellular tissue and organ levels. Such alternations decrease an organism's ability to with stand environmental stress and increase its descent towards death. Most of us view ageing as a disease whose symptoms include gradual retardation of eyesight, hearing, the immune system, vital capacity, smell, taste or loss of hair, memory, intelligence, muscles and reduction in properties of skin, heart, kidneys, coordination of skills and others etc. Functional signs of ageing generally include reduction in the carrying capacity of oxygen by the blood, reduction of blood volume, while cellular-level changes include changes in cellular enzymes, chromosomal aberrations and defective protein synthesis (Garg, A.D. 2005).

As soon as ageing strikes we start searching for means to mark ageing. Medicine companies earn in billion from anti ageing creams and medicines. Yet the cure is far from satisfactory we actually forget that our own activities of pollution are largely the reason behind pre-mature ageing. It's true that what ever we do against nature falls back against our own existences. It's surprising to note how environmental pollution can cause ageing in such a direct manner. (Garg, A.D. 2005).

Effects of environment pollution

The effects of environmental toxins on human body have been studied intensely in recent years. Overwhelming evidence now suggests that pollutants cause disease and accelerate the ageing process by interfering with normal metabolism at the cellular level. Empirical evidence showed that environmental pollutants trigger the production of an inflammatory enzyme that destabilizes cellular processes and causes cells to deteriorate prematurely. In other words pollution and ageing work together to make people live shorter, less healthy lives, and the mechanisms that trigger this acceleration are now much more widely and thoroughly understood. Science has known for years that cellular break down is the primary cause of ageing, but until recently it was not well known how this break down was triggered. Now it is clear that environmental pollution is a major trigger.

Air Pollution

It is now a fact, air pollution effects and causes millions of deaths. Outdoor air pollution effects and causes an estimated 800,000 deaths each year. Indoor air pollution effects and causes an additional 1.6 million premature deaths. Air pollution is the single greatest environmental threat to human health. According to the Canadian Medical Association, air pollution causes an estimated 21,000 deaths. In USA, air pollution causes 200,000 deaths each year.

People over 65 years old are the ones mostly affected. This year alone this population segment will count for 80% of premature deaths. Considering the ageing trend of the population, it means that there will be an important increase in the future air pollution causes and effects on health damages.

The mid-west population, where heavy industries are located, and population of big cities like New-York, will have the biggest share of

pre-mature and serious deaths. Rural regions are also affected because air pollution is dumped in those areas by wind. Over this death rate increase, other deplorable consequences can be forecast. For example, it is estimated that 180,000 people suffering from air pollution shall be admitted to hospital, this is an increase of 62% in the last 20 years and for the same period, the increase for the people **over 65 years old** will reach **102%**.

The world Health Organization estimates that about two million people die pre-maturely every year as a result of air pollution, while many more suffer from breathing ailments, heart disease, lung infections and even cancer. Five pesticides and microscopic dust from coal or wood fires and unfiltered diesel engine are rated as one of the most lethal forms on air pollution caused by industry, transport, household heating cooking and ageing coal or oil fired power stations.

There are four reasons of air pollution ; - emission from vehicles, thermal power plants, industries and refineries. The problem of indoor air pollution in rural areas and urban slums has increased.

In India, Bangalore holds the title of being the asthma capital of the country. Studies estimate that 10 per cent of Bangalore's 60 lakh population and over 50 percent of the children and below 13 years suffer from air pollution related ailments. ([http:// www. gits4u. com /envo /envo4.gtm.](http://www.gits4u.com/envo/envo4.gtm.))(2000).

Environment pollution alongwith stress can speed up the ageing process in people. It makes them prone to diseases at a very young age and aggravates the problem gradually.

One of the greatest disadvantages of the industrial revolution in the world is the environmental degradation with pollution. There is no dearth of sources of pollution that leave a wide range of toxicants and irritants in the air. These substances could be more than just harmful with repeated and prolonged exposure and can pose same dangerous health hazards.

