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HEALTH AND HUMAN RIGHTS OF OLDER PERSONS IN INDIA

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ABSTRACT

Health and well-being are important for maintaining physical independence and dignity of an ageing individual. Health and well-being depend not only on medical fitness but also on many other dimensions. Human rights of older persons therefore relate to varying realms of health and nutrition, social welfare, income security and employment, personal safety and protection and many other factors. This article has been written with an emphasis on health and medically related human rights of older persons and their violations.In the back drop of human rights issue, significance of distinguishing between “duty to provide” and “right to receive” the health care on one hand and between “responding to the health needs of older persons” and “realizing the health related rights of older persons” has been outlined. The article deals with three sections. Firstly, current Indian scenario on existing health care resources and health related rights of older persons and their violations have been highlighted. It is followed by an analytic consideration of four major health related barriers to human rights of older persons, namely older persons themselves, health care system, health care providers and the vulnerability of certain groups of elderly acting as barrier. Finally, potential steps have been given out in the direction of empowering the older persons to realize their right to health. Theseinclude education and awareness, innovations in health care and self care practices including spiritual development.

PREAMBLE

Health is a state of physical, mental, emotional, social and economic well-being. Spiritual well-being is also important for health. To achieve a healthy and active life during all stages including old age, these dimensions of health need to be nurtured throughout life. Right to health is one of the fundamental human rights and is closely interwoven with other human rights such as the right to life, to dignity, to liberty, to security and to self-determination (1). Right of enjoyment of the highest attainable standard of physical and mental health is enshrined in Article 25.1 of Universal Declaration Of Human Rights, 1948 (2). Principle 14 of

United Nations Principles for older persons promotes healthy ageing, recommending that older persons should be able to enjoy human rights and fundamental freedom when residing in any shelter, care or treatment facility (3).Right to health is of special significance to older persons because such persons are particularly vulnerable to health inadequacy. Nevertheless, phenomenon of ageism i.e. the stigma and discrimination against older persons is also responsible for denial of a range of rights which affect health, such as access to nutritious food, water and health care. In its most extreme, ageism manifests itself in abuse, violence and neglect, an area of public health issue (4). Realization of the right to health of older persons necessitates an integrated approach, combining elements of preventive, curative and rehabilitative treatment to maintain their functionality and autonomy; and attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity.

Older persons can enjoy various human rights and contribute to the development process only if they remain healthy and active. Otherwise, they become weak and lose self esteem and are liable to indifference, neglect and even abuse at the hands of those around them. Those who are very old (80 or 85+), dependent, disabled and females and particularly those residing in underdeveloped and remote areas are especially vulnerable. In rural India, more than half of the very old persons consider their health status either to be poor or very poor and utilization ofpublic health facilities by them is highly inadequate (5).

