

INDEPENDENCE IN OLD AGE

WITH SPECIAL FOCUS ON

LONG-TERM & PALLIATIVE CARE IN INDIA



**A
NATIONAL STUDY
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An Agewell Initiative Under
RESEARCH & ADVOCACY CENTRE
(For Needs & Rights of Older people)

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INTRODUCTION

Population aging is a global phenomenon, and India is no exception. Indian population has approximately tripled during the last 5 decades, but the number of elderly Indians has increased almost fourfold. The 2011 census has shown that the elderly (60+) population of India accounts for 98.3 million. 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 as a result today has also gone up to over 70 years. Today India has 130 million+ elderly and better medical facilities, care and liberal family planning policies, the elderly have become the fastest growing section of the society in India.

Older persons have equal rights to autonomy and independence in India, but due to their inability to live on their own & various other factors, sometimes their autonomy and independence is violated by their family members/caregivers and others.

The well-being of older persons is mandated in the Constitution of India under Article 41: "The state shall, within the limits of its economic capacity and development, make effective provision for securing the right to public assistance in cases of old age. The Right to Equality is guaranteed by the Constitution as a fundamental right. Social security is the concurrent responsibility of the central and state governments." National Policy on Older Persons also aims to create awareness regarding elderly persons to help them lead a productive and independent life.

Though it is important to respect autonomy for seniors who retain competence, not every older adult is able or willing to take on responsibility for important decision making. Patients who suffer from even moderate dementia are limited in their capacity to make choices that are in their best interests.



Family is the most cherished social institution in India and an important as well as non-formal social security for the old. Larger number of older persons stays with one or more of their children, particularly when independent living is no longer feasible.

Older persons of India are frequently victims of insidious stereotypes, negative attitudes, and utter abuse. It is common to force people to retire at a designated age, no matter what their state of health and capacities and capabilities are. Lack of physical infrastructure is a major deterrent for providing comfort to the aged. Many older persons need better access to physical infrastructure, both in their own homes and in public spaces.

Due to the emerging prevalence of nuclear family set-ups in recent years, older persons are likely to be exposed to emotional, physical and financial insecurity in the years to come. Family care for the elderly seems likely to decrease in the future with the economic development of the nation and modernization.

Social isolation and loneliness is creeping into the lives of older people. Elderly sensitive insurance cover is virtually non-existent in India. Needs and problems of elderly are generally ignored since the government classifies old people based on caste and other socio cultural dimensions.

Managing home care for the elderly is a massive challenge as multiple service providers – nursing agencies, physiotherapists and medical suppliers – are small scale, unorganized and therefore extend incomplete care. In India, health insurance coverage is essentially limited to hospitalization. The concept of geriatric care has remained a neglected area of medicine so far in the country.

Older persons living with their families are mainly dependent on the economic capability of their family unit for their economic security and well being. Majority of older persons often do not have financial protection such as sufficient pension and other form of social security in India. The single most pressing challenge to the welfare of older person is poverty, which is a multiplier of risk for abuse. Due to their financial dependence, older persons are most vulnerable to infections/old age related ailments and have low priority for their own health.

It is important to ascertain the social aspects concerning aged in the country as they go through the process of ageing. Increased life expectancy, rapid urbanization and lifestyle changes have led to the emergence of varied problems for the older persons in India.

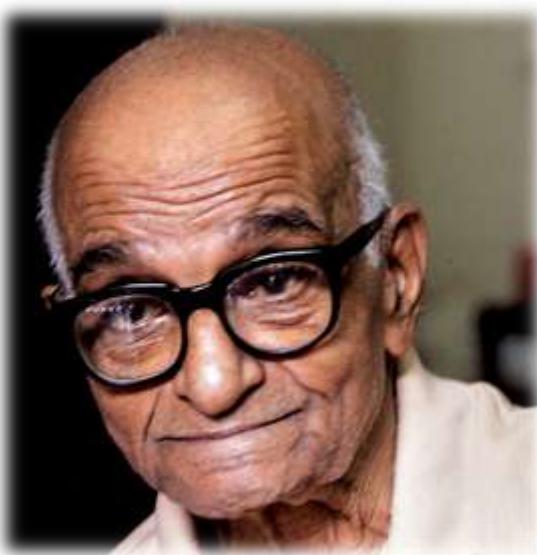


OVERVIEW

Long-term and Palliative care

Legal and policy frameworks

The moral duty to look after the parents and provide them with long-term care is recognized by all individuals across multiple societies in India. However, so far as actual care is concerned, the position and extent of such self-imposed liability vary from community to community. The statutory provision for maintenance of parents under Hindu personal law is contained in the Hindu Adoption and Maintenance Act, 1956. According to Muslim law children of older persons are bound to maintain their needy parents. The Christians and Parsis have no personal laws providing for maintenance for the parents. However, older persons who wish to seek maintenance can apply under provisions of the Criminal Procedure Code, 1973. In 1999 the Government of India adopted the National Policy for Older Persons, in order to accelerate welfare measures and empower the elderly.



Further, in 2007, the Indian parliament enacted a dedicated law titled *Maintenance and Welfare of Parents and Senior Citizens Act, 2007* to deal with the concerns of older persons in India. Under the various legal frameworks, many services and support mechanism are covered, viz. Provisions of old age pension, Old Age Homes, Specialized care for elderly, concessions and rebates in various services, social security, etc.

National Program for the Health-Care for the Elderly (NPHCE)

The Government of India has started National Program for the Health-Care for the Elderly (NPHCE) for providing an easy access to promotional, preventive, curative and rehabilitative services through community based primary health-care (PHC). Identifying health problems among the elderly and providing appropriate health interventions in the community with a strong referral backup support. It would be building capacity of the medical and paramedical professionals as well as the care-takers within the family for providing health-care to the senior citizen.

Palliative Care in India

The concept of palliative care is relatively new to India. In 1975, the Government of India initiated a National Cancer Control Program, which can be termed as the first step towards palliative care in India.

Being a tradition based society providing palliative care and end-of-life care is a common social and moral responsibility of people in India. Such care is classified under human rights of older persons. However, several studies suggest that violation of human rights of older persons, particularly with no social security/ financial independence in old age is on the rise.

Though providing long-term and palliative care to older persons comes in purview of family responsibilities in India, it is observed that financially independent older persons or older persons with high net-worth or having property entitlements in their name are comparatively treated well by their family. Majority of older persons with no / inadequate source of income in old age are prone to neglect and their healthcare, financial and social needs & requirements remain unaddressed.



Human rights of older persons, particularly older women remain vulnerable due to various factors like limited social interaction, disability, restricted mobility, dependence on family members, marginalization, etc.

The Government of India has also included palliative care in National Health Policy 2017. Some major features relevant to palliative care are:

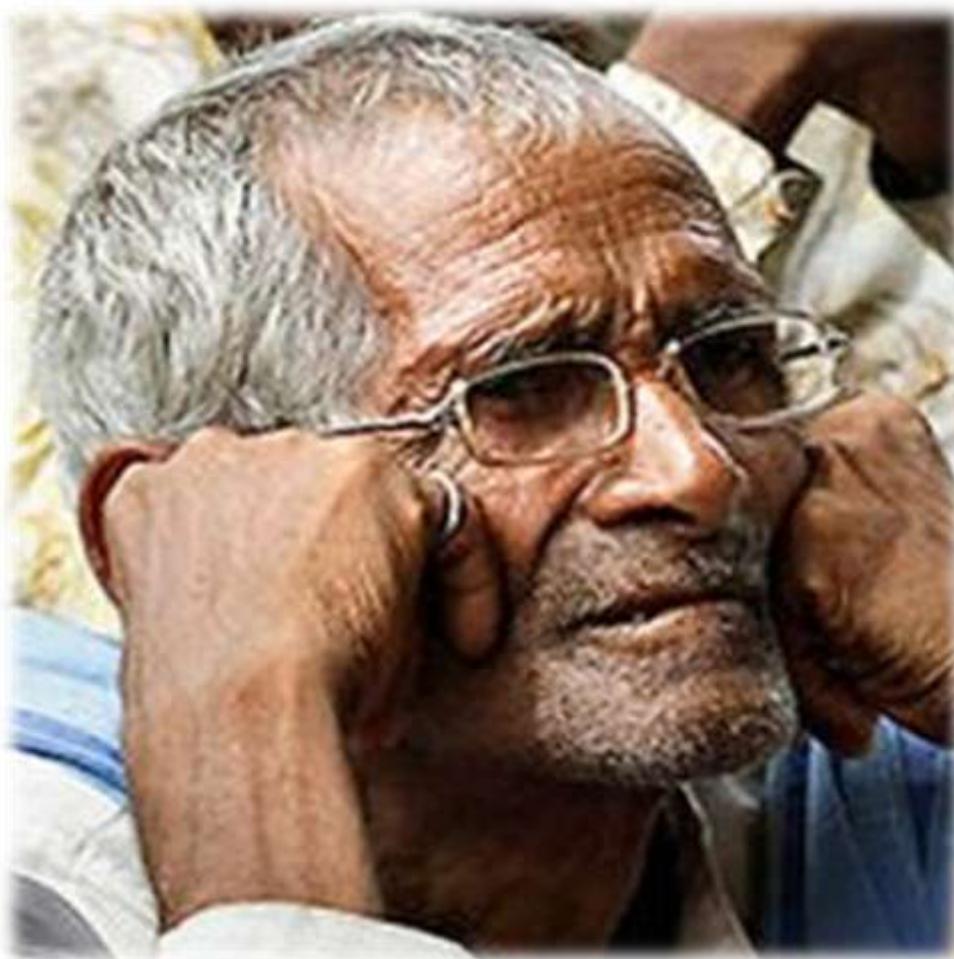
- The objectives mention specifically, “Improve health status through concerted policy action in all sectors and expand preventive, promotive, curative, palliative and rehabilitative services provided through the public health sector with focus on quality.”
- Community or home-based palliative care is included among the responsibilities of frontline health workers.
- Palliative care is mentioned as one essential feature of primary health care.
- In child and adolescent’s health, district hospitals have been specifically asked to provide palliative care.
- The policy recognizes the growing need for palliative and rehabilitative care for all geriatric illnesses and advocates for continuity of care across all levels.
- It recommends starting specialized nursing training courses in areas including “palliative care and care of the terminally ill”.
- In primary health care, particularly in urban health care, health and wellness centers are to be developed and they are to include palliative care.
- Right to healthcare is mentioned as covering ‘a wide canvas, encompassing issues of preventive, curative, rehabilitative and palliative healthcare across rural and urban areas’.



- The policy recommends integration of medical and paramedical education with service delivery systems.

Home-based palliative care services are becoming increasingly popular with care being taken to the doorstep of the elderly patients. Ideally, this is where people are most comfortable at the end of their lives, surrounded by their loved ones. It is also well suited to traditional conditions in India where a family member is usually available and willing to nurse the ailing family member.

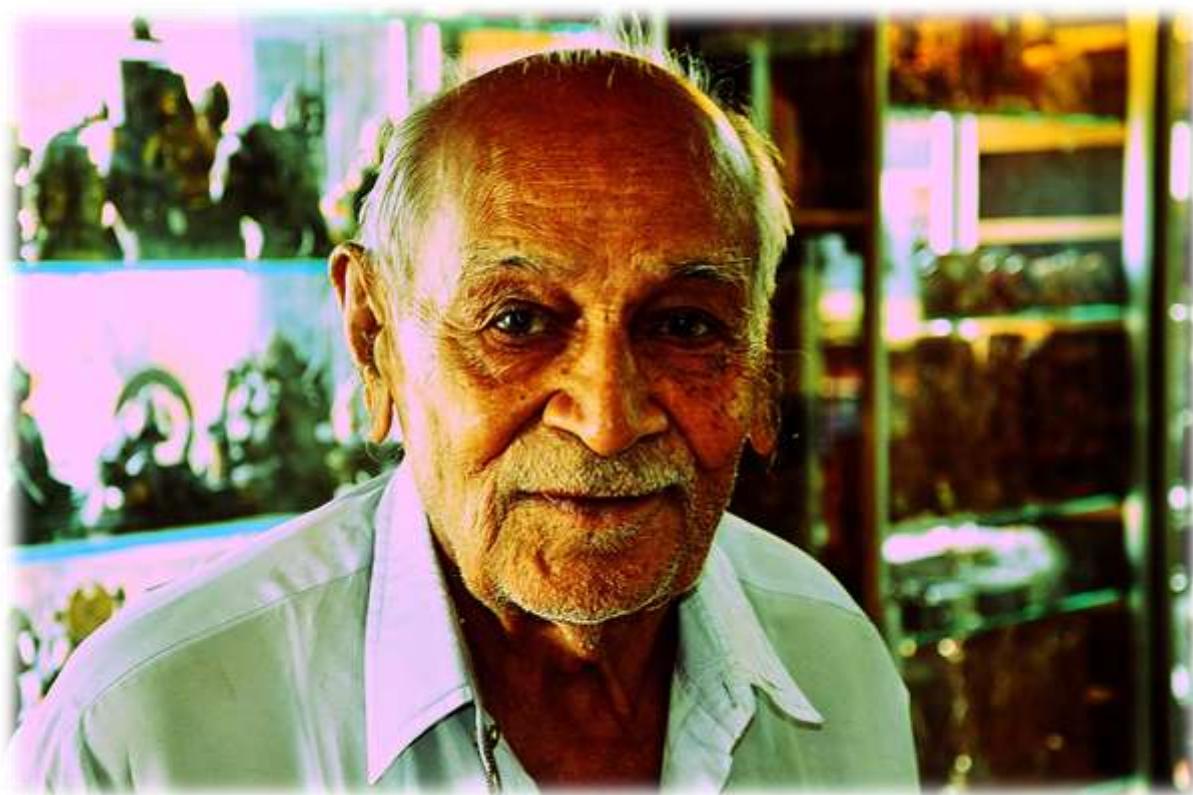
Awareness generation initiatives are being undertaken for various stakeholders including older people, their caregivers and the entire society about how to deal with the huge challenges of long-term care for the elderly. In order to ensure high-quality and sustainable long-term care systems for older persons, several initiatives have been undertaken at various levels- government, non-government and society. Provisions of Mobile Medicare units, setting up old age homes/ institutional care facilities, dedicated healthcare facilities at concessional or free of cost basis, healthcare training, health insurance scheme for poor elderly, etc. are among the key steps.