According to report on 'Environmental Threats to Healthy Ageing' (2009) environmental factors are key drivers in brain diseases i.e. Alzheimer's and Parkinson's diseases. According to this report, environmental factors like dietary patterns, toxic chemical exposures, inadequate exercise, socio-eco stress and other factors. These influences can begin in the womb and continue throughout life, setting the stage for the later development of neuro degenerative as well as other chronic diseases.

In addition, the report describes the substantial emerging evidence that, collectively, these environmental factors after biochemical pathways at the cellular and subcellular levels. These alterations fuel Alzheimer's and Parkinson's disease, as well as other chronic illness offered to in the report as the 'Western disease cluster' – diabetes, obesity, cardio vascular disease and metabolic syndrome. Each of these diseases in turn increases the risk of Alzheimer's.

This collection of diseases is being driven by dramatic alternation over the past 50-100 years in the U.S. food supply, an increasingly sedentary lifestyle, and exposure to toxic chemicals.

The scientific analysis in the report draws attention to several specific environmental risk factors in the development of dementia, Alzheimer's disease and Parkinson's disease. They include among others:

Lead: Recent evidence links environmental lead exposure in the community to increased risk of cognitive impairment. For example, a recent study of elderly men found that the highest lead-exposed groups had on an average an additional 15 years of cognitive ageing, compared to the lowest lead-exposure group. Several animal studies suggest that exposures in infancy and childhood may sharply increase the risk of Alzheimer's disease decades later. Evidence also implicates lead in increasing risk for Parkinson's disease as well.

Air Pollution: Recent studies show that air pollution is harmful to the brain, in addition to the lungs, heart, nose and blood vessels. This evidence is drawn from studies of brains of people living in clean air cities. These studies found evidence starting at young ages of inflammation and cellular damage associated with both early Alzheimer's and Parkinson's disease.

Pesticide: A large body of data links exposure to a variety of pesticides with increased risks for Parkinson's disease. Evidence also links chronic low dose exposure to a number of pesticides – primarily in the work setting – with subsequent cognitive decline, such as impaired memory and attention. A study in France found that a history of occupational exposure to pesticides more than doubled the risk of developing Alzheimer's disease. Exposure to some pesticides has also been linked to dramatically increased risks for diabetes, prediabetes and metabolic syndrome.

Dietary risk factors : Diet and nutrition as emerging as critical factors in brain health and health in general. A variety of nutrients increase the risk of disease.

As many as 51 Indian cities have extremely high air pollution. Patna, Lucknow, Raipur, Faridabad and Ahmedabad topping the list. An environment and forest report, released on Sept. 14, 2007 has identified 51 cities that do not meet the prescribed Respirable Particulate Matter.

Mahatma Gandhi had said that nature has enough to satisfy everyone's need but has not enough to satisfy man's greed.

Indoor air pollution: Indoor air pollution is the most important cause of chronic obstructive pulmonary disease (COPD) in India, says a prevalence study conducted by Pune based chest Research Foundation (CRF) and the Imperial College, London in Nov. 2010. Over 700 million people in India suffer from high levels of indoor air pollution affecting women.

Pollution and ageing: All types of pollution ultimately affect organisms in molecular form in the form of free radicate. Free radicates are molecules having an unpaired electron that's capable of independent existence. These are extremely reactive and short-timed. These radicates react with biological molecules and modify them. Industries, petroleum refineries, industrial processors, thermal power stations, automobiles produce many harmful products. These and other polluting bodies produce gases like carbon monoxide (CO), hydrogen cynide nitrozen oxide (No), phosgene (CoCl₂) sulphur compound (SO₂H₂S H₂SO₄) and many others.

