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Diversification of disability and health care among the elder population in India

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ABSTRACT

Disability among the elderly is serious challenges for a country that affect the individual, family and society. The objective of this study is to understand disability prevalence by selected characteristics, access to the health facility and the care providers to older disabled people in India. The study used the data from Census of India 2011, and SAGE Wave-1 (2007) data of India. Standardized Index of Diversity of Disability (SIDD) was used to identify the diversification of disability in India. Among 103.84 million (8.0%) older population, 5.34 million (5.19%) were disabled. Standardized index of the diversity of disability varies from 0.80 to 0.73, found highly diversified by all disability prevalence in all states of India. Thirty-eight percent of older disabled perceived their health care facility last sought as good and 17.0% as a bad healthcare facility. Fifty seven percent of the elder disabled accessed health care from private hospitals. Spouses were found to be the primary providers of physical, financial, and health support to older disabled. In conclusion, India exhibits a high and diverse disability among its older population. There is a need for customized state/district/disability specific targeted intervention for the welfare of the older Indian population.

Keywords: Elder, disability, Standardized Index of Diversity, healthcare

INTRODUCTION

In the recent decades, the world witnessed a demographic change, particularly in the developing countries i.e., population ageing, which brings the attention of policy shifting toward having a great emphasis on the population aged 60 and above years. Along with ageing, this change also brings many positive demographic phenomena like extended life expectancy, healthier life and on the other hand, negative consequences are often seen as a health-associated increased burden on medical, economic and healthcare services. According to the 2011 Census of India, about 104 million people (8.6%) are aged 60 and above years, which was 77 million (7.5%) in 2001 (Census of India, 2011; 2001). Acceleration of an increasingly older population reveals many health-related issues, financial dependencies, physical and functional impairment (Alam, 2004). With increasing life expectancy, it is evidenced that population ageing is also associated with disability and longterm healthcare (Agrawal, 2016). Population ageing with a disability has been often seen as losses of physical, mental and social functions. World Health Organizations (WHO) defined

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disability as "it is any restriction or lack of ability (resulting from an impairment) to perform in a manner or within the range considered for a normal human being." WHO estimated that worldwide one billion population are living with multiple disabilities (World Report on Disability, 2011). An estimated 26.8 million (2.21 %) of the Indian population was disabled in 2011, which was 21.9 million (2.13 %) in 2001 (Census, 2001, 2011). However, the percentage of disabled among the elderly population (aged 60 and above years) is 5.19 % (5.34 million) in 2011 increased from 4.93 % (3.77 million) in 2001 (Census, 2001, 2011).

The elderly people experience more ill-health, disability and many exhibits multiple health conditions (Rahman, Guntupalli, & Byles, 2018). Further, with increasing age, chronic and acute morbidities also increase. Morbidity patterns indicate that the elderly experience a greater burden of ailments compared to other age groups (National Sample Survey, 2004). There are many empirical studies on disability, and their healthcare status focused on developing countries (Sengupta, & Agree, 2002; Yount, & Agree, 2005; Konjengbam et al., 2007; Pandey, 2009; Parahyba, 2009; Awasthi, Pandey, Dubey, & Rastogi, 2017). In India, there is limited information available on the cause and impact of the disability. Census and National Sample Survey (NSS) are two large-scale data, which provides reported information on disability. Census uses the medical conditions for determining the type of disability as seven basic types of disability and one as multiple disabilities. It, however, lacks information more details about the cause and health-seeking pattern. The information on disabilities type and the socioeconomic profile of the disabled, chronic illness among the disabled were collected during 42nd, 52nd and 60th round of NSSO at national and state level in India. Another data source for disability estimation is WHO Study on Global AGEing and Adult Health (SAGE, 2013) survey Wave-1 (2007), which covered six representative states of India: namely - Uttar Pradesh, Assam, Karnataka, Maharashtra, Rajasthan, and West Bengal. Although the Census and NSSO both provide the estimate of disability type, both are considerably different in term of coverage and disability type & definition. With medical condition's based definition of disability and their type, Census 2011 is the important resource for estimating the disability prevalence with eight types across the nation and sub-group of the population of India (Census, 2011).

