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# AZAAD आवाज़

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Azaad **आवाज़** aims to tackle an erosion of empathy in our society. This monthly magazine (Patrika) aims to focus on the marginalized sections whose voices are often muted in the cacophony of flashy mainstream media discourse. When referring to the marginalization, this platform does not aim to restrict itself to the traditional focus on social aggregates like caste and race alone but aspires to include a discussion on class, gender, sexual orientation etc. Azaad **आवाज़** sculpted as a digital media station focuses on issues that debilitate the "deliberately silenced", drawing no boundaries and aspires to evolve and voice the needs of those silenced.

*AN INITIATIVE UNDER*

CNES
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# GERIATRIC CARE IN INDIA: REALITIES OF POLICY AND PRACTICE

Senior citizens are one of the most vulnerable demographic groups in societies worldwide. Most of them are not able to work after they reach a certain age, and are dependent on their offspring for their survival. In India, the population of senior citizens, that is, people aged 60 years and above, was estimated to be 103 million in 2011.

Despite this small proportion compared to the entire population of the country that stood at 1.21 billion people at that time, it is important to understand them and address their concerns now because of the imminent drastic demographic shift in population.

According to the Longitudinal Ageing Study in India (LASI), conducted by the International Institute of Population Sciences, it is expected that the population of senior citizens in India (the age of 75 and above) would increase by a whopping 340% between 2011 and 2050, and by the end of 2050, senior citizens will constitute over 40% of the total Indian population. The data suggests that giving care to senior citizens is of utmost importance.

Soon after globalization, care for senior citizens has become a burden for many, especially for people who had to migrate within the country, and outside the country in search of education and jobs. A paper investigating this aspect, written by Ajay Bailey, Jyoti Hallad, and K. S. James, talks about how senior citizens live despite the absence of their offspring.

In several cases, most of the families analyzed were able to find a place to live independently, but being surrounded by friends and other kith and kin. Their offspring would arrange for groceries and medicines to be delivered, and a caretaker to look after them. Children living outside were able to arrange for internet facilities to converse with their elderly parents every day.

This study highlights an important point - care for senior citizens, especially compensating for the absence of their children in their lives, heavily depends on the social and financial capital they have access to. Most of the families studied were able to afford caretakers and the other costs involved. However, this is not always the case.

This demographic is even more complex in India since senior citizens belong to different strata of society, both socially and economically. A study by Akanksha Srivastav and Sanjay K Mohanty, based on the 2004-05 data of the National Sample Survey, shows that the estimated percentage of the elderly, living in rural areas below the poverty line, is 22.17%, and that of the urban elderly is 22.4%.

They also observe that the level of poverty amongst the elderly depends on the average poverty and income levels of the states, with higher levels recorded in states of Jharkhand, Madhya Pradesh, and Chhattisgarh.

This trend of highly varying levels of poverty among senior citizens living in urban and rural areas continues even today. According to the LASI study, the monthly per-capita consumption in households with elders is higher than the national average in economically developed places like Chandigarh (Rs. 5691) and is lower than the national average in economically poorer states like Chhattisgarh (Rs. 1945).

Similarly, annual per capita income in elderly households is the highest in Chandigarh (Rs. 1,04,387) and is the lowest in states like Bihar (Rs. 26,628) and Jharkhand (Rs. 34,452). This data only shows that state intervention in elderly care is important.

This intervention should not only be in terms of social and economic security, but also in terms of an overhaul in the health infrastructure of the country. This is especially because there is also a rise in cases of serious illnesses such as dementia and Alzheimer's amongst the elderly; diseases that require constant care and attention.

In India, according to the report titled "Dementia In India 2020", it is estimated that 5.3 million people suffered from dementia in 2020, which translates to one in 27 people, and this number is projected to increase to 14.32 million people by 2050. Taking care of people with dementia is not inexpensive either: this report observes, after surveying other literature, that the cost of direct care (hospitalization, treatment), and the cost of caring for activities for daily living lies anywhere between Rs. 20,300 - 66,025 in rural areas, and Rs. 45,600 to 2,02,450 in urban areas.

***"This intervention should not only be in terms of social and economic security, but also in terms of an overhaul in the health infrastructure of the country.***

Therefore, it is important for the Government to take action, such as increasing awareness of early diagnosis and care of dementia, and allocation of resources to conduct research and provide palliative and other forms of care to patients with low income.

There is a necessity for the government, non-governmental organizations, and civil society to collaborate on a comprehensive policy that would make the transition of the population from the working youth to senior citizens less painful, more caring, and less expensive, especially to the majority of the senior citizens living in rural areas and under poverty.