OBJECTIVE OF THE STUDY

Research & Advocacy Centre at Agewell Foundation (*a consortium of over 1500 NGOs and 6500 volunteers spread across 540 districts of India, committed to initiate better interaction between generations and extend a helping hand*) has recently carried out a nationwide survey **to assess the autonomy / independence, and long term and palliative care in old age.** **Under the survey, it was attempted to identify factors responsible for poor healthcare and social status of older persons.**

In view of lack of core policies on protection of older people in old age and fast increasing elderly population, the study was also focused to suggest or recommend some specific points to policy makers, planners and decision makers so that rights of older persons could be respected in future and a standard framework could be developed to advocate for needs & rights of older persons.



SCOPE & METHODOLOGY

Scope of this Study

This study is an attempt to understand social and healthcare dynamics, highlighting the patterns that emerge in relation to the contemporary social and healthcare issues and the challenges faced by older persons.

Universe & Units of the Study

The entire country constituted the universe of the study. Therefore, rural and urban areas were selected for this study. All the male and female above sixty were taken as unit of this study.

Sampling Frame

India is a country of about 130 million elderly persons. For the study a list of older persons who were willing to be part of the study was first prepared. As the literature review suggests the older people are faced with diverse issues, problems and challenges ranging from frailty to functional inadequacies; physical & health problems; social isolation & loneliness; neglect, economic insecurity etc. Therefore, while developing this list of respondents or the sampling frame the representation of this diversity was kept in mind so that vast variety of challenges, particularly financial concerns that older people face are culled out from this research.

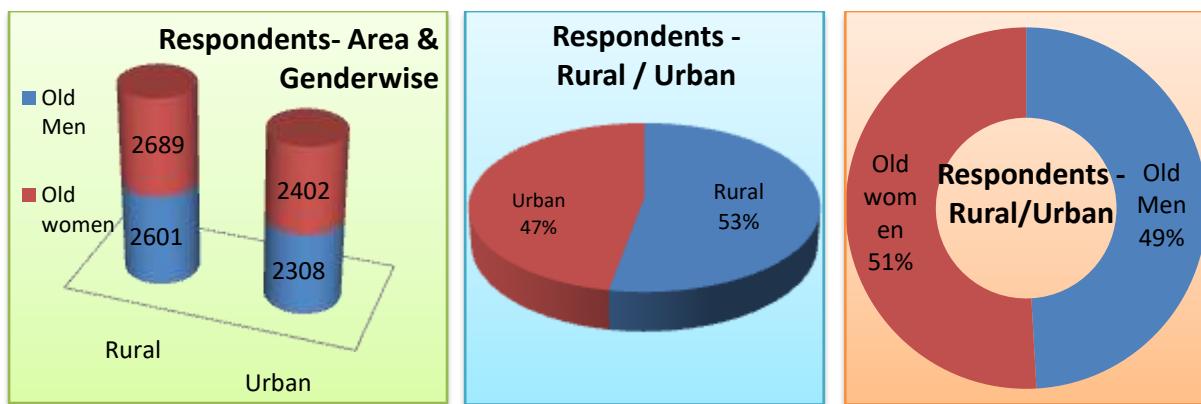
Sampling Method, Sample Size & Duration

The respondents who comprised the sample for the study were selected on the basis of **random sampling** made on the basis of gender , community (rural-urban), age-group etc.

Sample Size: A total of **10000** respondents were studied by 300 volunteers across all the five regions of Northern, Southern, Western, Eastern and Central India. The survey was conducted during the month of **May-June 2018**.

	Old Men	Old women	Total
Rural	2601	2689	5290
Urban	2308	2402	4710
	4909	5091	10000

Among 10000 respondents, 5290 were contacted in rural areas whereas in urban areas 4701 older persons included in sample size. As far as gender wise composition of the sample is concerned, out of 10000 total respondents, 4909 respondents were older men and 5091 older women. The number of older women respondents in both of the areas (rural and urban) was comparatively higher as is depicted in the diagram.

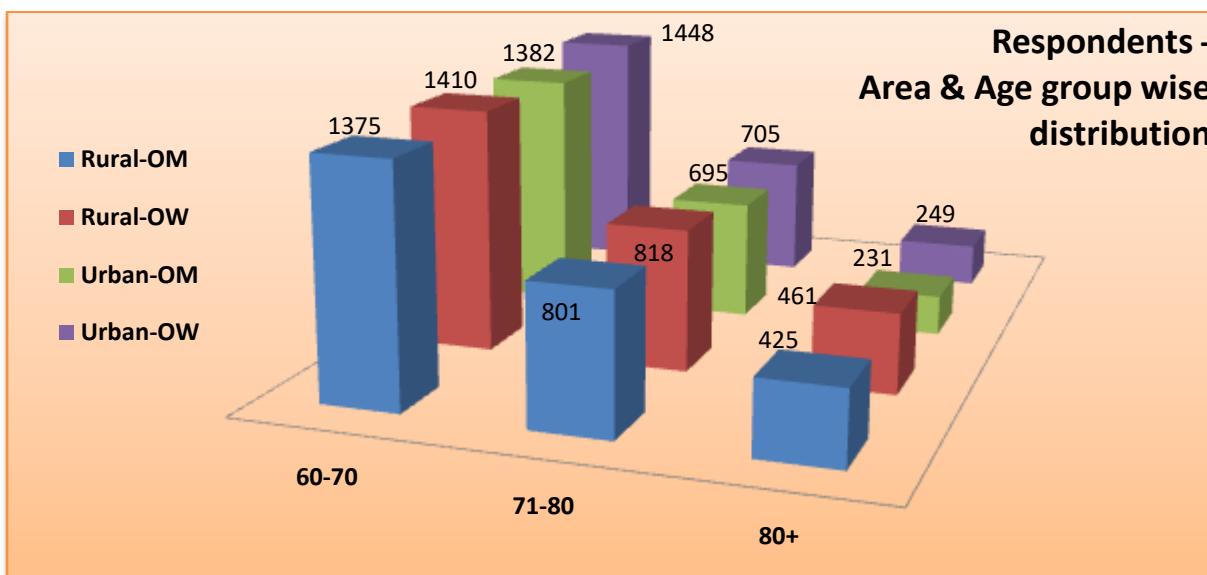


- Out of 10000 subjects interviewed during the survey, 5615 respondents (56.2%) were found to be in the age group of 60-70 years, 3019 respondents (30.2%) were between 71-80 years and the remaining 1366 (13.7%) respondents comprised the oldest old group (81+ years).
- Elderly respondents were divided into 4 categories on the bases of gender and community of the respondents. Each of the category, rural older men (26%), **rural older women (26.9%)**, **urban older men (23.1%)** and **urban older women (24%)** consisted of nearly 1/4th of the total respondents.

Area/ age group wise category	60-70	71-80	80+	Total
Rural-OM	1375	801	425	2601
Rural-OW	1410	818	461	2689
Urban-OM	1382	695	231	2308
Urban-OW	1448	705	249	2402
Total	5615	3019	1366	10000

Tools and techniques for data collection

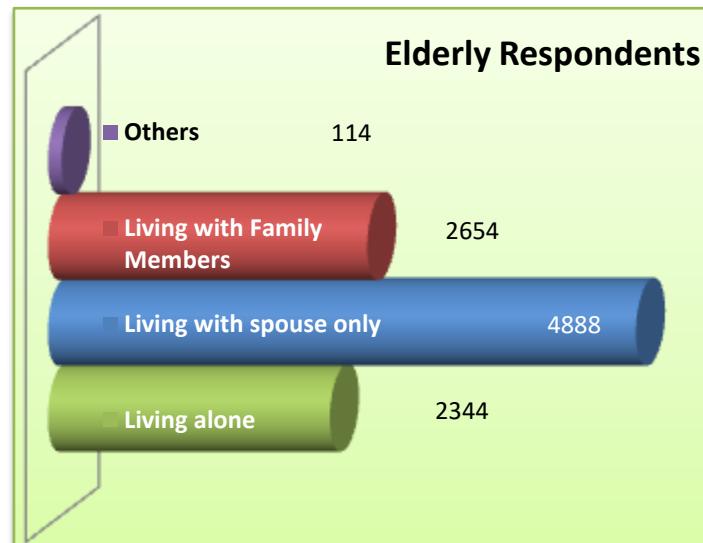
Main emphasis was on qualitative information therefore, a **more intuitive Approach** was adopted for the research so as to arrive at an understanding of this problem to cull out a pattern. The information was enriched with the help of focused group discussions and **in-depth interviews**.



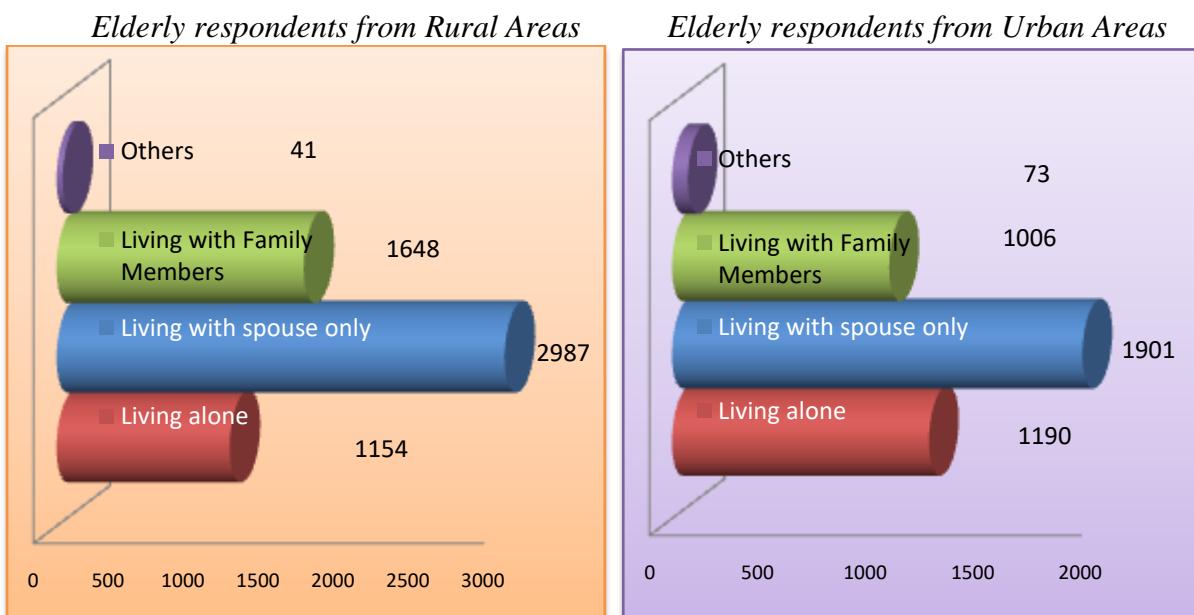
MAJOR FINDINGS

Independence in old age

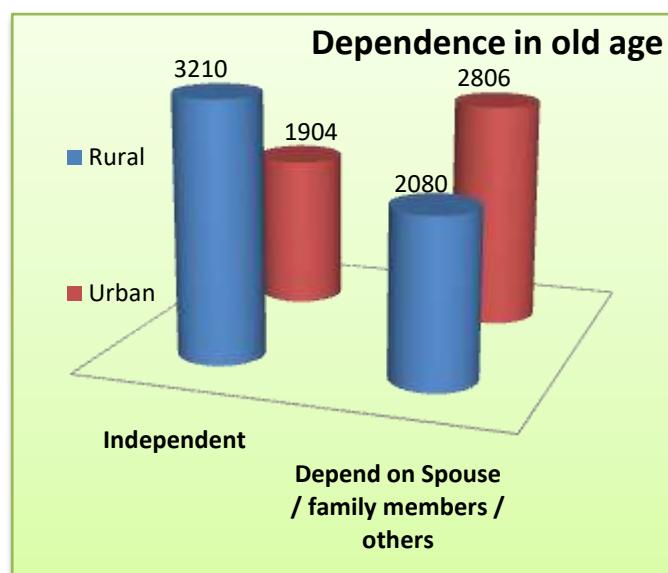
- During the survey conducted by Agewell Foundation, it was found that almost every fourth elderly (approx. 23.44% elderly respondents) was living alone. Almost every second (approx. 48.88% elderly respondents) elderly is living with their spouse only. Only 26.5 elderly respondents reportedly admitted that they are living with their children and/or other family members in old age.