Studies on the standardized estimation of disability prevalence among the elderly population and health outcome in India are rare (Velayutham, Kangusamy, Joshua, & Mehendale, 2016). With this gap, we try to estimate disability prevalence among the elderly population by type of disability, sex, and residence. The residence-based disability is calculated by using the Standardized Index of Diversity of Disability. This index formula suggested by Lieberson (1969) and further given by Rowland (2003) (Rowland, 2003). According to Lieberson (1969) and Rowland (2003), this index describes the actual level of diversity as a proportion of the maximum possible level specifies the number of categories (Rowland, 2003). This formula was further used by Ponapalli and F. Ram (2010) and constructed an index on religion using six major religious distribution of the population in India (Ponnapalli, & Ram, 2010). We used this formula on the distribution of diversification on disability. The study also attempted to study the scenario of healthcare for the elderly disabled population. This study might be helpful for an estimate of the diversified concentration of disability, which will be useful for creating awareness and develop need-based health care program as well as policy intervention for the elderly disabled population.

MATERIAL AND METHODS

The present study used the data from the Census of India 2011 (Census, 2011) and Study on Global AGEing and Health Survey (SAGE) Wave-1 (2007) (SAGE, 2013). Census 2011 is a whole enumeration and covered all states and Union Territories (UTs) with 640 districts. Census collected information on disability since 1872 but with the type of disability included first time in 1981 which collected on three types of disability (leprosy, deaf-muteness, blindness), while the disability question was dropped in Census 1991. Again, in Census 2001, information was collected on five types of disability (seeing, hearing, speech, movement, and mental illness). However, in 2011, the census included the eight types of disabilities with three new medical conditions i.e., mental retardation, mental illness, and any other disability. Of census 2011, table C-20 provides the information on disability by a social group (Scheduled Caste and Scheduled Tribes) and overall disability at the national level with selected sociodemographic characteristics.

Census 2011 apply the medical test-based model to collect information on self-reported disabilities. With the type of disabilities; seeing disability defined as asked to apply a simple test to ascertain blurred vision. For hearing, if the person using hearing aid treated as disabled. For speech disability, if a person 'speak a single word and are not able to speak in the sentence' treated as disabled. For movement, it included paralytic, crawl, walk with the help of aid, acute and permanent problem of joints/muscles, and stiffness/tightness in movement/have loose. involuntary movement, difficulty in coordinate body movement deformity of the body like hunchback or dwarf. Mental illness, mental retardation, any other and multiple disabilities were newly category introduced in census 2011. The mental illness and mental retardation both are covered under the category of mental disability in census 2001. For any other disability, the respondent enabled to report which are not listed in questions and information also not sure about the type of disability that included in any other disability. Multiple disabilities are defined based on a question designed to record as many as three types of disabilities reported by individuals.

SAGE Wave -1 is a multi-topic nationally representative survey in six populous states of India, i.e.; Uttar Pradesh, Assam, Karnataka, Maharashtra, Rajasthan, and West Bengal. SAGE Wave-1 has a total of 11,230 completed interviews: 4,670 individuals aged 18-49 and 6,560 individuals aged 50plus. For this analysis purposes, we have filtered out 3618 individuals aged 60 and above (1,706 women and 1,912 men). One of the objective is based on SAGE Wave-1 data is to obtain the scenario of health and health care provider to older disabled population. SAGE Wave-1 data provides detailed information on elderly healthcare and providers for the older population. Measurements of health included self-reported ratings on overall general health as related to eight health domain, disability and activities of daily living/instrumental activities of daily living (ADL/IADL) are also available in the data.