# Dementia Care Services in India

IN CONVERSATION WITH DR. JAYASHREE DASGUPTA

> ***We have a lot to do as a society to encourage active ageing and to help older adults recognize that it is a matter of their right to seek help when they need it; and we as a society, need to be able to provide the kind of support and infrastructure required for their care.***

***Dr. Jayashree Dasgupta***
*Co- founder,*
*Samvedna Senior Care*

Dementia is a chronic, debilitating, neurodegenerative syndrome that is characterized by a decline in cognitive function and abilities, beyond what may be expected from normal ageing. It affects behavior, memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgment. Everyday activities become a chore and taking care of oneself, a feat.

The symptoms of dementia are often misconceived as the effects of natural ageing and therefore, identification and diagnosis become challenging. Dementia is one of the major causes of dependency among the elderly community worldwide.

The physical, psychological, and socio-economic impacts of dementia affect not only those who contract it, but also their caregivers, families, and society as a whole.

Ageing is the primary risk factor in contracting dementia. The Indian demography is under flux. India which has hitherto been a young nation is aging rapidly. According to the projections UNFPA Ageing Report 2018, the elderly population in India is expected to triple by 2050, accounting for 20% of the total Indian Population i.e., 1 in every 6 people would be above the age of 65 years.

***Access the podcast here***

The incidences of dementia are bound to increase in correspondence with the increased volume of the ageing population. These statistics ask the question – is the Indian geriatric healthcare system as it exists today, prepared or sufficiently potent to effectively deal with dementia as a possible public health issue in the near future?

In pursuance of this question, this edition of Vichaar had the honor of hosting Clinical Psychologist, Dr. Jayashree Dasgupta, the co-founder and project director at Samvedna Senior Care, an organization that caters to the care needs of elders and dementia patients.

Dr. Dasgupta begins by evaluating the enormous socio-economic costs related to dementia which will be wholly incidental upon family members who not only bear medical expenses but also assume the role of care-givers. Next, she goes on to speak about how caregiver burden is disproportionately shared within the household. She explains that a woman's gender role relegates her to the status of a caregiver, often having to make the difficult choice of giving up her career to engage in full-time caregiving.

She goes on to talk about the impact long-term caregiving has on the mental and physical health of care-givers. She then provides insight on the medical aspects of dementia - the approaches taken to diagnose, treat and manage the symptoms and the level of care prescribed. Finally, we discuss in detail the challenges and the roadblocks to providing and seeking dementia care in India.

She asserts that the only way to get rid of the stigma surrounding seeking institutional and professional care, especially in the case of dementia, is to raise awareness about the interventions and educate the public about early detection and diagnosis.

> ***Dementia care must be based on collaborative and community-based models of care. Public awareness is the first step towards creating dementia-friendly and dementia-ready communities.***

Dementia care must be based on collaborative and community-based models of care. Public awareness, she suggests, is the first step towards creating dementia-friendly and dementia-ready communities.

The podcast discusses the condition of dementia care systems in India through a socio-economic and medical perspective and traces the challenges that lie ahead. This podcast is a must-listen!

*Dr. Jayashree Dasgupta, MPhil, PhD, NIMHANS is a clinical psychologist with a specialization in neuropsychology. She is the co-founder of Samvedna Senior Care. They cater to the elderly's physical and emotional health. Their mission is to provide best in class senior care services for elderly to help them live happy, active and independent lives, in the comfort of their home and community through interactive caregiving.*

SAMVEDNA senior care

# Challenges and Issues to Palliative Care in India

IN CONVERSATION WITH DR. ABHIJIT DAM

*Q. In 1973, the term 'palliative care' was coined and you started your hospice 'Kosish' in 2006. Can you explain what palliative care is and what 'Kosish' is all about? Could you also elaborate on the evolution and history of palliative care in India?*

To address palliative care in the most common sense, cancer patients are most often referred to. Most of the cancer patients in India are diagnosed quite late. By the time they are diagnosed, it's already in stage 3 or stage 4, when actually there is no cure available. Most of the times in these advanced cancer conditions, the doctor tells the family to take the patient back home and take care of them.

This is easier said than done. There are lots of issues surrounding caring for a very sick patient who is terminally ill, who has just a few days left to die; for example, going to the washroom. Passing stool while on your bed into a bed pan while having other people in the room watching you is very difficult.

Cleaning it up is even harder; a sense of revulsion and shame comes in. Suppose the patient is your father and you are his only child and have been assigned to clean him up, how would you go about it? How comfortable would you feel cleaning up the stool of your father, of whom you have looked up to all your life?

Collecting the stool in the bed pan, cleaning up the patient's private parts, then taking the bed pan to the bathroom and cleaning it.