- In urban areas the number of older persons living alone was slightly higher (25.3%) in comparison to older persons living in rural areas (21.8%), while the number of older persons living with only their spouse was substantially higher in rural areas (56.5%) in comparison to older persons contacted in urban areas (40.4%).



- In rural areas almost 1/3rd elderly respondents (31.2%) were found living with their children and/or other family members, while in urban areas only 21.4% elderly were living with their children and/or other family members.
- During the survey more than half elderly respondents (51.1%) claimed that they are independent in old age. In rural areas 60.7% and in urban areas 40.4% respondents said that they are not dependent on others for their needs.
- Among elderly respondents, who depend on spouse/family members/others, 59.6% respondents were from urban areas, whereas in rural areas 39.3% respondents admitted that they have to depend on others for their needs and requirements.

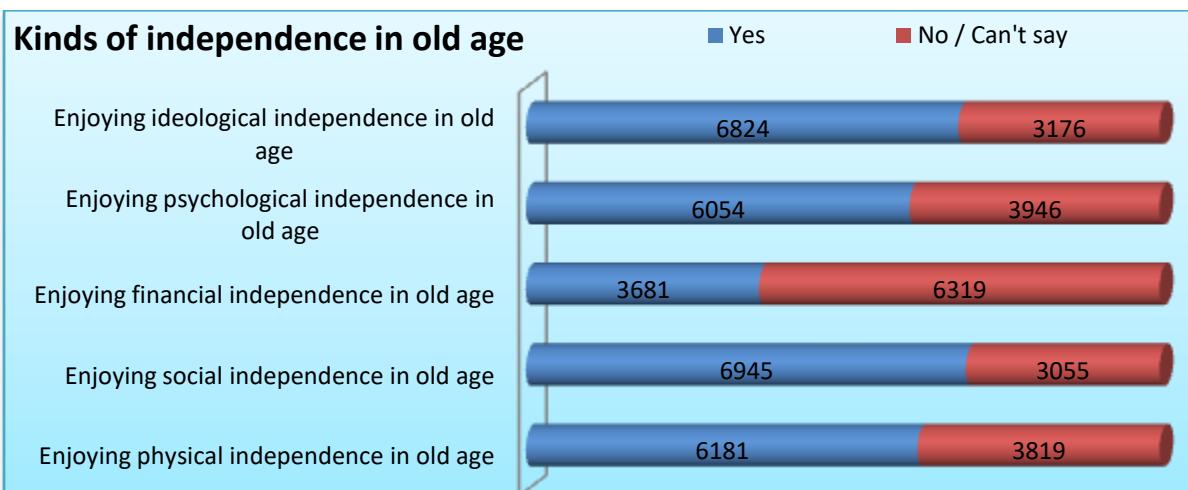


Interviewer's Observations

During the survey interviewers observed that a large number of older persons prefer to live alone or with only their spouse. Many older persons were found living in the same house, where their children's family were residing, but they have separate space/rooms/floor and kitchen in the same house. They hardly interact with their children and their family members. Hence they admitted that they are living alone.

Kinds of independence in old age

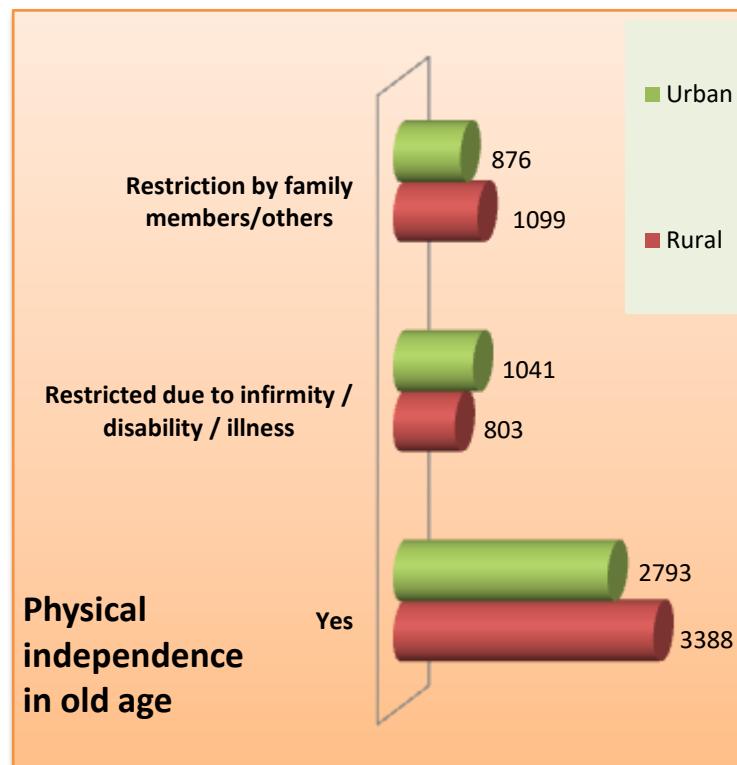
- When it was attempted to assess the kinds of independence in old age, it was found that 61.81% elderly respondents were reportedly enjoying physical independence in old age, while others claimed that they are not physically independent. Among them some expressed their inability to comment on this question.



- More than 2/3rd elderly (69.5% elderly respondents) claimed that they enjoy social independence while remaining 30.5% elderly respondents denied that they have social independence in old age.
- According to 63.2% respondents, there is no financial independence in their life, as they have to depend on other for their financial needs and requirements, while only 36.8% elderly respondents reportedly found enjoying financial independence in old age.
- As per 60.5% elderly respondents (6054 out of 10000 elderly respondents), they were psychologically independent in old age, while remaining 39.5% elderly respondents felt that they have to depend on others for psychological issues.
- During the survey 68.2% admitted that they enjoy ideological independence in old age while remaining 31.8% respondents either denied that they enjoy ideological independence or didn't reply to this question.

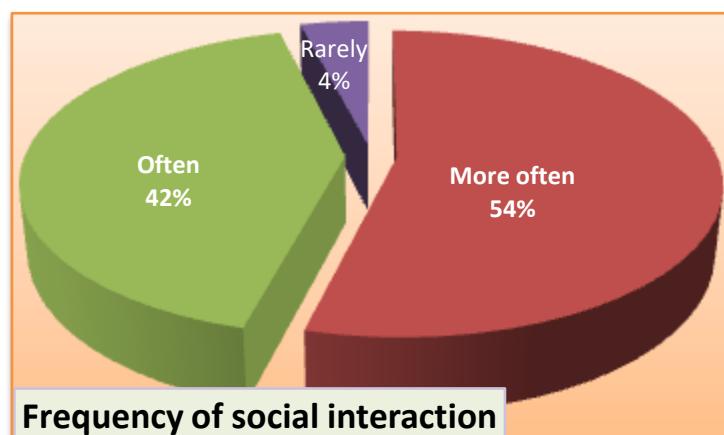
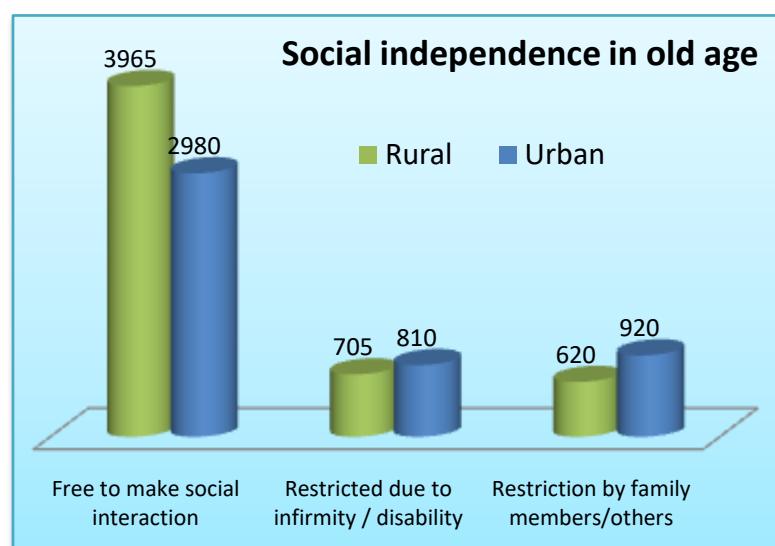
Physical independence in old age

- Physical independence among rural elderly is higher in comparison to physical independence among urban elderly, where 64% elderly reported that they are physically independent while in urban areas 59.3% elderly said that they are not independent physically in old age.
- Almost 1/5th elderly respondents (18.44%) claimed that they can't enjoy physical independence due to restricted mobility because of infirmity/disability/illness, etc. In urban areas 22.1% elderly respondents said that their physical activities are restricted due to infirmity/disability/illness, etc. In rural areas only 16.2% respondents (60+) complained that their physical independence is restricted due to old age related problems.
- Every fifth respondent (19.75% elderly respondents) claimed that restrictions on their physical activities are imposed by their family members. 20.8% rural and 18.6% urban elderly complained about such restrictions during the survey.



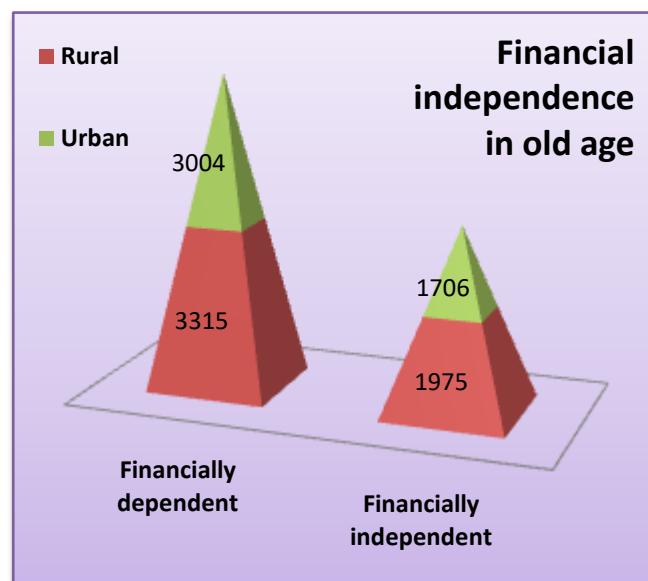
Social independence in old age

- In rural areas 75% elderly respondents claimed that they are free to make social interactions and enjoy social independence in old age, while in urban areas percentage of such elderly was 63.3%.
- When about frequency of their social interactions, more than a half (54.1%) of the elderly respondents said that their social interactions are more often, while 41.9% claimed that they often interact with people in their society and 4% respondents said that they rarely interact in society, that too on special occasions only.
- Overall 15% elderly (13% in rural areas and 17% in urban areas) claimed that there are restrictions on their social interaction due to infirmity/disability/old age related diseases.
- 15.4% respondents (11.7% in rural areas and 19.5% in urban areas) said that there are restrictions imposed by their own family members and other on their social life.