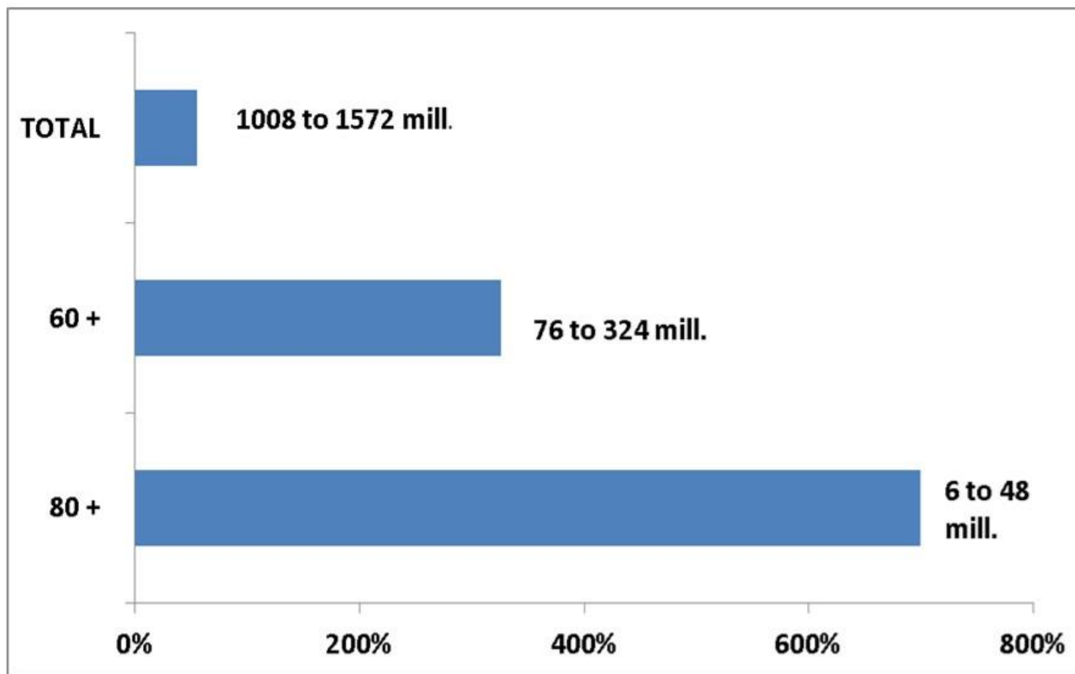
SITUATION ANALYSIS FOR INDIA

India is home to 1/8th of world's older persons (60+) i.e. 100 million of them which comes to 9% of total Indian population. Older females and rural elderly outnumber their male and urban counterparts respectively. Although this segment of population is rapidly increasing, 80+ individuals are growing the fastest. Thus 80+ individuals will increase by 700% between year 2000 and 2050 compared to 326% increase in 60+ population and only 55% increase in total population during the same period (Figure 1) (6). With such enormity and speed of this rising burden of older persons together with impoverishment in many, human rights are likely to be violated.

State initiatives for the care and welfare of senior citizens include constitutional, legislative and policy directives. Article 41 of Indian Constitution mandates that "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". Legal provisions include Section 125(1) (2) of Code of Criminal Procedure,1973, Section 20 (1) of Hindu Adoption and Maintenance Act, 1956 and more recently enacted Maintenance and Welfare of Parents and Senior Citizens Act (MWPSC Act), 2007.This Act provides for maintenance of senior citizens and other welfare measures such as protection of life and property, establishment of old age homes and better medical facilities. Under this Act, children or relatives are liable to legal action if they fail to pay maintenance to their elderly. Abandonment of the elderly is now a cognizable offence. NationalPolicy on Older Persons was first announced in 1999 and has recently been reviewed and reconsidered as National Policy on Senior Citizens in 2011. Proposed focus of the new Policy recognizes that senior citizens are a valuable resource for their own development and that of

the country and that ageing in ‘Place’ or ageing in one’s own home ensures best their dignity and empowerment while institutional care should be only the last resort. In November, 2010, National Human Rights Commission constituted a Core Group on health, safety, and welfare of the elderly people to collect and compile data base on the magnitude of the problems and challenges faced by the elderly.

Figure 1:Projected increase in Indian population by age (2000-2050)



Source: National Policy as reviewed in 2011

Health Resources

Traditional resource providers for older persons’ health care in India include family, community, civil society, NGOs, philanthropic organizations and older persons themselves. Many of these providers give informal care while public and private health sector mostly provide formal health care. In certain areas, as many as 60 to 70% of older persons use private health care facilities (7). Practitioners of indigenous systems of medicine are consulted in good measure especially in rural areas because they are readily available there and care provided by them is more affordable. Indigenous systems such as Ayurveda, Yoga, Naturopathy, Unani, Siddha and Amchi (Tibetan) methods of therapy are practiced with maintenance of health as their main objective and are therefore elder friendly. Some of the traditional home remedies have their origin in these systems. Homeopathy, Acupuncture and Reflexology are other indigenous systems. In the study carried out by Nair, home remedies were part of medical treatment

throughout the lives of elderly females in Kerala, South India (8). A number of grandma's remedies are in use in various households like turmeric, ginseng, tulsi, garlic, ginger, cinnamon etc. Indigenous systems together known as Complementary and Alternative Medicine are specially suitable for older persons because they emphasize on disease prevention andtherefore help in disability prevention as well. Moreover, these systems can also effectivelydeal with many symptoms that are complained by older persons and these are also affordable, easily available systems and are associated with lesser drug induced complications (9).