***Dr. Abhijit Dam***
*Founder,*
*Kosish-The Hospice*

People don't think of the details unless they are suddenly faced with it. And when they are faced with such challenges, they are totally unprepared.

This is when there is a lot of resistance which comes up, there is shame, guilt, anger and most of the time these frustrations are taken out on the poor patient. Patients are abused, either verbally or even physically at times. So, palliative care basically is a speciality which addresses all these symptoms.

A terminally ill patient who is alone in a hospital or at home, say who has severe pain or nausea or vomiting - how to make the last few days of his life worth living and of comfort, to die with dignity

We are not focused on death, we are concerned with life. Even if you have only one day of life left, that day should be as comfortable as possible. That is the aim of palliative care. Here we are not trying to cure the disease; the disease has no cure. But that doesn't mean that nothing can be done; a lot can be done. We can take care of systems such as nausea, vomiting, anorexia, bed sores, painful dressings.

Addressing other issues like cultural issues. The patient may go into depression because no one wants to talk to him. Even if you just focus on the elderly, a patient who is parlaysed, how does the family cope with the patient's illness? You literally become a social outcast because your friends will stop visiting you out of stigma of having a patient at home. The suffering is not of the patient alone.

The whole family suffers with the patient. So the problem is not just physical but also psychological, social, financial and cultural.

Then there are spiritual issues; you start blaming god. Even if you don't believe in god, you might think "why is this happening to me?" You start seeking answers but most of the time you don't find them because there is anger, frustration, guilt. So, palliative care is a branch which addresses all these concerns of a terminally ill patient where there is no scope for a cure.

You know the patient is not going to survive for very long but here we are not concerned with the quantity of days a patient has but the quality of life the patient has during those days.

> ***The whole family suffers with the patient. The problem is not just physical but also psychological, social, financial and cultural.***

Palliative care started off in India around 1992. The first so-called hospice was in Mumbai and the Indian Association of Palliative Care gradually started. But the palliative care movement saw a lot of resistance because doctors don't want to give up on their patients, even those that are terminally ill. In the medical profession, we are taught, wrongly, to never give up.

Dying, is a normal thing. If you are born, you will die. We need to accept the fact that death is normal. Death doesn't simply happen, there is a cause for death. It could be a heart attack or a stroke or anything else. Doctors need to understand that death is a physiology and should be given a chance too.

You should learn to let go at times. That is where there is a lot of resistance on the part of doctors because they don't want to give up on their patients easily, there are financial concerns and many other things. There is also a lack of awareness.

So the palliative care movement was pretty slow to start in India and it went about in hiccups. The social and cultural building of our unique country is such that we are a death denying society. Death is not spoken about. As children we are taught to fear death. But death can be a beautiful thing, a sort of release, for a person that is suffering.

If you look up the near-death experiences of people who nearly died and were resuscitated and then brought back to life, they say that death was very beautiful.

The so-called out-of-body experiences of seeing the white light or whatever it is. Those were very peace-giving moments. And so death is not something we should be scared of as at some point we are all going to die. Death is the only guarantee that you have.

***Most of us in this death-denying culture, die in hospitals, die very lonely, undignified deaths, die in neglect. This is where a lot of advocacy is still needed.***

Sadly, although, we realize that death is the only guarantee, and as we are a death-denying society, we don't plan for our death. The only thing which matters to us in this life of ours is our death because that is the only reality that will happen and it requires a bit of planning. And so you need to ask yourself a very simple question: where would you like to die? If you had a choice, would you like to die in a hospital? Or at home, surrounded by your family?

Ask yourself this and see yourself having the answers already. Sadly, most of us in this death-denying culture, die in hospitals, die very lonely, undignified deaths, die in neglect. So this is where a lot of advocacy is still needed.

But if you asked large hospitals to not admit their terminally ill patients and let them die at home, they will not listen to you. That is where their billing comes from. If their hospital beds are empty, then they can't survive. They need their finances to start flowing in.

Whatever money a person earns in his life, whatever savings he has, most of it is spent in the last few days or years of his life on medical bills. The sad fact is that although you are spending your savings on hospitals in the last few days of your life, still those expenses can't save you.

That money spent also isn't going to prevent death. So people need to understand and change their whole thought process about death and dying so they can focus on making their last days of life more comfortable, dignified, and peaceful.

This is my understanding of palliative care. Palliative care is not limited to cancer patients. The single largest group of people who require palliative care is the elderly because even if we don't die of cancer we will die of old age. So the elderly, especially those who are bedridden, require palliative care. There are other illnesses such as chronic heart failure, chronic liver diseases, dementia, and other neurodegenerative diseases.