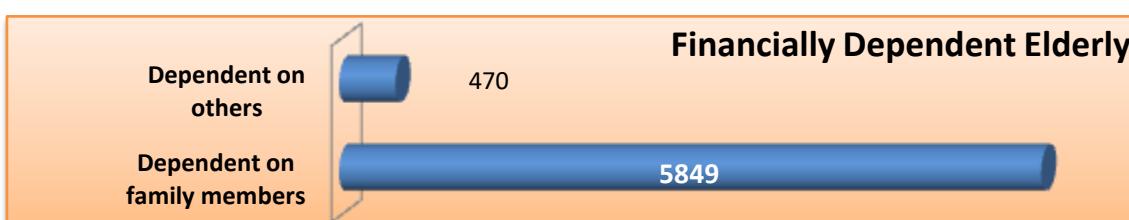
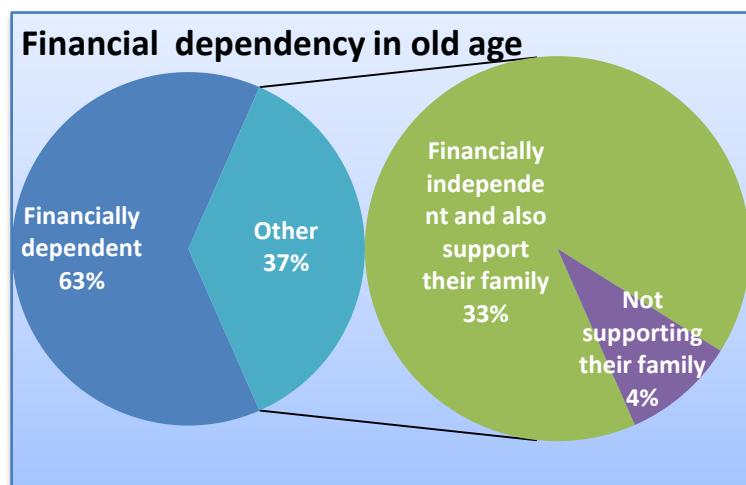


Financial independence in old age

- Overall 36.8 % elderly respondents (37.3% in rural areas and 36.2% in urban areas) claimed that they are financially independent in old age. Out of 5290 rural elderly 1975 said that they have some kind of income, which makes them financially independent. In urban areas out of 4710 elderly contacted during the survey, 1706 elderly claimed that their income is enough to make them financially independent in old age.

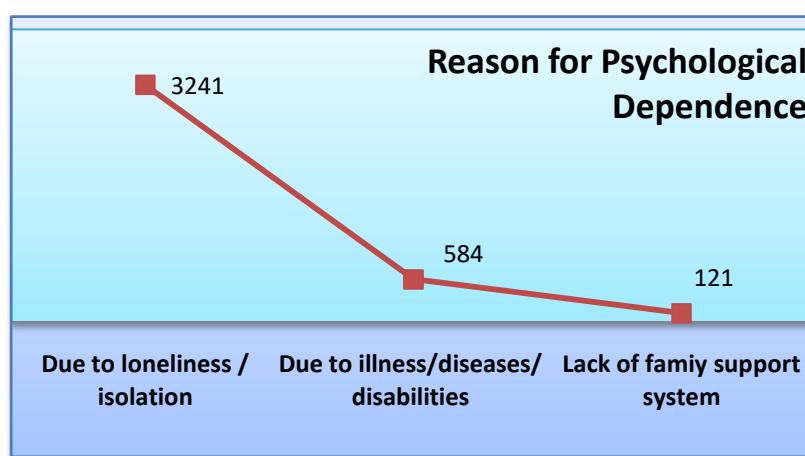
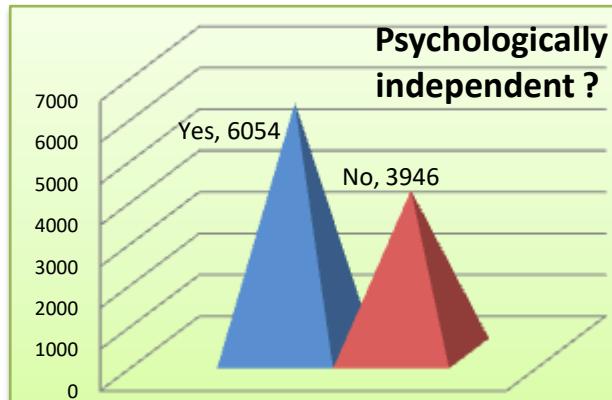


- When these financially independent elderly were asked whether they support their family/children, 90.5% elderly agreed to support their respective families and children.
- Among financially dependent older persons, 92.6% older persons were found dependent on their family members, while 7.4% were dependent on other than their family members.

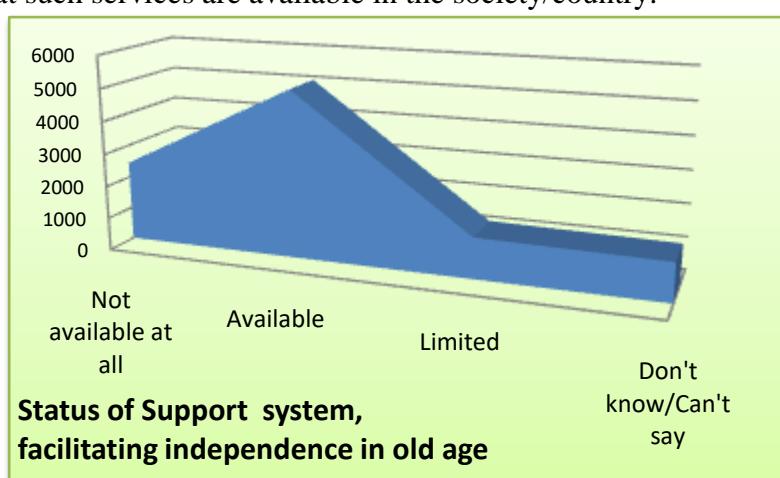


Psychological independence in old age

- While majority of older persons (60.54%) claimed that as far as their psychological life is concerned, they felt themselves psychologically independent and they have no major psychological issues in their old age life, almost 2/5th elderly respondents (39.46%) claimed that they feel themselves psychologically dependent.
- When interviewers asked them about the reason of their psychological dependence in old age, 82.1% elderly termed their loneliness and isolation in old age responsible for this, 14.8% elderly said that they are psychologically dependent due to their chronic diseases/illness etc. and 3.1% elderly said that due to lack of family support system in old age they have psychological issues.

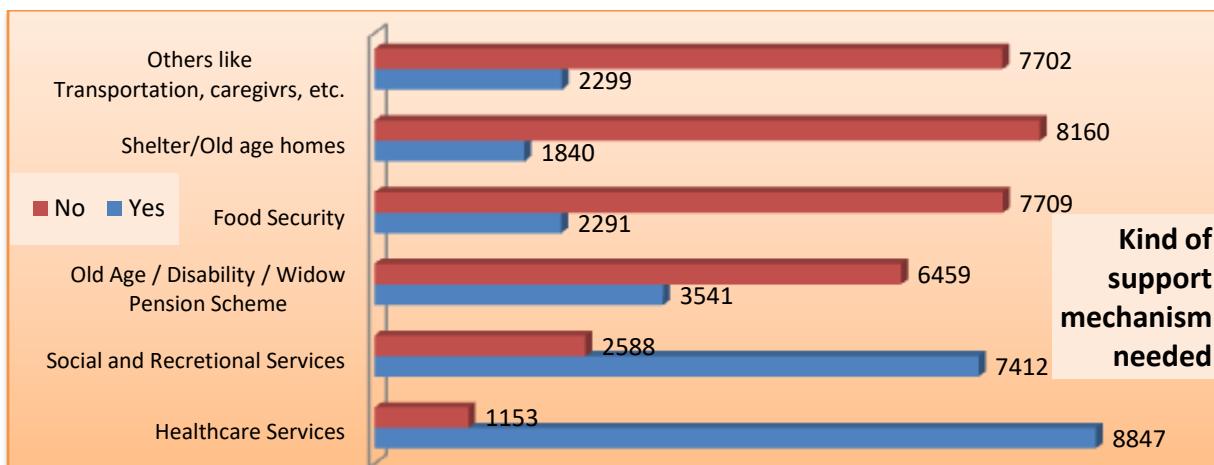


- When status of support system (services/ facilities) for older persons to facilitate their independence was tried to be assessed, majority of older persons (51.24% respondentss) claimed that such services are available in the society/country.
- Every 4th elderly respondent (24.54% respondents) said that support system is not available at all in the society/country, while 12.45% respondents said that such services/facilities are available but are limited. 11.77% elderly respondents either have no idea or they expressed their inability to respond to the question.



Kind of support mechanism needed to ensure independence in old age

- According to 88.5% elderly respondents, healthcare services for older persons are much needed to ensure their independence in old age. Out of total 10000 respondents, 8847 elderly said that network of healthcare services and facilities can increase independence in old age.
- 74.1% elderly respondents suggested that they need social support system and Recreational Services/facilities urgently in their localities, so that they can enjoy more independence in old age.

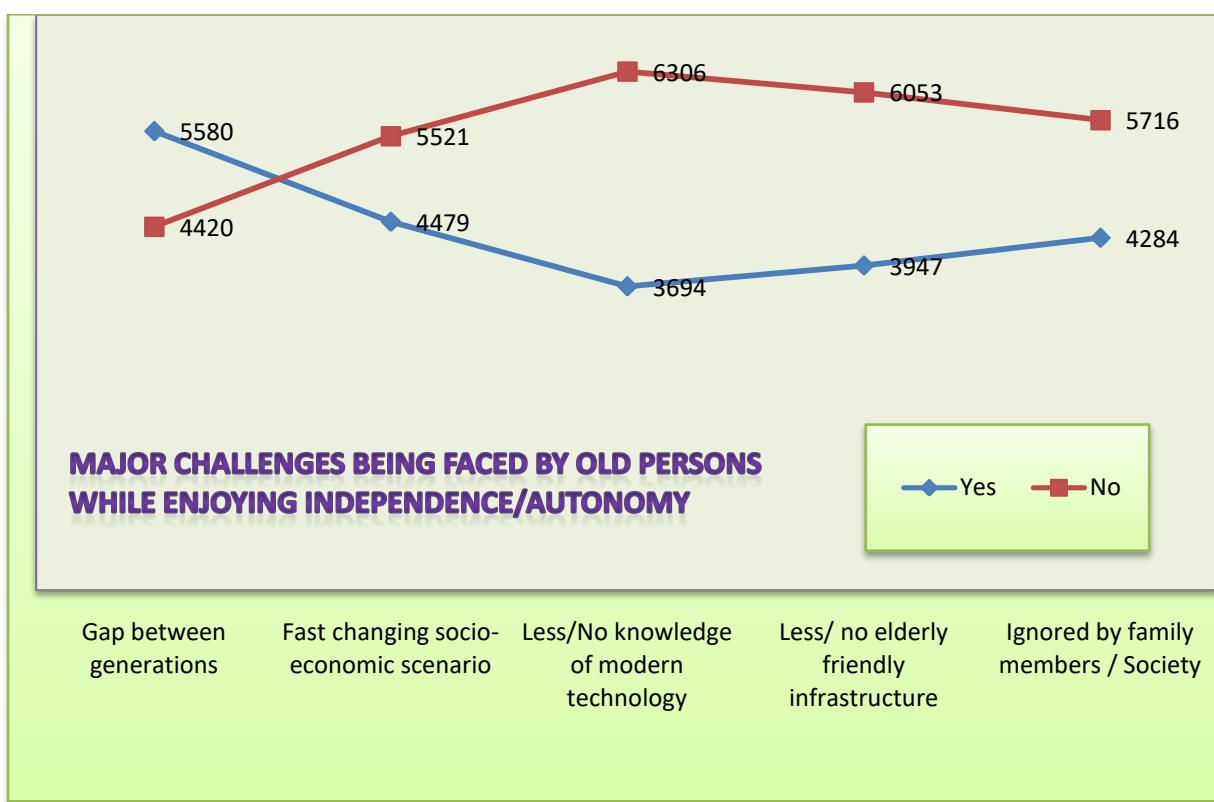


- Out of all the older persons interacted during the survey, 35.4% elderly respondents said that schemes such as Old Age/Disability /Widow Pension and support services are needed to be made more effective and favorable for people, so that a large number of older person, who depend on others can live independently.
- Food Security schemes are also among effective tools to make older persons independent in old age according to 22.9% elderly respondents.

- According to 18.4% elderly respondents, provision of old age homes, shelters, short stay homes for older persons in the need of the hour for ensuring independence in old age.
- Approx. 23% elderly opined that provision of other services and facilities like transportation, provision of caregivers, etc. at grass-root level can ensure independence in old age.

Major challenges being faced by older persons while enjoying independence/autonomy

- According to 55.8% older persons, interviewed by volunteers during the survey, gap between generations is a major challenge, which restricts older persons from enjoying fuller independence and/ autonomy during their life after 60.
- Approx. 44.8% older persons termed fast changing socio-economic and demographic scenario as the most challenging factor which is affecting independence and autonomy of older persons.
- Approx. 37% elderly respondents said that less or no knowledge of modern technology is one of the biggest challenges that older persons face while enjoying independence/autonomy.