From a broader context, apart from National Policy on Older Persons, a large number of programs have been launched and some of these are Maintenance and Welfare of Parents and Senior Citizens Act 2007 already referred to, National Initiative on Care of the elderly, Integrated Program for Older Persons, National Old Age Pension Scheme, National Program for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke, various Medical Insurance Schemes for elderly and more recently, the National Program for the HealthCare of the Elderly (NPHCE). National Rural Health Mission 2005-2012 aims to provideeffective health care to Indian rural population with a focus on 18 states that have low public health indices and/or inadequate infrastructure. NPHCE is a Ministry of Health initiative being implemented in 100 backward and remote districts over 21 States, to be extended to all the640 districts of the country over the 12th plan period. Core strategies to achieve the objectives of NPHCE include primary health care approach including home visits, dedicated services at PHC/CHC level and at district hospitals of 10 bedded wards each and strengthening of 8 regional medical institutes to provide tertiary services for elderly and training facilities for different levels of health workers including postgraduate courses in geriatric medicine. These regional medical institutes are located in Delhi, Chennai, Jodhpur, Guwahati, Mumbai, Thiruvananthapuram, Srinagar and Varanasi.

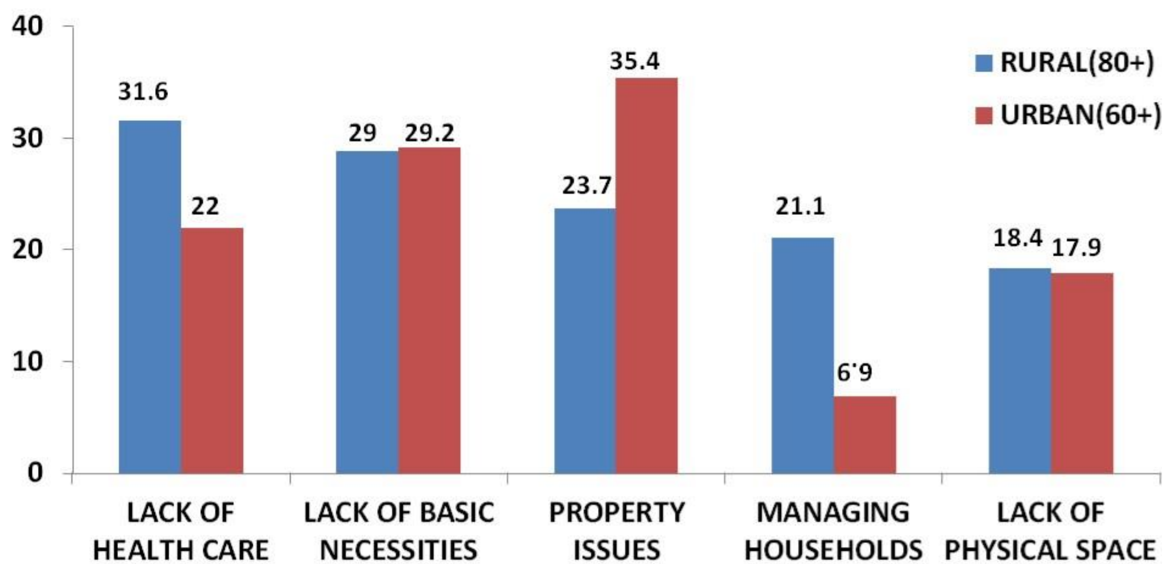
Health and Human Rights of Older Persons

According to one estimate, 6-10% of older persons in India face abuse in one form or another and in extreme cases may face abandonment. Agewell Research and Advocacy Centre in a survey of 50000 older persons reported that every third older person in the country was not getting proper medicines/health care and 12.9% were not getting proper food (10). Interviews with 10000 older women by Agewell Foundation revealed special challenges faced by them. Elderly couple living alone, with woman looking after an older husband was common (nearly 18%). 8.3% of women were bed ridden and disability rate was almost 10%. HelpAge India observed major health problems such as asthma, low eye sight, cold, cough, joint pains and problems related to physical weakness. amongst rural oldest old persons. Their study revealed that 1/6th of such persons experienced some kind of abuse, commonest context of which was lack of health care and accounted for 31.6% of cases (5). There were also cases of insufficient food intake and dependence on family members for medical expenses and in some cases old age pension was forcibly taken away by family members. Medical officers recommended that oldest old persons need love, care and affection from the family members for providing them a healthy life. In another study which was urban based and included 60+ older persons across 8 cities, HelpAge India found property as the main context for elder abuse (35.4%) while lack of health care was experienced by 22%. Other contexts of elder abuse both in rural and urban

areas included lack of basic necessities, managing households and lack of physical space (Figure 2)(11).