*Q. As of 2018, there are approximately 150 centers for palliative care. However, the total number of people that require it is likely to be 5.4 million people per year. What is your opinion about the policy changes that are required to improve the palliative care system?*

Way back in 2008, I had decided to go on a tour of India. I wanted to tour the whole of India, taking the lesser travelled routes, going through villages and small towns rather than big cities, to find out what exactly are the palliative needs of the patient.

> ***The single largest group of people who require palliative care is the elderly because even if we don't die of cancer we will die of old age.***

Whether the general public is aware of what palliative care stands for and whether or not they justify the use of palliative care. I had no access to any funding and with great difficulty, arranged a car. I was accompanied by one OT technician of mine.

We just started driving and managed to cover seven states in Eastern India. We used to start driving at 6 o'clock in the morning, stop at 11 o'clock for a combined breakfast and lunch because there was a shortage of money and around 5 pm whichever Dhaba or Dharamshala or gurudwara we could find, we used to sleep.

And we used to talk to people. During this tour which lasted a total of 15 days, what I found out was that in India, the basic need still is food. There is poverty. As they say, you can't pray on an empty stomach. So, in a house, if there is a dying person, and if it is in a family which can hardly afford food, the family actually prays that the person dies early. Because if that person dies, then his share of food can be shared with the rest of the family.

So poverty is a real issue and it's a big issue that needs to be addressed. So in India, our priorities are slightly different. These people cannot even focus on the quality of life as the term itself means something very different.

For us, it may mean an AC room, a private bathroom, a soft mattress, and a bottle of pepsi. But for them, quality of life may mean a full meal at least once a day, some water to drink. They don't mind the pain - I have seen such people in villages because I practice in a rural setting.

The rural people are more tolerant to physical stress because they have faith. It is said that faith can move mountains. They won't have access to medications but they have faith. They have full faith that god or some superpower will take care of them. They are not afraid of death; they know that they have to die and they accept it. That is the difference.

So as I said, poverty is a big issue in India and unless it is addressed, we can't go to the next level which is palliative care. Of course, in big cities where bellies are mostly full, you might go ahead, but the real stumbling block from the grassroot level is to first satisfy the basic needs. You need to give food and shelter to people before you think of the next level which is quality of life.

We still don't have a national policy on palliative care although suggestions were given to the ministry which is pretty positive about it and have been working on those suggestions. I hope that very soon we have a national policy on palliative care but until then, the ball doesn't go rolling really fast. Some states do have state policies but there is still a lot of work required. Still, the first priority remains food and shelter.

*Q. Although palliative care is critical to managing symptoms, pain, and transitions to end-of-life care among those facing serious or chronic illness, however, it is often overlooked due to the stigma attached to it. Can you elaborate a little bit regarding the stigmas surrounding palliative care and explain why is it such an overlooked issue?*

> ***You need to give food and shelter to people before you think of the next level which is quality of life.***

As I had mentioned earlier, there are many stumbling blocks towards the acceptance of palliative care, especially in urban society. One of the largest blocks, especially in the urban population is 'Bagal wala kya bolega' (What will others say?).

For instance, you have a relative who has terminal cancer, requests and pleads to you to not take them to the hospital, and that they want to die at home. However, you still take them to the nearest hospital as soon as their condition would deteriorate. This is only because you start wondering what society will think and say? This is the social stigma.

Here, sadly, we are not focusing on the patient's last wishes, instead, we are focusing on ourselves. It is our selfish interest that is coming forth. Here your love for your family member who is terminally ill gets overshadowed by your selfish nature and ego.

Although most people realize the fact that dying at home is blissful and satisfying, yet they take the patients to hospitals, where they would die in isolation, without dignity, hooked onto a ventilator. Do you know what it feels like to be hooked onto a ventilator?

There is a tube that goes down your windpipe, your hands and feet are restrained so that you don't pull out the tubes. Suppose your nose starts itching, you can't call out for help because you can't speak, you can't do it yourself because your hands are restrained. It is a very costly death.

On an average, a person pays Rs. 25-30 thousand per day for the ICU. So not only are you spending money but at the same time, you are dying in pain and paying for neglect, all without dignity. This is the so-called blessing of modern medicine. The choice is ultimately yours, and it has to be a very firm choice.

Whether you would opt for that type of death or would you rather choose to die with dignity and comfort, with palliative care coming in and supporting you and your family throughout the journey of your life. As far as pain is concerned, morphine is a big issue, however, narcotics are very useful.

The NDPS Act of India, which was implemented to prevent the misuse of narcotics, is a draconian law. This is because, under its umbrella, the use of narcotics for medical use also got restricted. There are a lot of legal and licensing issues, to handle, procure, store and dispense narcotics.