The sulphur dioxide content of new Delhi has reached 0.233 ppm whereas permissible limits (as in USA) are only 0.1 ppm. So₂ is responsible for chest constriction, headache etc. carbon monoxide is another dangerous compound. It reduces the oxygen –carrying capacity of blood.

No or No₂ produced by motor vehicle exhausts, soft coal etc. is responsible for pulmonary discomfort, hemorrhage and many serious respiratory ailments. According to a report New Delhi, is the most polluted city among the Asian metropolitan cities. Mumbai ranks fifth in the list just behind Kolkata (Garge A.D. 2005).

Today Greece, Japan, Maxico, Sweden and Poland are amongst the most air pollution affected areas. A research has shown that Greece, Italy, Sweden and Japan are amongst the top 5 nations affected the most by ageing problems. Italy ranks first followed by Sweden, Greece, Belgium and Japan according to the survey of the National Research Council of USA. These statistics give an astonishing exposure of the dreadful situation. All the nations listed above are worst hit by pollution of oxides of nitrogen expelled industries and automobiles. Nitrogen dioxide (NO₂) plays an evil trick in Earth's atmosphere.

'Keep Environment Clean – Delay Ageing': premature ageing can

also be accompanied by cancer, cardiac ailments, Alzheimer's dementia, Parkinson's disease, ageing immune deficiency, arthritis, cataract, oest eoporosis, arteriosclcerosis, benign prostatic, hyperplasia, xeroderma pigmentosum etc. Your every automobile or industrial work could be the reason behind your deterioration. Elders can create awareness to create a pollution free world. This can save you from premature ageing and ensure a healthy old age later. . Remember that your awareness to create a pollution free world can only save you from premature ageing and ensure a healthy old age later. (Garg, A.D. 2005) Elders should follow the legislative measures like the motor vehicles Act, 1988. The Environment Protection Act, 1986 and the Air Prevention and control of Pollution Act, 1981 (amended in 1987) laid down by the Government of India.

Elders can conserve and promote the environment in multivariate ways like; they can use the solar devices in homes to save energy and to reduce the air pollution. They can do indoor planting, can promote the use of organic pesticides, use of eco-friendly technologies, use of exhaust fan in the kitchen, can recycled the waste .by use of inorganic waste for making compost, use the domestic waste water for gardening etc , can use energy efficient products, can replace conventional light bulbs with compact fluorescents in the home and must make minimum use of electricity and polythin bags . They can help in the National Campaign of 'Grow More Tree . There is need to follow 3 Rs. system for environment conservation and promotion at all level i.e. reduce, re-use and re-cycle.

Growing population is continuously putting a strain on the country's resources therefore, they can promote small family norms among younger generation to check the population explosion in the country. Finally they can diffuse the value for conservation of environment among children, family members and kin groups. It will check the environment pollution and the problem of premature ageing and to enjoy healthy life in twilight years.

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MODELLING OF A SINGLE INDEX TO MEASURE THE WELL-BEING OF THE ELDERLY

S. K. Chakravarty *

ABSTRACT

Population ageing is widespread across the world. It is most advanced in the highly developed countries. Basic as well as innovative programmes for the well-being of the elderly is a common concern in the developed and the developing societies.

Ingress of ageing occurs in life within an envelope of several problems, each one may be treated as a variable for any mathematical analysis. But without having one Single Index, measurement of the impact of any rehabilitation programme is very complex as it involves several variables of different units.

This study improvises the modelling of Single Index to measure the well-being of the elderly. This will provide a handy tool for the planners to deploy resources and draw the action plan in right perspective.

Key Words : Single Index, Modelling, Population Ageing, Impact Rehabilitation

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Introduction

Population ageing is widespread across the world. It is most advanced in the highly developed countries. However the oxford institute of population ageing¹ has concluded that population ageing will have the greatest future impact in Asia- specially in a populous country like India. The demographic profile² depicts that in the years 2000 – 2050 the overall population in India will grow by 55% where as population of people in there 60 years and above will increase by 326% and those in the age group of 80+ by 700 % the fastest growing group – Table 1.