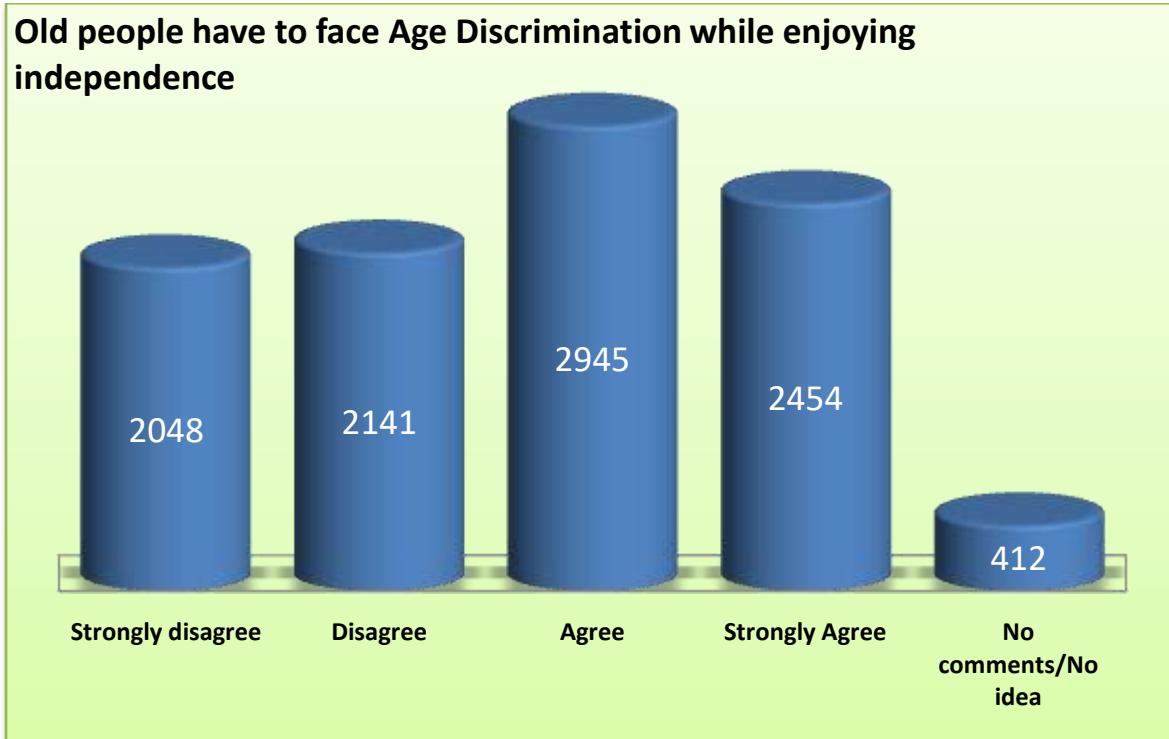


- About 40% elderly respondents reportedly claimed that limited and / or no elderly friendly infrastructure in their localities / areas is among the major challenges being faced by elderly community in our country.
- Almost 43% older persons accepted that they are being ignored by their own family members/societies, which is also one of the major challenges before older persons, and

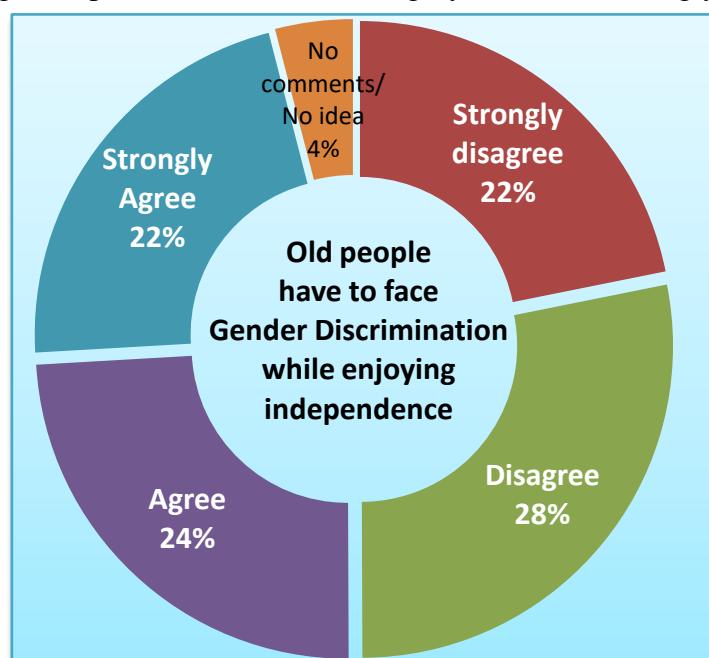
due to which behavior they are no longer able to enjoy independence / autonomy in old age.

Age and gender discrimination v/s Independence in old age

- 54% old people agreed that they have to face age discrimination while enjoying independence. 29.45% elderly respondents simply agree to this fact, while 24.55% elderly respondents strongly agreed that they face age discrimination which restricts their independence.



- 41.89% older persons contacted during the survey disagreed that they have to face age discrimination while enjoying independence. In this category, 20.48% strongly disagreed to this fact.
- Remaining 4.1% elderly respondents either have no idea about direct relation between gender discrimination and independence in old age or they didn't comment on the subject.
- 46% old people agreed that elderly women have to face age discrimination while enjoying independence. Among them, 24.1% elderly respondents agree to this fact while 21.9% elderly respondents strongly agreed



that elderly women face age discrimination while enjoying independence/autonomy in old age.

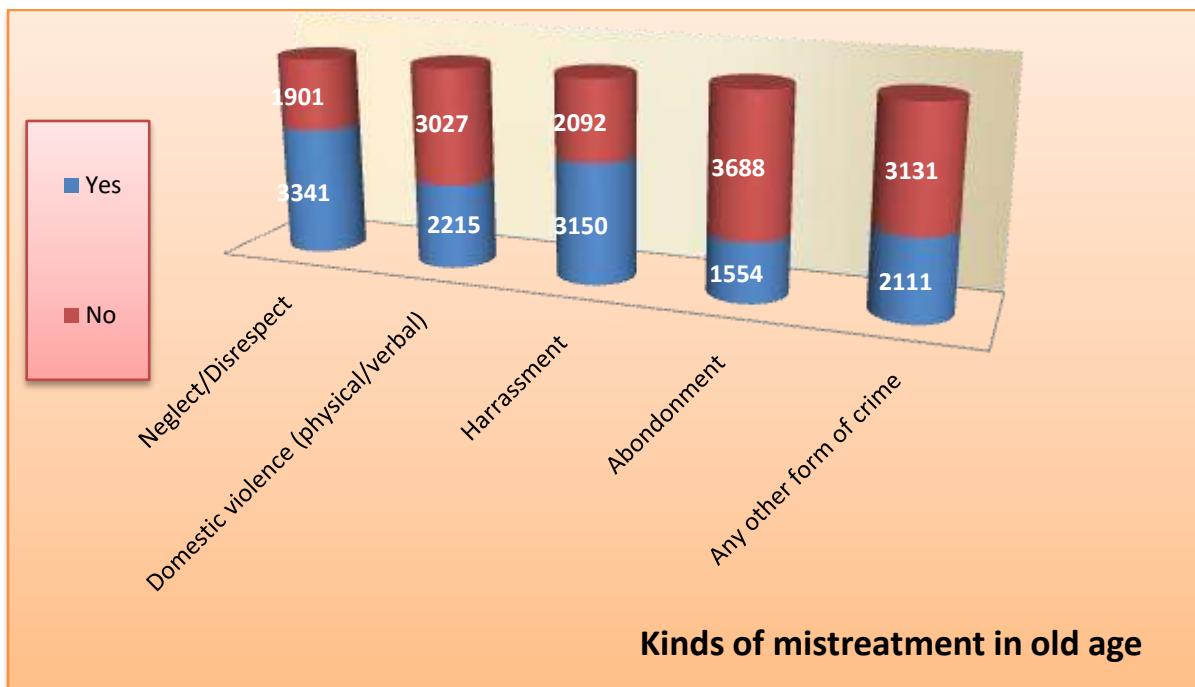
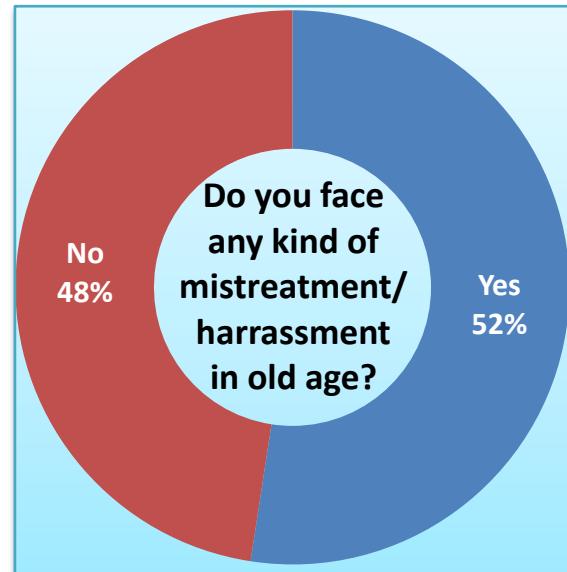
- 49.9% older persons contacted during the survey, disagreed that elderly women have to face age discrimination while enjoying independence. In this category, 21.48% respondents strongly disagreed to this fact.
- 4% elderly respondents either have no idea about relation between gender discrimination and independence of older women or they didn't comment on the issue.



Elder Abuse in India

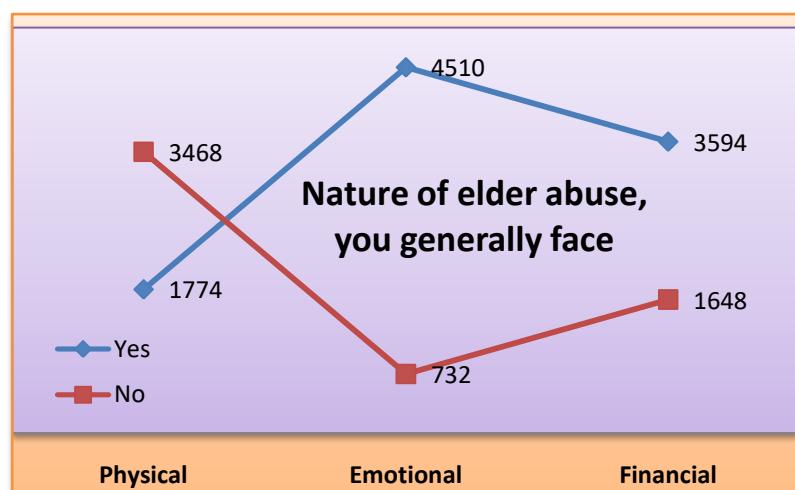
Mistreatment / Harassment in old age

- More than half of the elderly respondents (52.4%) spoke to during data collection for the survey, admitted that they have to face some kind of mistreatment / harassment in old age, while remaining 47.6% either responded in negative or didn't comment on this issue.
- When asked about kinds of mistreatment they are facing in old age, 63.7% elderly respondents, facing mistreatment (3310 out of 5242 respondents), admitted that they face neglect/disrespect in old age. 42.3% elderly (2215 out of 5242) accepted that they have to face domestic violence (physical / verbal) and 60.1% elderly respondents (2150 out of 5242) admitted that they are being harassed in old age



- Among them, there were 29.3% elderly (1554 out of 5242 respondents), being mistreated/harassed in old age, who reportedly claimed that they are facing abandonment or are left behind by their children/other family members.
- Every 2/5th elderly, facing mistreatment in old age, also claimed that they are facing other form of crime and mistreatment like robbery, snatching, abusing, etc.

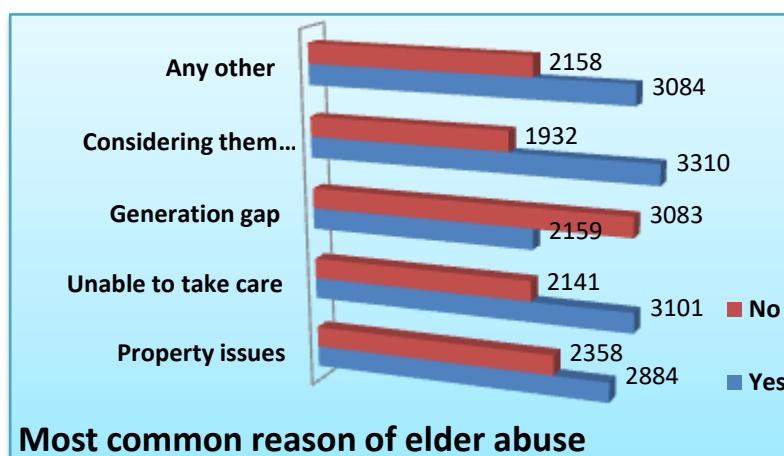
- Among elderly facing mistreatment / harassment in old age, 1/3rd respondents accepted that they are being mistreated/ harassed physically by their family members/others.



- 86% of such elderly respondents claimed that they are being mistreated/harassed emotionally. Out of 5242 suffering elderly, 4510 elderly said that their family members/relatives/other cause emotional problems in their life.
- 68.6% elderly respondents, who were mistreated, claimed that they have to face elder abuse for financial reasons.

Most common factors responsible for elder abuse

- Most elderly respondents (63.1%) reportedly claimed that they become victim of elder abuse because their family members/ society treat them as a burden. Out of 5242, 3310 people were found to be of this view.