> ***Not only are you spending money but at the same time, you are dying in pain and paying for neglect, all without dignity. This is the so-called blessing of modern medicine.***

This is one of the main reasons for the decrease in the usage of narcotics. These drugs go a long way in the prevention of physical pain. Here I am stressing about the physical pain. Pain is not just physical. Imagine a person who is terminally ill, with only three months to live. S/he is immobile with severe pain- this pain is not always physical, it can be psychological, social, or even spiritual pain.

There was a recent study conducted at AIIMS-Delhi, where they found out that the physical pain of terminally ill patients accounts for hardly 33% of the total pain. The rest of the pain is psychological, spiritual, and social pain. This is something we should never forget. These kinds of pain can be tackled by family members, friends, and volunteers.

The common man can contribute a lot to improve the quality of life. Palliative care is not just the responsibility of the doctors and nurses, it is a social movement and a social responsibility. This is the essence of palliative care.

*Q. The pandemic brought along a lot of changes concerning access to public healthcare. How has the virus and the lockdown impacted the access and functioning of palliative care?*

Palliative care, like any other medicare, relied a lot on home visits, as compared to hospital visits. In palliative care, the health professionals believe in visiting the homes of the patients, because the patients are not in the state to walk over the clinic. Home care is the backbone of good palliative care. Naturally, due to the lockdown, home visits were curtailed to a severe extent.

However, we used social media to help the patients as far as possible. In the case of the pandemic, especially during the first wave, patients died lonely deaths. There was fear on part of the healthcare personnel, fear for your own lives and then there was a dehumanization of care. In one case, a person was dying due to the virus and had only a few hours to live.

He would try to look up to the doctor or nurse to see their face, but couldn't because of the PP kits and masks. It was a horrible way to die because it was a lonely death. No one would come close, in the fear of contracting it.

Apart from that, after the death, the body would be packed up and zipped up in a black bag. The family members were not allowed to perform the last rites in a culturally appropriate manner. The whole process of grieving had to be curtailed. Grieving is a very important part of the process of bereavement. After people die, the relatives need the period of grieving, as it gives a sort of meaning and purpose to whatever that person stood for.

Paying your last respects, in a culturally appropriate fashion, was also denied during the lockdown. There were hurried burials and cremations, which was not an appropriate thing. Palliative care took its own thrashing, just like other specialties of medicine.

> ***"In the case of the pandemic, patients died lonely deaths. There was fear on part of the healthcare personnel, fear for your own lives and then there was a dehumanization of care.***

Dr.Abhijit Dam is the founder of KOSISH- The Hospice. KOSISH, is an NGO which has pioneered the provision of palliative care services to the elderly and the terminally ill in the states of Jharkhand and West Bengal. Starting from humble beginnings in 2006, this is one of the few genuine initiatives in palliative care to have sustained their efforts in rural settings over time.

# Geriatric healthcare - A few perspectives

By Divyanshu Dembi

> ***India, the world's second most populous country, has experienced a dramatic demographic transition in the past 50 years, entailing almost a tripling of the population over the age of 60 years (i.e., the elderly).***

The study of elder healthcare and the various factors that it depends upon has been a difficult problem statement and although adult health and ageing is increasingly attracting a substantial amount of attention, most scholarship focuses on numbers and statistics and does not employ the language of policy analysis to better understand the healthcare issues of the elderly.

India, the world's second most populous country, has experienced a dramatic demographic transition in the past 50 years, entailing almost a tripling of the population over the age of 60 years (i.e., the elderly). Of the 7.5% of the population who are elderly, two-thirds live in villages and nearly half are of poor socioeconomic status.

Half of the Indian elderly are dependents, often due to widowhood, divorce, or separation, and a majority of the elderly are women (70%).

Of the minority of the elderly living alone, more are women than men. Thus, the majority of elderly reside in rural areas and are dependent upon their families. Nearly, 90% of the elderly in India are dependent on informal sectors such as agriculture, business, and wage work, and only 29% have pension and renting property as a source of income.

Studies have shown that nearly 58% of the elderly women and 45% of the elderly men are dependent in rural areas, whereas in urban areas, it is 64% and 46%, respectively.

A total of 73 % of elderly persons were illiterate and dependent primarily on agriculture. About 90 % of the elderly were from the unorganized sector, i.e., they have no regular source of income. Two-thirds of them were reported to be living below the poverty line, i.e., 66 % of older persons were in a vulnerable situation without adequate food, clothing, or shelter. The old-age dependency ratio increased from 10.9 % in 1961 to 13.1 % in 2001, as a whole.