Outcome variables

The disability prevalence has been considered as the main outcome variable and is defined as the proportion of the disabled population to the total population of aged 60 and above years covered in the Census 2011. The pattern and perceived quality of healthcare received in the last 12 months by the disabled population gathered in SAGE Wave-1 has been analyzed as the other outcome variables. In SAGE Wave-1, there is information about the health care obtained from healthcare workers, hospitals, clinics, and the healthcare system. A question asked as "the last time you needed healthcare, did you get healthcare?" The response is recorded as yes '1' and no '2'.There is some additional information about the care received from the household member when an older person needed care which includes physical, emotional, health, personal and financial care and also about their perception about the quality of health care services received.

Exposure variables

After detailed literature review and available data, we have analyzed the disability prevalence by gender (male, female), age group (60-69, 70-79, and 80+), and place of residence (rural, urban). Inter-state and district wise variation in disability prevalence has also been estimated to understand the differentials in disability in the country.

Statistical analysis

The prevalence rate of disability has been calculated for the person reported to suffer from any disabilities by the total population. For methodological perspective, we use Standardized Index of Diversity of Disability. The concept of Standardized Index of Diversity (SID) formula suggested by Lieberson (1969) and further given by Rowland (2003) (Rowland, 2003). This formula was used and constructed index on religion by K.M. Ponnapalli and F. Ram (2010). We apply this index to disability in India. This Index is calculated as:

Standardized Index of Diversity of Disability = $[1 - {(PSE)2 + (PSP)2 + (PME)2 + (PMV)2 + (PMR)2 + (PMI)2 + (PMD)2 + (PMD)2 + (PAD)2 } / {1 - (1/1/8)}]$

- PSE: Proportion of seeing disability in the total disabled population.
- PSP: Proportion of speech disability in the total disabled population.
- PHE: Proportion of hearing disability in the total disabled population.
- PMV: Proportion of movement disability in the total disabled population.
- PMR: Proportion of mental retardation disability in the total disabled population.
- PMI: Proportion of mental illness disability in the total disabled population.
- PMD: Proportion of multiple disabilities in the total disabled population.
- PAD: Proportion of any other disability in the total disabled population
- SIDD values fall between 0 to 1. The 0 value shows the region has very less diversification in types of disability, while 1 value means the region is highly diversified by all types of disabilities prevalence.

RESULTS

Figure 1 presents the disability prevalence among 60+ populations by place of residence. The prevalence rate of disability was higher (5.2%) among the older population living in rural areas (5.6%) compared to urban areas (4.2%). Irrespective of residence, the prevalence of disability increases with increasing age. It was higher in oldest age (80 and above) and lower in younger old age (60-69) population.



Figure 1: Disability Prevalence among 60+ populations in India

Among older population, the percentage of movement (20%), seeing (19%), hearing (19%) and any other (18%) disabilities

was higher while mental illness and mental retardation was lower (Figure 2).

The prevalence rate with type and gender shows that movement disability was higher in older male (27.6%) than female (23.0%) population. However, higher percentages of female had seeing disability compared with the male population.

The almost equal proportion in both older male and female population had the hearing, mental illness, and mental retardation disability (Figure 3).







Figure 3: Disability prevalence by type and sex among 60+ populations, 2011in India

The result of the total older population (in a million) and the prevalence of disabled older population by type of disability in all states and Union Territories (UTs) is presented in table 1. The prevalence rate of any disability varies from 11.11% to 2.53% in the older population. The higher disability prevalence among the older population (top five states) found in Sikkim (11.11%), Rajasthan (10.92%), Jammu and Kashmir (9.09%), Chhattisgarh (8.73%), and Arunachal Pradesh (7.62%). However, it observed lower in Tamil Nadu (2.53%), Dadra and