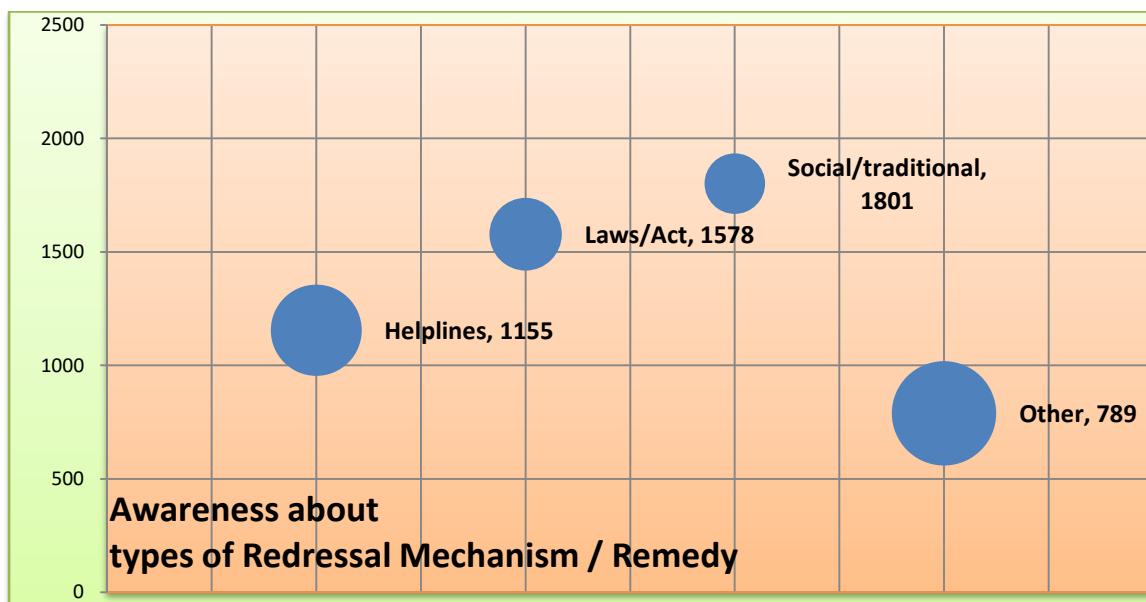
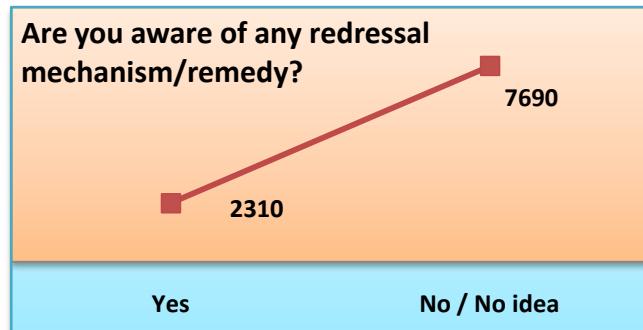


- In the opinion of 55% respondents, property related issues is the major factor responsible for occurrence of elder abuse in old age, while 41.2% elderly respondents said that due to generation gap they have to suffer from incidences of mistreatment/harassment in old age.
- 58.8% elderly respondents, being mistreated/ harassed suggested that there are many other reasons and factors that may be termed as most common factors responsible for elder abuse.

Redressal and remedy in case of abuse and violations of rights of older people

- As far as awareness about any redressal mechanism for cases of abuse and violations, survey data indicate that only 23.1% older persons were aware of such kind of mechanism or redressal system.

- More than 3/4th elderly respondents (76.9%) admitted that they have no idea about any redressal mechanism/remedy. Out of total 10000 elderly respondents, 7690 expressed their ignorance about redressal mechanism for cases of mistreatment and harassment of older people.
- Among those, who were aware of any kind of redressal mechanism, half of them (50%) said that they are aware of some helplines, working as kind of redressal mechanism. Out of 2310 informed respondents, 1155 said that they are aware of helplines for older persons.
- Among these elderly, 68.3 % elderly said that they know about legal provisions/laws/acts meant for protection of rights and interests of older persons.
- 78% elderly respondents who were aware of some kind of redressal mechanism/remedy for cases of mistreatment and harassment of older persons, admitted that they are aware of social/traditional redressal mechanism/remedy for issues concerning old age.
- 34.2% elderly respondents claimed they are also aware of some other redressal mechanism/remedy procedures, set up for protection of older persons and for strengthening their rights and interests.

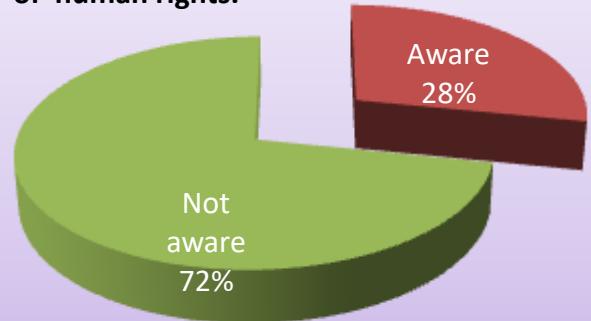


Awareness about safety and security services for older persons

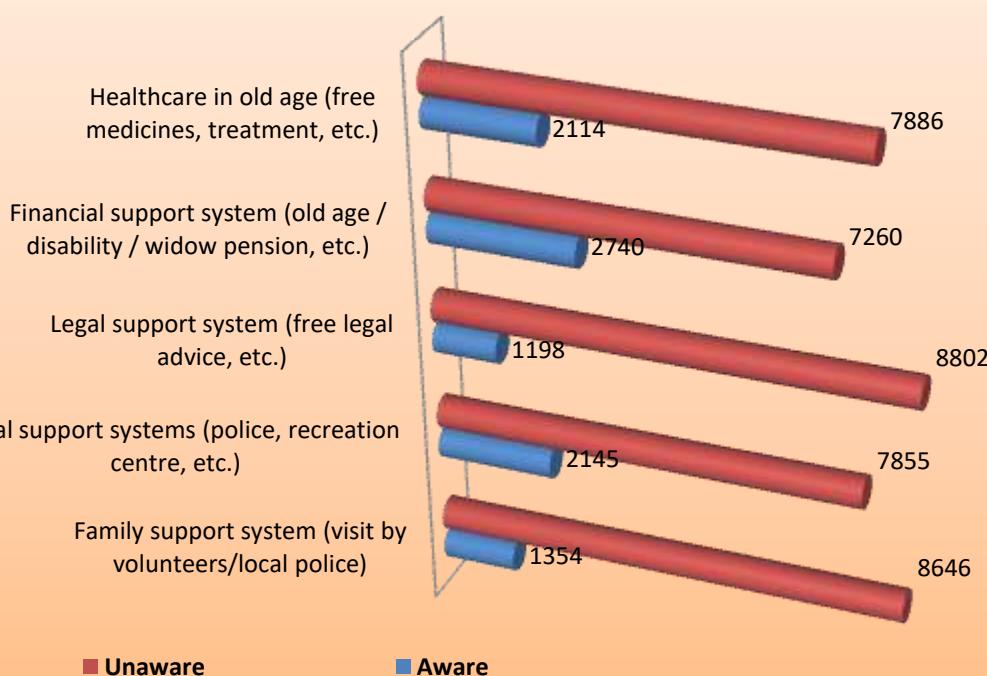
- During the survey, approx. 28% elderly respondents claimed that they are aware of safety and security services for protection of their human rights of older persons, while remaining 72% expressed their ignorance about such services.

- When it was attempted to assess the level of awareness among older persons about types of safety and security services available for older persons in India, it was found that 86.46% elderly were unaware of any kind of family support system (like visits by volunteers/local police, etc.). Only 13.54% elderly respondents claimed that they are aware of such family support services.
- 78.55% elderly respondents admitted that they are not aware of any social support system (like police, recreation center, etc.) while only 21.45% elderly agreed that they are aware of such kinds of safety/security services.
- Among elderly respondents, 12% said that they are aware of legal support system like free legal advice, etc. available for older persons, while 88% elderly either have no idea about such services or didn't comment on this subject.
- 27.4% elderly respondents claimed that they are aware that financial support system, like provisions of old age / disability/widow pension, etc. can be recognized as safety and security services in old age.
- 21.1% respondents said that in their opinion, healthcare services in old age like free medicines, treatments, etc. can be seen as safety and security services in old age.

Safety/ security services protection of human rights.



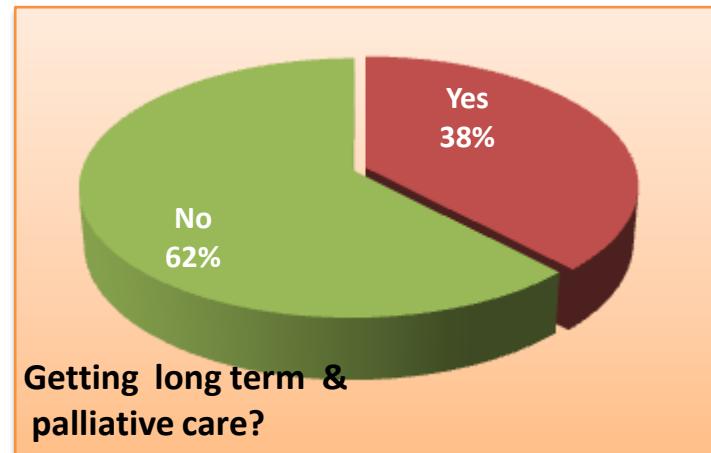
Types of safety and security services



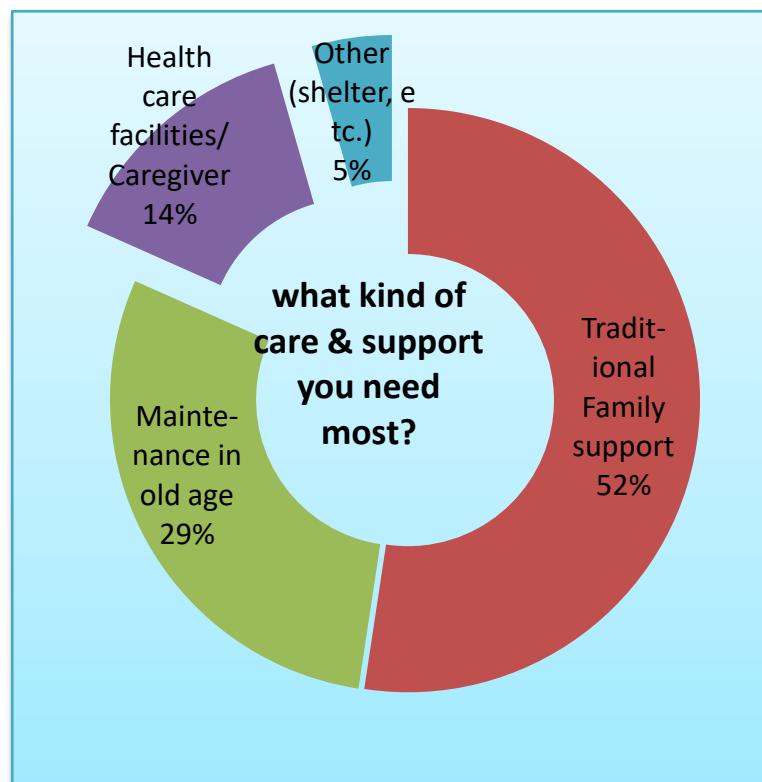
Long-Term and Palliative Care in India

Status of Long term and Palliative care system available for older persons

- During the survey conducted by Agewell Foundation among older persons, it was found that 62.1% elderly respondents didn't get any long-term and palliative care in their old age so far.
- Only 37.87% older persons admitted that they are getting long-term and palliative care. According to 3787 elderly respondents out of total 10000 elderly respondents, interacted during the course of survey, said that they are being provided with long term care and /or palliative care by their respective family members / others.

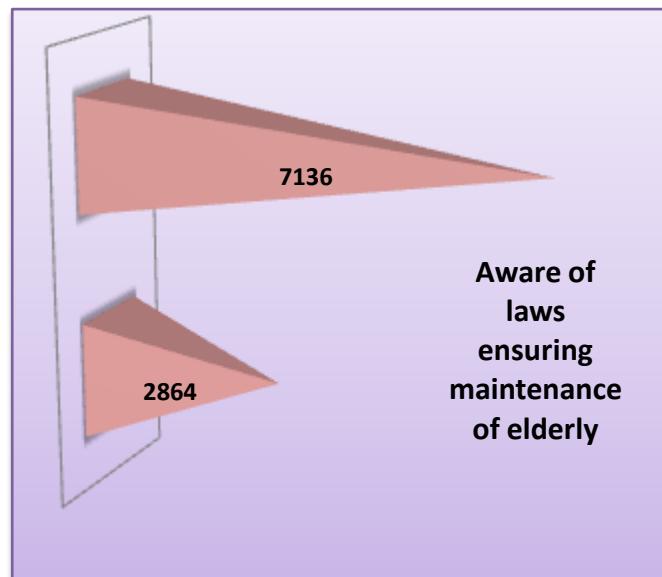


- When older persons, who were not getting any kind of care in old age were asked about kind of care and support they need, more than a half of them (52.4% i.e. 3255 elderly out of 6213 elderly respondents) said that they primarily need traditional family support.
- Approx. 29% older persons, deprived from long-term or palliative care, acknowledged that they need maintenance in old age, so that their basic needs can be met and they can lead a comfortable and peaceful life in old age.
- Approx. 13.9% older persons demanded more healthcare facilities and care giving services in old age as long-term care.
- 4.4% older persons, deprived from care and support services, said that they need other kinds of care and support like housing, counseling, etc. and they need it the most.