As per the prevailing socially sanctioned roles for elderly in India, most of the time symptoms of illness are disregarded both by patient and family as part of the "normal aging process" or something "not serious". Even if it is acknowledged as a problem, some choose to self-medicate or use home remedies. Alternative healing practices, especially religious healing, are still the first resort for many.

A study found that as many as 46.3 % of the study participants were unaware of the availability of any geriatric services near their residence and 96 % had never used any geriatric welfare service.

When it comes to viewing elderly as a valid and contributing part of the society worthy of competent state policies, what is often forgotten is that, they make important contributions to the society not only via the formal workforce (primarily in agriculture), but also in raising grandchildren, volunteering, caring for the sick, resolving conflict and offering counsel, and translating experience, culture, and religious heritage.

On the double question of accessibility and affordability of healthcare by elderly it is imperative to highlight the various forms of vulnerabilities – vulnerabilities such as arising due to poverty, poor health, and weak social support. At a time when the traditional support system (family) for the elderly is decreasing – state policy must step up to combat such challenges.

Some of the findings of the study conducted by the UNFPA in collaboration with Tata Institute of Social Sciences (TISS), Institute for Social and Economic Change (ISEC) and Institute of Economic Growth (IEG) on the issue are as follows: a) One fourth of the elderly population did not own any assets, b) 6 percent of the elderly population was living alone, c) Two fifth of the elderly have no personal income..

In addition to gender and marital status, religion, caste, education, economic independence, and sanitation have bearing on elderly health.

A study in Maharashtra found that elderly in scheduled tribe/ scheduled caste (SC/ST) categories were 54% less likely and other backward classes (OBC) 35% less likely to seek treatment for existing ailments in Maharashtra compared to other castes.

***Family and care***

The Indian elderly generation is caught between the decline in 'traditional family values' (that morally obligated the younger to take care of their elder) on the one hand and the absence of an adequate social security system, on the other. It has led to increased incidences of the elderly being abandoned as homeless by family members.

State provided facilities for day care centres and respite care are scarce and inaccessible for most. There is a sheer absence of any home based rehabilitation measures or benefits accorded by the state to families to address caregiver burdens.

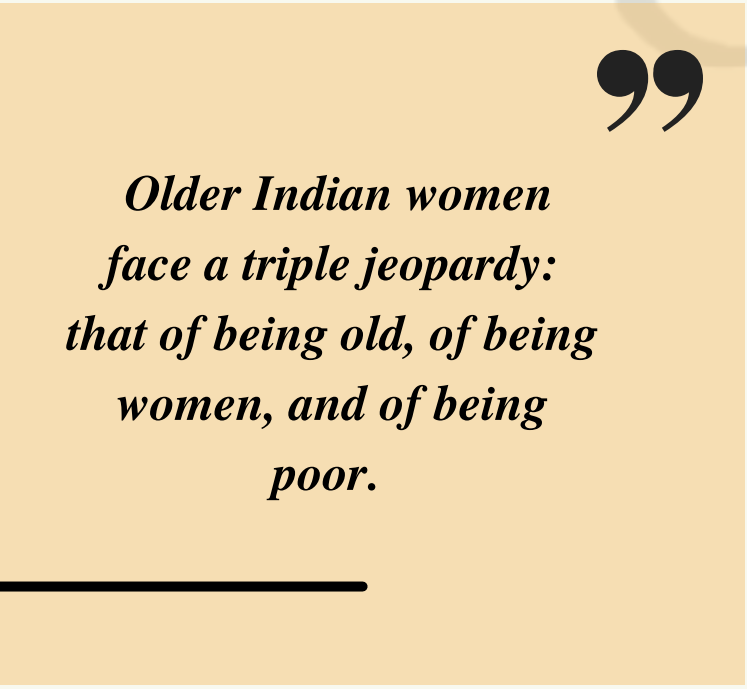
The decline of the joint family system, migration of youth to cities and increasing costs of healthcare are a few of the problems of the aged in India.

***“The Indian elderly generation is caught between the decline in ‘traditional family values’ (that morally obligated the younger to take care of their elder) and the absence of an adequate social security system.***

The unconditional respect, power and authority that older people used to enjoy in rural extended traditional families are gradually being undermined in India in recent years. Indian Older women face a triple jeopardy: that of being old, of being women, and of being poor.

Women live longer than men with more disabilities, as a result of demanding workloads, repeated child births, inadequate nutrition and limited access to healthcare.

Although broader trends of economic dependence are changing, kinship systems and social support still have strong bearing on access to healthcare among the elderly. More importantly - a strong link can be established between ownership of property and kin-based caregiving arrangements. Property-less elders have a relatively higher likelihood of residence in old-age homes, living alone, and being looked after by relations other than their children when widowed.