Nagar Haveli (3.10%), Daman & Diu (3.53), Chandigarh (3.58%), and Karnataka (3.79%). Almost 17 states and UTs reported disability prevalence above than the national average. Seeing disability among older populations vary from 2.67% to 0.44% that was higher in Rajasthan and lower in Tamil Nadu. The top five states having seeing disability older population are Rajasthan, Sikkim, Jammu and Kashmir, Arunachal Pradesh, and Chhattisgarh, where the prevalence rate was more than 2.08% than other states of India. Hearing disability was higher among older population in Sikkim, Nagaland, Arunachal Pradesh (more than 2.23%); while speech disability in Maharashtra, Goa, Sikkim (more than (0.36%), movement disability in Rajasthan, Chhattisgarh, Odisha (more than 2.0%); mental retardation in Manipur, Mizoram, Jammu and Kashmir (above 0.16%), and mental illness in Uttar Pradesh, Maharashtra and Andhra Pradesh (above 0.23%). Any-other disability was higher in Sikkim, Jammu and Kashmir and Punjab (more than 1.0%), and multiple disabilities were more in Rajasthan, Sikkim, and Jammu and Kashmir (above to 1.50%) among the older population.

Table 1:Disability Prevalence among 60+ populations in different states of India

| States/UTs | Elderly | Disabled | |
|----------------------|--------------|----------|--|
| | (in million) | | |
| Uttar Pradesh | 15.440 | 4.28 | |
| Maharashtra | 11.107 | 4.64 | |
| Andhra Pradesh | 8.278 | 5.96 | |
| West Bengal | 7.742 | 4.73 | |
| Bihar | 7.707 | 4.26 | |
| Tamil Nadu | 7.510 | 2.53 | |
| Karnataka | 5.791 | 3.79 | |
| Madhya Pradesh | 5.713 | 5.84 | |
| Rajasthan | 5.112 | 10.92 | |
| Gujarat | 4.787 | 4.00 | |
| Kerala | 4.193 | 5.37 | |
| Odisha | 3.984 | 7.52 | |
| Punjab | 2.866 | 4.24 | |
| Jharkhand | 2.357 | 6.27 | |
| Haryana | 2.194 | 5.66 | |
| Assam | 2.079 | 5.18 | |
| Chhattisgarh | 2.004 | 8.73 | |
| Delhi | 1.147 | 4.37 | |
| Jammu and Kashmir | 0.923 | 9.09 | |
| Uttarakhand | 0.901 | 4.93 | |
| Himachal Pradesh | 0.703 | 6.94 | |
| Tripura | 0.291 | 4.60 | |
| Manipur | 0.188 | 4.80 | |
| Goa | 0.163 | 5.65 | |
| Meghalaya | 0.139 | 3.96 | |
| Puducherry | 0.121 | 5.47 | |
| Nagaland | 0.103 | 6.96 | |
| Mizoram | 0.069 | 4.20 | |
| Chandigarh | 0.067 | 3.58 | |
| Arunachal Pradesh | 0.064 | 7.62 | |
| Sikkim | 0.041 | 11.11 | |
| Andaman & Nicobar | 0.025 | 5.82 | |
| Dadra & Nagar Haveli | 0.014 | 3.10 | |
| Daman & Diu | 0.011 | 3.53 | |
| Lakshadweep | 0.005 | 6.02 | |
| Total | 103.84 | 5.19 | |

Table 2 presents the result of Standardized Index of Diversity of disability among the older population by place of residence among states of India. The SIDD index value varies from 0.80 to 0.73 meaning that all states and UTs found highly diversified by different types of disability prevalence in India. In rural areas, SIDD index varied from a 0.80 to 0.63, and in urban areas, from 0.80 to 0.73% for all states and UTs in India. The diversification of disability among older was found higher in Goa, Maharashtra, West Bengal, Kerala and Punjab states of India.

The district-level disability prevalence among 60+ older populations presented in figure 4 through the map generated in Arc-GIS. The district wise result shows that the disability prevalence among older population varied from high of 22.83% to low of 2.01%. The prevalence of disability found higher in Rajasthan, Odisha, Chhattisgarh, Sikkim, Arunachal Pradesh, Jammu and Kashmir states of India. The disabilities prevalence was higher (top 10 districts) in Anantnag (22.83%) and Pulwama (17.73%) from Jammu and Kashmir, the Tawang (15.29%) from Arunachal Pradesh, Pali, Tonk, Udaipur, Jalor, Jaisalmer, and Bundi (more than 14.0%) were from Rajasthan states of India.