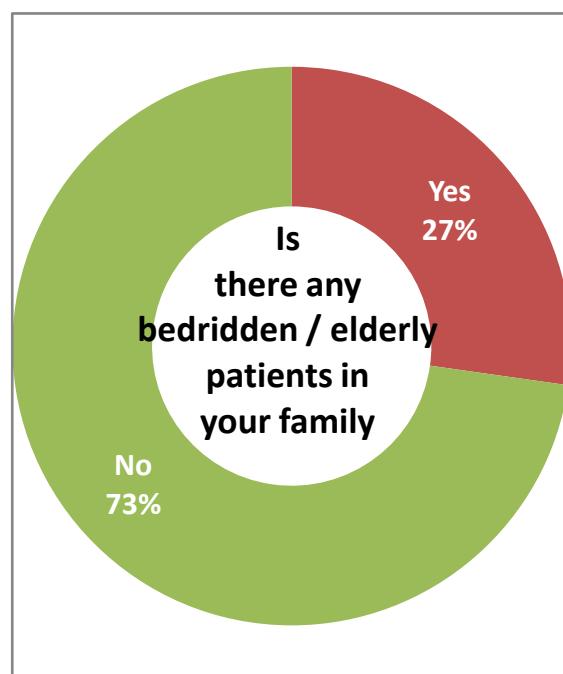
Status of Policy framework and awareness about the support and services

- When level of awareness about the provisions of support and services for older persons among older persons themselves was tried to be determined, it was revealed that only 28.6% older persons are aware of laws and schemes ensuring maintenance of older persons in India.
- Approx. 71.4% elderly respondents admitted that they have no or very limited knowledge of provisions/schemes meant for them.

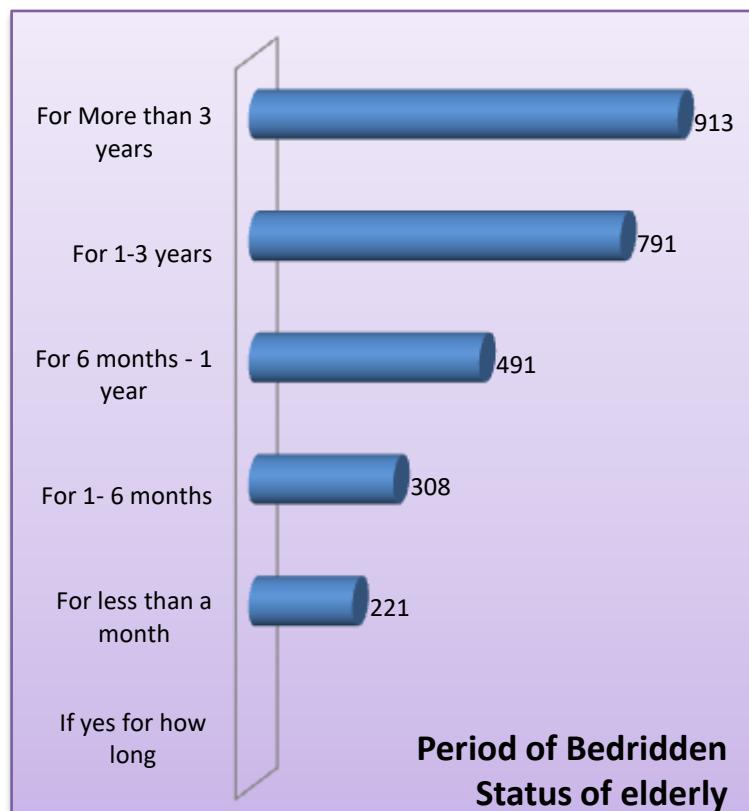


Bedridden / Elderly patients

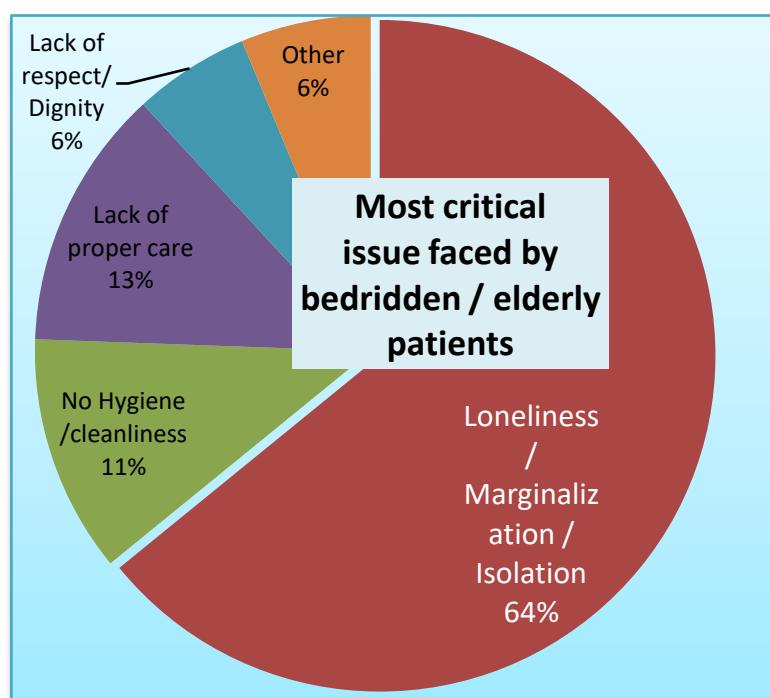
- When elderly respondents, were asked about whether there is any bedridden / elderly patients in their family, 27.24% elderly respondents replied in 'Yes', while 72.76% respondents said that none of their family members is bedridden or ailing from some disease.
- Among elderly respondents with one or more bedridden/elderly patients in their respective families, 1/3rd respondents (33.5% i.e. 913 out of 2724 respondents) claimed that average period of bedridden status of their bedridden elderly family members is more than 3 years.
- In this category of elderly respondents, 29% elderly respondents (791 out of 2724) admitted that the average period of bedridden status of their bedridden elderly family members is between 1- 3 years.
- Approx. 18% elderly respondents i.e. 491 elderly out of 2724 respondents said that average period of bedridden status of their bedridden elderly family members is 6 months to 1 year only.
- Among these family members of bedridden / elderly patients, 11.3% claimed that average period of bedridden status of their bedridden elderly family members is 1-6 months.



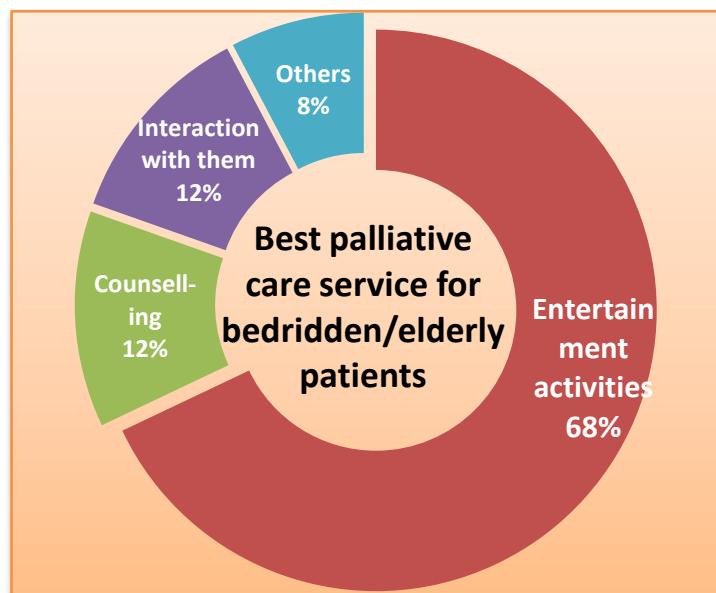
- 8.1% respondents, with bedridden family member/s said that the average period of bedridden status of their bedridden elderly family members is less than a month.
- According to 64.12 elderly respondents (6412 out of 10000 respondents), loneliness / marginalization / isolation is the most critical issue faced by bedridden / elderly patients as they cannot visit/ meet / interact with their relatives / friends / neighbours, etc.
- 12.58% elderly respondents claimed that lack of proper care is most critical issue faced by older patients and bedridden due to various factors like busy lifestyle of family members, etc.
- 11.45% respondents said that no hygiene / cleanliness is the most critical issue generally faced by older patients and bedridden in their opinion. 5.6% respondents said that they think lack of respect and dignity is their major issue, which disturbs them most while according to 6.3% elderly respondents there were other issues like mistreatment, abuse, etc., which affect bedridden/ elderly patients adversely.



- When elderly respondents were asked about the best palliative care service for bedridden/elderly patients in their opinion, more than 2/3rd respondents (approx. 68%) reportedly agreed that organizing entertainment activities like music, dance, etc. in their houses can be the best palliative care service for bedridden/elderly patients.



- According to 12.45% and 11.88% counseling and interaction activities respectively are the best ways to provide palliative care to bedridden/elderly patients. While in the opinion of 7.72% elderly respondents, bedridden elderly patients can be looked after with care services other than entertainment, counseling and interaction more effectively.

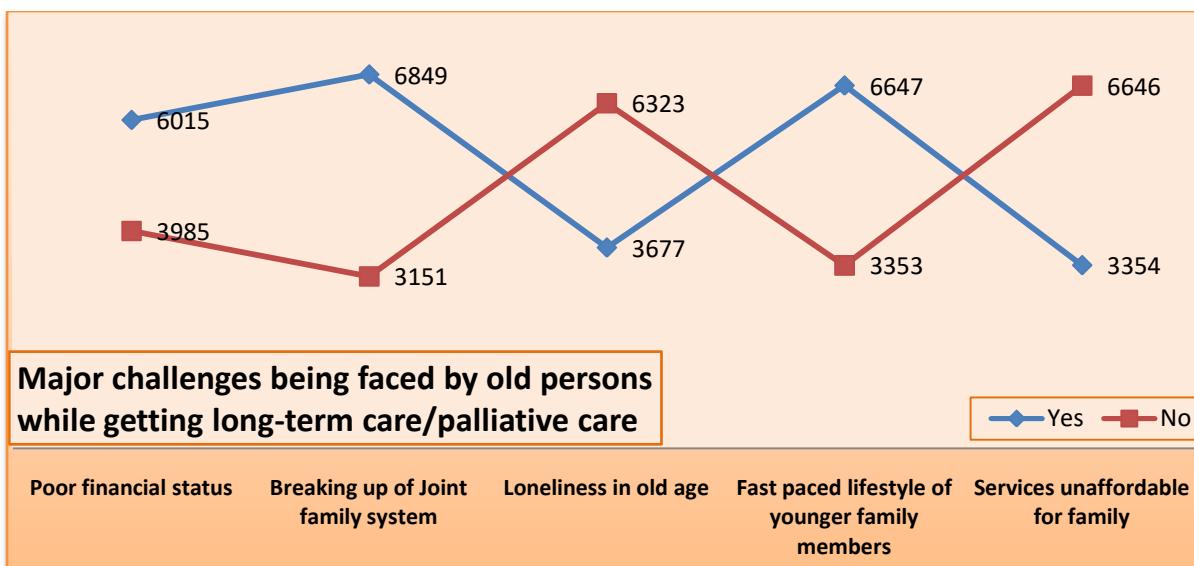


Interviewers Observations

During the survey many interviewers observed that older persons who are bedridden or suffering from some old age related diseases for long time, feel very happy when they recall their past life experience and memorable moments. When someone entertain them with music, dance, games, other activities of their choice etc. they forget all their pain and depression, as entertainment / recreational activities leaves a soothing impression in their minds.