Given this variable provision of support, "discourses of neglect" may emerge, where in their everyday lives, the needs and problems of the elderly are invisible to those who offer them support in times of acute ill health.

***Mental Health & the Elderly***

The most overlooked issue when it comes to the discourse on geriatric healthcare is mental health issues in the elderly. The most common psychiatric illness in the Indian elderly population are depression, dementia and anxiety disorders.

Even though India has four types of resources to address geriatric mental health issues: 1) state funded government psychiatric hospitals and nursing homes; 2) private psychiatric hospitals and nursing homes; 3) non-government organisations; and 4) the most important, informal sources- family as caregivers – Indian elderly mostly fall through the gaps in these safety net due to inadequate assessment or treatment – whether by state or family.

In an ever changing familial landscape there is a greater need for the state apparatus to aid the elderly. But a combination of factors including but not limited to - lack of awareness, inadequate training opportunities; inequitable distribution of health resources and virtual absence of chronic care disease models plague the geriatric landscape in India.

In terms of infrastructure, very few Indian hospitals have geriatric units and most elderly patients are treated in general medical/psychiatry wards. Public sector hospitals suffer from problems of inaccessibility, inequitable distribution, and lack of staff, drugs and equipment.

The private sector on the other hand is largely unregulated with serious complaints regarding poor quality of care and unethical behaviour. The health insurance sector in India doesn't cover mental illnesses; otherwise too, in general, less than 20 % of Indians have some form of health insurance. A large portion of the population is forced to bypass free public services to pay out-of-pocket in private institutions.

***State Policies***

The existing social assistance programmes for the poor in India comprises of state and national pension schemes such as - Integrated Programme for Older Persons (IPOP), National Policy for the Health Care of the Elderly (NPHCE), Indira Gandhi National Old Age Pension Scheme (IGNOAPS), Annapurna Scheme and Maintenance and Welfare of Parents and Senior Citizens Act (MWPSC Act), 2007.

The central government came out with the National Policy for Older Persons in 1999 to promote the health and welfare of senior citizens in India. This policy aimed to encourage individuals to make provision for their own as well as their spouse's old age. It also encouraged families to take care of their older family members.

The policy aimed at enabli and support voluntary and non-governmental organizations to supplement the care provided by the family and provide care and protection to vulnerable elderly people.

This policy also aimed at outcomes such as – a) strengthening of primary health care system to enable it to meet the health care needs of older persons, b) Training and orientation to medical and paramedical personnel in health care of the elderly,

***The health insurance sector in India doesn't cover mental illnesses; otherwise too, in general, less than 20 % of Indians have some form of health insurance.***

c) Promotion of the concept of healthy ageing, d) Assistance to societies for production and distribution of material on geriatric care, e) Provision of separate queues and reservation of beds for elderly patients in hospitals, f) Extended coverage under the "Antyodaya Scheme" with emphasis on provision of food at subsidized rates.

The National Programme for Health Care of the Elderly (NPHCE) is an articulation of the International and national commitments of the Government as envisaged under the UN Convention on the Rights of Persons with Disabilities (UNCRPD), National Policy on Older Persons (NPOP) adopted by the Government of India in 1999 and Section 20 of "The Maintenance and Welfare of Parents and Senior Citizens Act, 2007" dealing with provisions for medical care of Senior Citizen.

Major objectives of the NPHCE were to provide long-term, accessible, affordable, dedicated, quality care services to the elderly and to promote active and healthy ageing, so that the elderly could contribute to the development of the nation as was the case with elderly worldwide.

The aim was to converge with the National Health Mission (NHM) from sub-district to tertiary level. The strategies to be adopted were preventive, promotive, rehabilitative, capacity building and use of information and communication.

The Ministry of Social Justice and Empowerment, Govt. of India also constituted 'National Council for Older Persons' in May 1999. The policy stipulated that State Govt. will take affirmative action to provide facilities, concessions and relief to senior citizens for improving their quality of life and to ensure that the existing public services are user friendly and sensitive to older persons.

It provided a comprehensive picture of various facilities and covered many areas like financial security, health care, shelter education, welfare, protection of life and property etc.

The Integrated Programme for Older Persons is a scheme that provides financial assistance up to 90 per cent of the project cost to non-governmental organizations. This money is used to establish and maintain old age homes, day care centres, mobile Medicare units and to provide non-institutional services to older persons.

The scheme also works towards other needs of older persons such as reinforcing and strengthening the family, generation of awareness on related issues and facilitating productive ageing.