Table 2: SIDD among 60+ disabled population indifferent states of India by place of residence, 2011

| State/UTs | Urban | Rural | Total |
|----------------------|-------|-------|-------|
| India | 0.79 | 0.77 | 0.78 |
| Uttar Pradesh | 0.78 | 0.78 | 0.78 |
| Maharashtra | 0.80 | 0.78 | 0.79 |
| Andhra Pradesh | 0.79 | 0.75 | 0.76 |
| West Bengal | 0.80 | 0.78 | 0.79 |
| Bihar | 0.78 | 0.77 | 0.77 |
| Tamil Nadu | 0.77 | 0.77 | 0.77 |
| Karnataka | 0.78 | 0.76 | 0.77 |
| Madhya Pradesh | 0.77 | 0.76 | 0.76 |
| Rajasthan | 0.76 | 0.74 | 0.74 |
| Gujarat | 0.78 | 0.76 | 0.77 |
| Kerala | 0.79 | 0.79 | 0.79 |
| Odisha | 0.78 | 0.76 | 0.76 |
| Punjab | 0.78 | 0.79 | 0.79 |
| Jharkhand | 0.77 | 0.76 | 0.76 |
| Haryana | 0.78 | 0.77 | 0.78 |
| Assam | 0.80 | 0.79 | 0.79 |
| Chhattisgarh | 0.76 | 0.74 | 0.75 |
| Delhi | 0.74 | 0.75 | 0.74 |
| Jammu & Kashmir | 0.79 | 0.79 | 0.79 |
| Uttarakhand | 0.79 | 0.77 | 0.78 |
| Himachal Pradesh | 0.79 | 0.78 | 0.78 |
| Tripura | 0.79 | 0.78 | 0.78 |
| Manipur | 0.80 | 0.77 | 0.78 |
| Goa | 0.80 | 0.80 | 0.80 |
| Meghalaya | 0.79 | 0.76 | 0.77 |
| Puducherry | 0.74 | 0.73 | 0.74 |
| Nagaland | 0.77 | 0.74 | 0.74 |
| Mizoram | 0.77 | 0.77 | 0.77 |
| Chandigarh | 0.76 | 0.63 | 0.76 |
| Arunachal Pradesh | 0.76 | 0.75 | 0.76 |
| Sikkim | 0.80 | 0.76 | 0.77 |
| Andaman & Nicobar | 0.79 | 0.76 | 0.76 |
| Dadra & Nagar Haveli | 0.73 | 0.75 | 0.74 |
| Daman & Diu | 0.75 | 0.69 | 0.73 |
| Lakshadweep | 0.75 | 0.72 | 0.74 |



Figure 4: Disability prevalence among population aged 60+ years in India, 2011

About two-fifths of the older population perceived to have availed good/very good health care from health facilities from 2007 to 2008 period. About a half (46%) of them have availed moderate health care facility while 17% perceived their received health care to be bad. (Figure 5).



Figure 5: Perceived health care from health facilities among 60+ disabled populations

Fifty-six percent of the older disabled population accessed health care from private hospitals, 36% from public hospitals and only eight percent from a charitable health care facility and other sources (Figure 6).



Figure 6: Accessibility of health facilities, 2007

Figure 7 depicted the result of health care among the older disabled population. About 43% spouse and 38% son/daughter in law provided financial support while 75% son/daughter provided social support to older disabled. Overall, higher percentages of the spouses had provided physical, personal, financial, and health support to the older disabled population.