More specifically, treatment related human right violations can occur in any or more of the following ways namely, abuse and rough treatment, bullying attitudes, dignity in personal care needs, discriminatory treatment due to age and disability, inadequate assessment of personal needs, inappropriate medication, poor hygiene, nutrition and privacy, mistreating those with communication difficulties and those with dementia, hasty discharge from hospital/unnecessary length of stay/overdiagnosis/treatment and care with neglect, carelessness..

FIGURE 2: CONTEXT OF ABUSE IN INDIA



Poor health, insufficient food, medical/financial dependency especially for rural oldest old

The WHO World Report on Violence and Health framed elder abuse that still remains hidden in many countries as a violation of human rights and demonstrated how it is significant cause of injury, illness, lost productivity, isolation and dispair. Victimisation or neglect or poor tretment of older persons within the healthcare system is an infringement of the right to life and can be examplified by the following.

- People with dementia are significant users of healthcare services but most often the staff have only limited understanding of their needs.

- Older persons admitted in hospitals may remain soaked in urine for long hours before they are attended to.
- Time schedule for feeding the older persons including those who are malnourished in a treatment facility may not be adhered to.
- Response to agression by a dementia patient may be in the form of prescribing a powerful sedative by the staff.

Certain special groups of older persons are particularly vulnerable. For instance since older females are no longer able to act as traditional care providers in the families, they lose importance and self esteem and may get depressed and vulnerable to abuse and crime. Furthermore, in the event of lack of nutrition or an inadequate reproductive health during young age, these women, as they grow to old age, they may become victim of osteoporosis and cancer of reproductive organs respectively leading to higher morbidity in them. Other vulnerable segment includes inmates of old age homes whose condition may be pathetic. In Andhra Pradesh where only 5% of old age homes accept bed ridden or medically compromised older persons, All India Senior Citizens Confederation have filed a petition before the State Human Rights Commission (SHRC of Andhra Pradesh) pleading for protection of human right to health care of these inmates (12). Recently some positive developments have also taken place. SHRC passed a judgement on January 9, 2012 asking the State Government to identify inmates of old age homes who are below poverty line and issue them ration card/health card/identity card and to cover them under health insurance and ensure payment of old age pension to them. On June15, 2012, a Lok Adalat for senior citizens was inaugurated in Hyderabad, Andhra Pradesh which may be quite helpful in solving elder abuse cases.

HEALTH RELATED BARRIERS TO HUMAN RIGHTS OF OLDER PERSONS

Barriers to human rights in context of health originate from multiple sources such as older persons themselves, health care system, health care providers and certain especial vulnerable groups of older persons.

Older persons

Acceptance of failing health and dependency as a part of old age is a highly prevalent mindset among older persons and the people around them. A sense of fatalism seems to set in old age so that the initiative for accessing health care is lost. They come to believe that it is all a part of ageing and nothing can be done about it. Consequently, they become indifferent to many things in life including the simple and affordable self-care practices like care of their own food, engagement in physical and mental exercise, social and spiritual relaxation and even for undergoing regular health check-ups. It is a real challenge to alter this mindset which in fact is a serious barrier for the right to health. Older persons instead appear more receptive to cheap and easily obtainable home remedies of unproven value, religious prayers or even letting the time pass for anxieties to subside or preferring to suffer in silence even if they are advancing to frailty and disablement. D’Souza (7) reported that constraints in maintaining regular annual health check-up included lack of proper consciousness about one’s health (37%), feeling that

they have already reached the end of their life (26.9%), lack of health facilities (18.75%) and unavailability of an escort (17.25%).

Practice of spirituality which is known to promote health and improve coping skills (13-15) may also remain neglected due to similar lack of drive and such neglect is compounded in the face of mounting tensions of modern life. There is no time or desire for spiritual development either through meditation or through counseling sessions for inculcating positive thoughts. Consequently, a powerful and affordable tool for enhancing the quality of life remains unattained and unutilized.

Health care system

India spent 2.4% of GDP in 2009 on health care and on comparison to the world, we rank 185. Parameters to evaluate right to health viz. availability, accessibility, affordability, acceptability and quality of health care in the existing primary health care system are not robust. The system is state driven rather than demand driven and does not address the felt needs of geriatric population Serious lacuna in the areas of home/family based care, palliative care, respite care and long term care is a barrier to realization of rights for old persons specially those who are very old, dependent and bedridden. Public health facilities are generally ineffective, inadequately managed and staffed and have poorly maintained medical equipment.Quality private health care in the absence of universal insurance coverage is at best a dream and very few can afford. Health care by NGOs serves only a miniscule of older population.