However most of the state policies have not translated into robust state facilities on the ground level. Some factors that have played a role in non-implementation of such policies are -

Non-availability of trained manpower, no concept of home-based care, competing priority with other health programmes, difficulty in establishing geriatric centres, especially in nodal medical colleges, lack of advocacy and research on geriatric issues, lack awareness of problems of the elderly among others.

Additionally some further barriers in the implementation of these polices are - First, there is a lack of knowledge about these schemes. Second, even if people are aware, they have problems accessing these schemes. It was reported in the study that 53% of the elderly find it difficult to access and utilize the social security schemes.

Third, there is a problem of inadequacy. If they are able to cross all the structural barriers, the money they get is not enough to support them. 79% of the respondents found the schemes are insufficient to meet their basic needs.

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***However most of the state policies have not translated into robust state facilities on the ground level.***

***Conclusion***

In an ever evolving landscape of the deterioration of 'traditional family systems and values' in India, the need for institutional care cannot be underestimated. Institutionalisation in many ways is the last resort in cases of severe dependencies, and more and more families are becoming increasingly insufficient to care for a progressively more ill geriatric population.

It is happening and will continue to happen as a result of economic, social and cultural issues as well as health care burden. Therefore it is imperative to stress upon improving the state capacity for dispensing better elder healthcare in India and increasing focus on preventive measure rather than post illness healthcare.

***Institutionalisation in many ways is the last resort in cases of severe dependencies, and more and more families are becoming increasingly insufficient to care for a progressively more ill geriatric population.***

# In Conversation with Dr. Arun Kumar Aggarwal

*Q. Could you please tell us about palliative care?*

Palliative care treatment has four main stages. The first is explaining the diagnosis to the attendants of the patient. Second is to take care of the needs of the patient. This has two parts - pain management and managing food intake.

Third is to guide the attendants through the process of providing care and helping them prepare for the arriving loss of their loved one. We try to provide comfort to them through feelings of depression that naturally arise through such a phase.

Then we must look at the course of treatment, as there are also financial limitations of the patient that we must consider. A problem India faces is in the shortage of palliative care experts along with resources dedicated to building hospices and providing palliative care.

And so, an important step is to teach the attendants how to take care of the patient, in terms of feeding and cleaning. There is a very low awareness of how to provide palliative care and so we must show them how to do it in a correct manner.

***Dr Arun Kumar Aggarwal***

*MBBS, MD (Radiative Oncology),*

*Q. What is the impact of being in this stage of receiving palliative care on the patient and their family?*

The aim of palliative care is not to prolong life or cure the disease. We can only provide medicines to give patients as much comfort and relief from pain as possible.While treating patients our role also becomes to provide support to the patient and their attendants to deal with the psychological toll that the diagnosis and illness causes.

Upon diagnosis, when we break the news to the attendants that their loved one is going to pass away, they sometimes try and seek opinions from other doctors and hospitals in hopes of finding a cure. But when they do accept that there is no cure, they go into depression.

But sometimes when they see the patient getting slightly better because of treatment, they gain some hope. However, when the patient's health deteriorates again they again fall into a depression and so it becomes a cycle.

*Q. What are the problems that are faced?*

There is a stigma against hospices in our society. They are seen as places where people go to die, that no one who enters a hospice comes out alive. It is very hard to convince the attendants of a patient to take the patient to the hospice for this reason. In a hospice, the focus is on pain relief and to avoid feeding.

By giving terminally ill patient food in their final days, we are only prolonging their pain and suffering. At this stage, we only try to give them as much comfort as possible so they can pass away as peacefully as possible. But there is a shortage of means to invest in and create hospices.

***There is a stigma against hospices in our society. They are seen as places where people go to die, that no one who enters a hospice comes out alive.***

Dr. Arun Kumar Aggarwal is the Head of the Department of Radiative Oncology in Aadhar Health Institute, Hisar. Aadhar Health Institute has been established with the aim of providing best-in-class healthcare facilities. It is offering comprehensive, integrated and quality healthcare through fully equipped ultramodern hospital to people in tier III city at an affordable cost.

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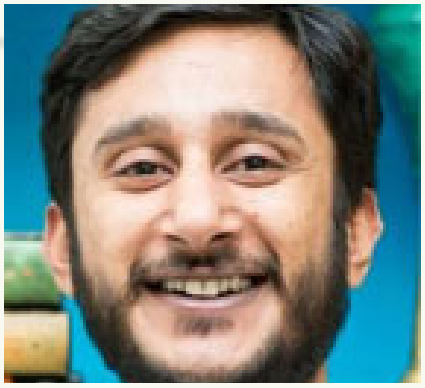

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