Spouse Son/Daughter Son/Daughter-in-law Others members

Figure 7: Health and care provider to 60+ disabled population by houehold members in India, 2007

DISCUSSION

This study provides the prevalence and diversity of older disabilities in 35 states plus union territories, and 640 districts of India along with the elderly's perceived quality of health care and healthcare providers. The disability prevalence among the older population was higher compared to the other age group population in India. The study found that those who are living in rural areas were more suffer from a disability then urban areas. This finding conforms with an earlier study conducted in the state of Tamil Nadu, where physical impairment reported higher in rural areas compared to urban areas (Sowmiya, Kumar, & Nagarani, 2015). We found that movement, seeing and hearing disability are commonly observed among the older population. This may be due to advancing age (Sowmiya, Kumar, & Nagarani, 2015). Another study also depicted that one in every 20 Indian of 60+ populations is either physically or mentally disabled (Velayutham, Kangusamy, Joshua, & Mehendale, 2016). This study also found that seeing hearing and multiple disabilities are a common problem among older female than male. The study finding is similarly observed with study found that physical disability higher in male and vision problem in women (Rahman, Guntupalli, & Byles, 2018). Elderly women bear excess blindness compare to men (Abou-Gareeb, Lewallen, Bassett, & Courtright, 2001). Some studies highlight that it could be due to increased longevity and a higher risk of developing cortical cataract (Klein et al., 1994; Courtright, Kim, Lee, & Lewallen, 1997). Women accounted the higher risk of

trachoma blindness due to some factors such as active infection acquired from children care, poor household's environment, and sanitation facility (Courtright et al., 1989; Congdon et al., 1993). The determinants as social circumstances and risk behaviours play a significant role in the health and functional status of the disabled population (Medhi, Hazarika, Borah, & Mahanta, 2006). There is also a need to study primary level health care to determined health need for older disabled (Sowmiya, Kumar, & Nagarani, 2015).

The disability prevalence rate varies considerably among states and also by districts. The geographical variations in the distribution of disability observed in this study are further needed to explore the utilization of the type of health facility and cause of disability with local and primary level interventions. Also, this study recommended focussing on primary level interventions on the cause behind disability in high prevailed states and district in India. This study also focused on health care among the older disabled population and the findings reveal a mixed picture of the perceived quality of availed health care. A study in China also shows that less health care use observed among older disabled male, less educated, rural dwellers and those without medical insurances coverage (Guo, Du, Hu & Zheng, 2016). Majority of the 60+ population have availed health care from a private health facility. The probable reasons may be due to the availability of doctors, high socioeconomic status, medical insurance, distance and transportation services, employment status, and better treatment facility than public sector (Landerman et al., 1998; Mattson, 2011; Alkhawaldeh et al., 2014; Gong, Kendig & He, 2016). We further found the spouses as the most important caregiver and the children mostly providing social support.

There are several on-going programs on disability in India namely- National Mental Health Programme (NMHP), National Programme for Health Care for Elderly (NPHCE), National programme for prevention and control of deafness (NPPCD), and National Blindness Control programme which provide the curative, preventive and rehabilitative services to the older disabled population (Velayutham, Kangusamy, Joshua, &Mehendale, 2016). There is a pertinent need to develop training programme at village and community level to provide need-based health care and rehabilitative services (medicine, care, and support) to older disabled that have no social and personal support.

The strengths of this study are it provides useful information on standardized disability prevalence by state, district and also according to the place of residence which is of immense use for any policy and program targeting elderly welfare. The findings on the caregivers and the perceived quality of healthcare received by the disable 60+ population is an addition to the limited existing evidence on their healthcare utilization. However, the estimate on disability prevalence is based on selfreported census data, which may vary from the actual disability prevalence. The SAGE Wave-1 data is a survey limited to six states and the results based on it have usual concerns of a survey data like sampling and non-sampling errors and lack of temporal association due to cross-sectional nature of the survey.

CONCLUSION

The burden of disability is higher in India where physical impairment is a common problem among older disabled. The

burden of disability is concentrated in a few districts which need customized policy intervention along with better public health targeting the older disabled people.

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