Recently launched NPHCE referred to earlier is a milestone in the health care delivery to Indian older persons on national scale. The program provides for multilayered players for implementation. However, it needs closer partnering with family, community and civil society organizations so important to achieve preventive care through day care centers and home health care. Although the program appears to aim helping the families prepare themselves for possible health eventualities but it perhaps stresses on treatment of such eventualities only when they happened. Differential regional dynamics of the country also needs to be addressedfor proper implementation of this program.

In the absence of clear accountability of public, private and voluntary health care providers under human rights legislation, instances of care without dignity and respect or care with neglect, abuse and discrimination go unnoticed and without redress. Current environment is such that distinction between "duty to provide" and a "right to receive" is totally blurred A shift of paradigm from responding to the needs of older persons to realizing the rights of older persons is therefore required (4).

Health care providers

At the primary care level, greater involvement of health care providers in mother and child care and their attitude of ageism and discrimination against older persons act as barriers.They do not always fully understand diverse health needs of older persons or able to make a distinction between medical impairments and normal signs of ageing. Lack of this knowledge leads to mistreatment and abuse. Although trained personnel know basics of various geriatric disorders like diabetes, high blood pressure, heart disease, bronchitis, pneumonia, dementia, stroke,

arthritis, falls, cancer, cataract, prostate and urinary problems, they may not be sensitive enough to understand the significance of health related quality of life for which independence in terms of mobility, vision, hearing, cognition, nutrition and continence is also very important for older person. Furthermore, many age related chronic symptoms like weakness, lack of physical strength, reduced appetite, fatigue, constipation, body pains, breathlessness, impotence, sleeplessness and impaired memory do not always fit the bill with any of the above mentioned geriatric disorders and in spite of controlling these disorders such symptoms can continue to interfere with quality of life. Since many older persons seek relief of various symptomatic morbidities from cheap traditional and alternative systems of medicine and many times do get a genuine relief, a health care provider coming from a particular stream of therapyand without an integrated holistic training is not able to fully handle a medically compromised subject.

Vulnerable groups

Firstly the female elderly is a vulnerable group. Convention on the Elimination of Discrimination Against Women (CEDAW, 2008) (16) have addressed important issues. Perceived as weak and defenseless, older women suffer from a longer period of morbidity compared to older men. Being more immobile, widowed and financially dependent, they are liable to greater discrimination and abuse in matters of health. Secondly with regard to other vulnerable groups, the very old, dependent and bedridden old persons are also more liable to abuse particularly inthe absence of services to help them in activities of daily living, safeguarding them against falls and institutionalizing them in emergencies.

EMPOWERING OLDER PERSONS THROUGH HEALTH CARE

Several measures to achieve successful ageing have been cited in literature. Davies reported that members of kibbutzim, essentially a rural commune (a concept prevalent in Israel), are healthier and live longer with greater autonomy and life satisfaction in their old age than their urban counterparts (17). The Kibbutz is a voluntary cooperative village with property collectively owned and work allocated according to the needs of the group. There are about 270 such settlements with between 300 and 1200 residents and accounting for 2.5% of Israeli's Jewish population. Reason for successful ageing among kibbutzim members is the practice of egalitarianism, independent of age, gender, health or functional ability of theindividual. There is social equality, equal rights, equal access to resources and to decision making. They enjoy right to work, primary care, long term care and enjoy secure personal status without any fear of the future because the group continues to care for all the needs of itsmembers.

While studying the centenarians and the very old persons, Ramamurthy (18) and Nair (8) reported that active healthy life, absence of chronic diseases and good emotional intelligence were useful determinants for healthful longevity. Proper diet and physical activity, practice of fasting, family longevity, stress adjustment, good family relations, spirituality and religiosity were also important distinguishing determinants in such persons.

Some of the steps to help realization of right to health for older persons include education and awareness, bringing innovations in health care and inculcating self care practices.