Major challenges being faced by old persons while getting long-term / palliative care

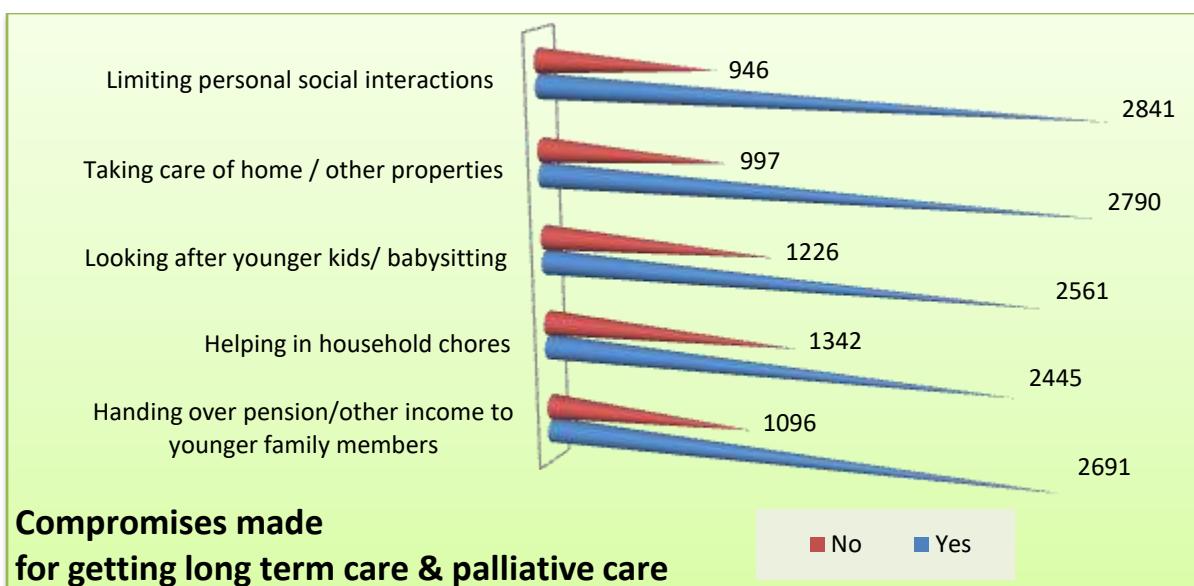
- Most elderly respondents (68.5%) asserted that breaking up of joint family system is one of the biggest major challenges being faced by old people while getting long term care/palliative care.
- More than 2/3rd elderly respondents (66.5%) reportedly claimed that fast paced lifestyle of younger family members is the most common challenge for older persons, as it leads to loneliness and isolation in old age, due to which older persons don't get long term and/or palliative care.
- Approx. 60% elderly termed poor financial status in old age as the biggest and a major challenge being faced by older persons while receiving old age care and support services.
- Further, 36.8% elderly respondents opined that loneliness in old age can be recognized as a major challenge, affecting long term and/or palliative care for older persons.



- 1/3rd elderly respondents also found services unaffordable for their family members/caregivers, due to which they remained deprived from long term and/or palliative care.

From the data collected from elderly respondents, it was found that majority of older persons have to compromise with circumstances for the sake of care and support from family members/others.

- On analysis of the data, it was revealed that 71.1% elderly who were getting long term and/or palliative care were handing over their entire pension / other income to their younger family members. Out of 3787 older persons being provided with care and support by their family members, 2691 admitted that they have handed over money to their family members or their family members forced them to do so.



- 64.6 elderly respondents accepted that they have to take care of household chores so that they can expect care and support from their family members when they need it.

- 67.6% elderly being taken care of their family members, have to look after younger kids of their respective families. They have to perform work like babysitting, etc. in return of proper care and support in old age.
- 73.7% said that they have to take care of house and other properties of their younger family members to ensure long-term and palliative care in old age.
- 3/4th elderly respondents (75% i.e. 2841 out of 3787 respondents) have to limit their personal social interactions as their family members direct them to do so, otherwise their family members can avoid their basic needs of food, medicines, etc.



Representative statements

"We are living alone in our flat because we want to live independently and lead a peaceful and happier life in old age. Till a few years ago, we were living with our children and grandchildren, but we could not adjust with them due to frequent misbehavior of our daughter-in-law with us. Since we don't want to upset our son's life as well, we decided to live alone."

- Subhash Sharma (71) & Savitri Devi (65), Saket, New Delhi

"I am totally dependent on my family members for my old age related issues. Since I am partially bedridden for last 2 years, my social life has decreased dramatically. At this stage, independence in old age has no meaning for me. Though I am financially independent, I have to depend on others for other issues like family/social support, healthcare, etc."

- Srinivas Reddy (81), Bangalore, Karnataka



"My children and grandchildren are settled down abroad who hardly come to India to visit me. Though I am independent, financially, physically as well as socially, but due to loneliness, I find my psychological issues more critical, which are affecting my health as well. For that I am dependent on my relatives, neighbours and other support system for psychological support."

- Ram Pratap Thakur, 75, Chandigarh

"My family members don't allow me to visit my relatives, neighbors and others. Even on special occasions they don't allow me to interact with guests, relatives and keep me busy with household chores. After the death of my husband, they treat me as their maid. I have to bear all this, as I have no other place to go".

Ranjana Patil, 61-year-old widow, Mumbai, Maharashtra

"I am a diabetic patient and suffering from many old age related diseases, like weak eyesight, arthritis, etc. I cannot take care of household chores, my house and grandchildren when there is no one at home. My children take care of all my healthcare related needs."

Pushpa Srivastava, 83, Kanpur, UP

"I am a bedridden old woman and need care and support from my family and society. My daughter-in-law & grand-children keep me locked in my own house, whenever they have to visit others. Sometimes, for even longer hours I have to live in prison like conditions. They take all my pension money and never take proper care of my food, hygiene and medicines. I am helpless.

Dayaram Bhandari, 87, Jaipur, Rajasthan

OBSERVATIONS

Respecting and protecting the right to autonomy and independence of older persons is the social responsibility of all. Apart from various initiatives undertaken at government level, other stakeholders i.e. non-government agencies, individuals, and the society are equally liable to ensure autonomy and independence of older persons at every stage. Providing them proper food, shelter and healthcare/medicines, ensuring their dignity in old age, extending the emotional support, ensuring their safety and security and protecting their rights and interests are among the universal responsibilities of a community towards their senior citizens.

In order to provide social interaction opportunities and to strengthen their right to autonomy and independence, recreational centers are being set up across the country. But so far it is only symbolic to say the least.

There is a growing need to promote self-help groups of older persons and set up volunteers' network to extend a helping hand to needy older persons and conduct various activities to entertain older persons, who are facing psychological problems like loneliness and depression. Simultaneously, there is an urgent need to provide healthcare equipment like wheelchairs, adult diapers, medicine, etc. to bedridden and destitute elderly to make them independent to some extent and ensure care for them.

To protect rights and interests of older persons several initiatives have been undertaken at various levels like launching of dedicated helplines for older persons, setting up Senior Citizen security cell, Home visit to older persons living alone, etc. However, these are so far limited only to urban areas.

Fast growing elderly population, lack of health awareness among elderly, breaking of traditional joint family system and ever increasing generation gap are among the major challenges of our health care delivery system. Older persons of India often face problems like disability in old age, restricted mobility, loneliness, poverty, lack of awareness while accessing old term care.

Due to fast growing population of older persons, ever-increasing gap between generations and fast demanding lifestyle of young generations, for majority of older persons life is still a struggle for independence, even in Old Age.



Experts' Observations

Aging can often reduce an individual's independence. In changed socio-economic circumstances, older persons cannot possibly expect more from their family members as well as from the society in India. For leading a comfortable and respectful life in today's changing environment older persons have to be prompted to become self-reliant in every field of their life – socially, medically, financially as well as emotionally. In Old Age when serious disability or illness occurs, those with good personal resources and social support system are more likely to be able to access the necessary support system. For this older persons should have adequate income, support with personal health needs (including speedy and affordable access to health services), appropriate housing and security, and concerns about transport.

Older persons are productive even after their retirement, but due to lack of post retirement job opportunities they remain unproductive throughout their remaining life. People consider older persons a rich source of experience, knowledge and wisdom but always doubt their performance. Due to increased life span in old age, there is an urgent need for post-retirement income generational opportunities and long term institutional and palliative care provisions.

Older persons face many health related problems, but it is not easy and convenient for them to undergo treatment and checkups at various hospitals and clinics in our country. Healthcare in old age is the most urgent area in which government and other stakeholders should work intensively.



CONCLUSION

With medical advancement, increased healthcare awareness and economic progress in India, many older persons, particularly young older persons (age group of 60-70 years) are living longer and enjoying independence in old age. However, majority of older persons in the age group of (70+ years) are in need of long-term and palliative care.

Today, we urgently need an inclusive social security program for older persons at the grass root level while utilizing tools like value based education, awareness generation, research & advocacy in order to provide long term / palliative care to older persons, when they are in need and protect their Human Rights.

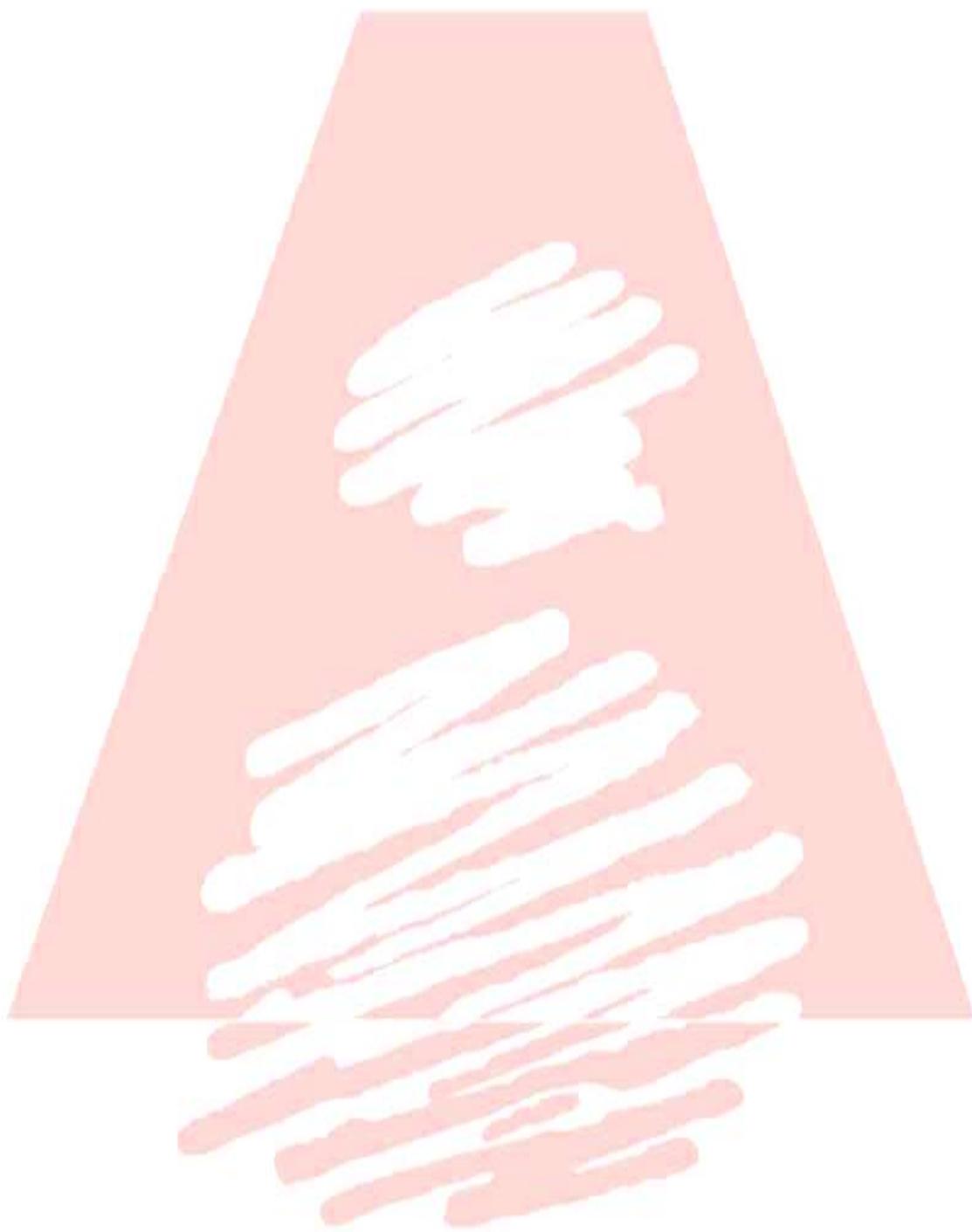
There is an urgent need to make every older person financially independent in old age, so that they can afford long-term care and palliative care, whenever they need it.

Since number of bedridden elderly persons and long-term elderly patients is increasing rapidly, there is an urgent need to initiate some innovative programs and schemes like organizing soothing musical and dance performances, recreational games, and activities for such older persons, who are in constant pain and who have to undergo immense psychological pressures.

At the same time, for destitute older persons who are bedridden and suffering from acute mobility issues, healthcare equipment like wheelchairs, relief material like adult diapers, and care giving service, etc. must be provided to them on regular basis.

Study recommends that provisions for ensuring independence in old age and long-term / palliative care for frail elderly must be made at all levels – family, society and government.







Agewell Foundation

(In Special Consultative Status with the ECOSOC at United Nations since 2011)

-Associated NGO Status with UN-DPI-

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