Table -1

YEARS	TOTAL POPULATION	60+ Mn	80+ Mn
2000	1008	76	6
2050	1572	324	48

SOURCE : NPSC (India)- 2011

As a result of the current ageing scenario, there is a need to address all aspects of the Problems of Ageing & the Aged, namely, financial, health, shelter, friendliness to the various interfaces³⁻⁷ of the society, care giving & technology intervention. Problems in any of these areas have impact on the well-being of the elderly.

Increasing life span also brings chronic functional disabilities creating a need for assistance required by the elderly to manage simple chores. Lack of care giving emerges as a prime parameter in the measure of the well-being as old becomes older & older.

Single Index Modelling

Ageing ingresses in life within an envelope of many problems, each one is a variable in terms of mathematics. Problems of the elderly

population is global and the welfare measures are also receiving the concern of policy makers all over the world. However, it is really difficult to make assessment of any welfare application in the society without having one Index. Measuring the changes over all the variables are impractical and not tenable.

Each of the problems of ageing is a variable. There are many variables with proper weightages to define the well-being for the Aged.

During this study, the author has reviewed the definition and measurement of the well-being of elderly in all published materials under REFERENCES. No one so far has defined a Single Index for the well-being of the older persons.

Multi-dimensionality of the issue in relation to different intervention effects have been reviewed in detail.⁸⁻¹¹

In formulating the single index following parameters have taken care of –

Independent life

Home help makes life easier

Community help/Municipal help/GP home health services should be priority in the action plans for any rehabilitation programme.

Increasing frailty, reduced mobility may be compensated by technology intervention.

Pension scheme for the aged need to be defined and redefined (where it exists).

Sampling Frame

In order to carry out the process of formulations, author (for the sake of convenience) selected Athalia, in GP-II, Singur., this is a village with urban facilities at the fringe of Kolkata Metropolis.

The total population of Athalia Village is 800. The population of above '60' is 28. This group belongs to middleclass mostly; (20 out of 28) whereas 8 out of 28 are living below poverty line.

Author found that communication with the group below poverty line is difficult in framing any perception. Thus, respondents for the basic material of formulation remains limited to 20 only.

Formulation of the Single Index (SI)

The genesis of the formulation is the selection of prime variables to define the Index, their weightages and the mathematics to convert the raw variable, say X, into a unit – free index between 0 and 1. This technique allows different indices to be added. The formula used is given below.

$$X \text{ (Index)} = \frac{X - X(\text{MIN})}{X(\text{MAX}) - X(\text{MIN})} \quad \text{Equation(1)}$$

Where X (MAX) and X(MIN) are the highest and the lowest values of the variable X. Value of X lies between 1 and 0. 1 indicates complete fulfillment, 0 indicates total deprivation.

Selection of Variables

This study reveals that at least three basic variables should be considered for an inclusive definition of the Single Index for the well-being of the aged. They are – Finance, Health (Mental, Physical) & Care Giving of any sort.

Above said variables are superset of many elemental variables ,

Mathematically, $X = F(x_1, x_2, x_3, \dots)$. This point would be cleared through Data Sheet. (Placed in the APPENDIX)

Let us denote the variables Finance, Health and Care giving as X, Y, Z

Finally the Single Index SI for the in the well-being Twilight Years of Life is derived from the Geometric Mean of the three Normalized Indices

$$SI = \sqrt[3]{X \cdot Y \cdot Z}$$

Measurement Technique for the Variables of Different Units

Variables selected for Index are normalized by Equation

$$X = \frac{X - X[\text{MIN}]}{X[\text{MAX}] - X[\text{MIN}]}$$

Each of the three variable X, Y & Z are Superset ;. they have several elements as indicated in the Questionnaire Schedule

Measurement Technique adopted is 'Binary Response' – Yes (1), No (0). Thus the each Super Set Normalized Variable results into series of 1s and 0s. Count of 1s and 0s gives the value of the variable measured in Number (always less than 1). Maximum value of any normalized variable is 1 and minimum value is 0.