Education and awareness

Education is one of the most effective ways to prevent abuse (1). Messages about older persons' human rights and their abuse should be disseminated to all levels viz. older persons and their families, lay public, legislators, policy makers, judiciary, police, administrators and health care workers of various treatment facilities. NGOs, media and activists should facilitate this process of creating mass awareness. National Commission of Human Rights should encourage surveys to determine the extent of human right violations of older persons particularly in remote and unfavorable locations which can be widely publicized. The curriculum content in medical, psychiatric and psychology schools and other relevant institutions should be modified accordingly. Overall objective is to change negative attitudes towards older persons in our societies and to harness the contribution of older persons. This will help in following WHO's concept of promoting active ageing which is better health and quality of life and refers to continuing participation in social, economic, cultural, spiritual and civic affairs, not just the ability to be physically active or to participate in the labor force. At the same time, older people who retire from work, are ill or live with disabilities can remain active contributors to their families, peers, communities and nations. Good health is the key for all this.

Innovations in health care

Family and community, public health, private health, and voluntary health sector along with health insurance, the five pillars of available, accessible, affordable, acceptable and effective health care for older persons should be so integrated as to provide fully subsidized care for the poor and a graded system of chargeable care for other users. Increasing number of older persons demonstrate a preference for home and community based care and accordingly, a number of workers stress its importance (19-23). Concept of nutritional care, mental health care, rehabilitative care, spiritual care and other forms of care already alluded to under the section of health care system related barriers need special attention.

Initiatives for assisting weak and dependent older persons confined in their homes in carrying out activities of daily living and other help, reminding for taking medicines on time and institutionalizing them in cases of emergency on the lines of Nightingales Medical Trustinitiative need to be augmented. More homes are also needed for abandoned and destitute older persons to provide them shelter, health, care and food and protect them from neglect andabuse. Health and well being of old age home residents specially those below poverty line whoare at times deprived of state sponsored health care for lack of government documents should be declared as state responsibility. Special attention should be given to reduce health burden due to poor housing which is an area relatively left unattended by authorities so far. It must be recognized that certain shelters may not protect the occupants against extremes of whether, insects, rodents, overcrowding and injuries and may be situated in areas with inadequate water supply, waste disposal and poor drainage (24).

Steps should be introduced to counter the failure of government departments in giving leadership and guidance to providers of health and residential care on the protection of older persons' right to health. Right to health of older persons must be included in National Health Policy. Measures to strengthen human rights obligations and duties, to bring public, private and voluntary facilities within the scope of human rights legislation, to establish more robust complaints procedures, to advocate better staff training in human rights principles and their inclusion in health professionals' qualifications as well as a duty to blow the whistle on abuse are some of the steps (25). National Accreditation Board of Hospitals (NABH) must be advised to include as one of the standards for compliance by hospitals to have in their policy and practice statements on enforcement of human rights of patients, particularly older ones (26).

In view of the fact that costly drugs and their adverse reactions together with expensive medical and surgical procedures of modern medicine acting as a deterrent to acceptance of the system by many older persons, training of health care provider should be more inclusive to incorporate the benefits of alternate therapy systems like ayurveda, homeopathy, naturopathy, yoga, meditation, reflexology and other systems.

Self care practices

Tobacco use, unhealthy diets, harmful use of alcohol and physical inactivity are common risk factors for non communicable diseases (NCDs) and there is a link between the prevention and control of NCDs and the full realization of the right to health. Addressing these risk factors requires strong government leadership underpinned by the obligation of the government to respect, protect and fulfill the right to health, but many of these and several other risk factors can be avoided through appropriate self practices on the part of older persons themselves. Older persons should involve themselves in self enhancing programs (SEPs) for increasing their self-esteem which helps improving their quality of adaptation, well-being, life satisfaction and health. SEPs include individual or group reminiscences therapy, life review programs and physical exercise (27).

Practicing of spirituality and religiosity is also a self care practice. Majority believe in God; 9 out of 10 people pray and 97% believe their prayers are answered. While religion is generally linked with a faith, spirituality is reflected in every day thoughts, feelings and actions. Both spirituality and religion can impact mental health by bringing a sense of wholesomeness and well-being, help tide over the despair of age decline and contribute to risk reduction for cancer, cardiovascular disease and depression. Spirituality is also useful for dementia through practice of music, incense touch, visual symbols all of which do not require cognitive pathways (28). Motivational steps are needed for spiritual enhancement through meditation and other methods of concentration or by developing positive thoughts of love, compassion, contentment, optimism, composure, forgiveness, and wisdom of right and wrong which to many give a sense of feeling high and great (29).

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