Deliverables – Importance of Single Index (SI) Concept

- o Without one Index, measurement of the impact of any rehabilitation program of my short is complex as it involves several variables of different units.
- o Single Index for well-being of the elderly is a handy tool for

the planners to deploy resources and draw action plan in right perspective.

- o SI extends the horizon of Sociological studies in time domain, regional domain, domain of different states and countries.
- o Equal weightage given to variables X, Y & Z may be debated. Whether the variables – Finance, Health & Care giving are the only variables, may also be challenged. But more we do so, the anatomy of SI will be consolidated, mathematical modeling will remain unchanged.

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APPENDIX

Patients Name :		Age :		Date	
Address :					
HEALTH CARE STATUS		CARE GIVING		FINANCIAL STATUS	
1.Joint Pain	2.Eye Sight	3.Hearing Ability	4.Blood Sugar Level	5.Blood Pressure	6. Other Diseases
1.Adequate Income		2.Social Support		3.Hapless	
4.Family Support		Remarks :			

RESULTS

	HEALTH STATUS						CARE GIVING			FINANCE				SI
	1	2	3	4	5	6	1	2	3	1	2	3	4	
r ₁	1	1	1	0	0	0	1	1	0	1	0	0	0	.377
r ₂	0	1	1	0	1	1	1	0	0	1	0	0	0	.377
r ₃	0	1	1	0	1	1	1	0	1	0	0	0	1	.533
r ₄	0	0	0	0	0	1	1	0	0	1	1	0	1	.333
r ₅	0	1	1	1	1	0	1	0	1	0	0	1	1	.611
r ₆	0	1	1	0	0	0	1	0	0	1	0	1	0	.388
r ₇	1	1	1	1	1	0	1	0	0	1	0	0	1	.666
r ₈	1	1	1	0	1	1	1	1	0	1	0	0	1	.666
r ₉	0	1	0	1	0	1	1	0	0	1	0	0	1	.444
r ₁₀	1	0	1	1	1	1	1	1	0	1	1	1	0	.666
r ₁₁	0	1	1	1	1	1	1	1	0	1	1	1	0	.333
r ₁₂	0	1	1	1	1	1	1	1	0	1	1	0	0	.555
r ₁₃	1	1	1	0	1	1	1	1	0	1	1	0	1	.666
r ₁₄	0	1	1	1	1	1	1	1	0	1	1	0	1	.666
r ₁₅	0	0	0	1	1	0	1	0	1	1	0	0	0	.388
r ₁₆	0	0	1	1	0	0	1	1	0	0	1	1	0	.444
r ₁₇	1	0	1	0	0	0	1	0	0	0	1	0	0	.333
r ₁₈	0	0	1	0	0	1	1	0	1	0	1	0	0	
r ₁₉	0	0	0	1	0	0	1	1	0	0	0	1	1	
r ₂₀	0	0	0	0	0	0	0	1	1	1	1	0	1	
r ₂₁														
r ₂₂														
r ₂₃														
r ₂₄														
r ₂₅														
r ₂₆														
r ₂₇														
r ₂₈														
	HEALTH STATUS						CARE GIVING			FINANCIAL STATUS				
	1 = Joint pain 2 = Eye Sight 3 = Hearing ability 4 = Blood Sugar (Low = L) (High = H)						1 = Family Care 2 = Community Care 3 = Social Support			1 = Income Adequate 2 = Social Support 3 = Hopeless				
	5 = Blood Pressure (Low = L) (High = H)									4 = Family Support				
	6 = Other Diseases						Care giving : 1 = Yes, 0 = No Health Status : 1 = Good, 0 = Bad Financial Status : 1 good, 0 = Bad							