

# Title: **SOCIAL DIFFERENCES in DEMENTIA-FREE LIFE EXPECTANCY (DemFLE) in INDIA**

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## **Abstract 250 words**

Globally Dementia is a substantial public health concern and its impact on aging population is of rapidly growing importance. Previous research has predominantly established social differences in life expectancy (LE) in India reflecting the country's complex socio-demographic landscape, but there is a paucity of research on dementia health expectancies from low and middle-income countries like India. We have used Longitudinal Aging Study of India – Diagnostic Assessment of Dementia (LASI-DAD) and National Family Health Survey (NFHS 5) data for investigating this study. The motivation for this research arises from our preliminary findings that LE at age 60 and above in India varies considerably across castes, and religious communities and so do the dementia prevalence that have confirmed the social differences across India. So, our hypotheses posit that castes, and religious groups with higher LE will also tend to exhibit longer dementia-free life expectancy (DemFLE) at later ages. In this preliminary analysis, we aim to project the remaining life expectancies at age 60 across various social groups. Subsequently, in the second stage, to be completed prior to the conference, we will integrate these life expectancy estimates with the prevalence data for dementia. If our final findings align with our expectations, it would imply that individuals from these groups not only live longer but also have extended periods of late years free from dementia. Addressing these dynamics is a significant step forward in a diverse social construction like India which will not only underscore the longevity but also the overall quality of life among India's rapidly aging population.

## **Background & Theoretical framework**

Dementia, is an umbrella term for a group of neurodegenerative disorders characterized by a decline in memory, thinking and the ability to perform daily activities (NCBI Bookshelf, 2023; WHO, 2023). The impact of dementia extends far beyond the cognitive impairment (Cipriani, Danti, Picchi, Nuti, & Di Fiorino, 2020). Dementia has gained increasing attention due to its profound impact on aging populations. It is anticipated that the prevalence of dementia will increase significantly in the ensuing decades also in low and middle-income countries, making it a crucial public health issue (Ferri et al., 2005; Prince et al., 2012; Prince et al., 2013). In the context of India, due to the country's distinctive demographic and social composition, the impact of dementia has become more challenging (Ravindranath & Sundarakumar, 2021). India is a nation with rapid aging and witnessing a surge in aged population. Because of this demographic shift, the incidence and the prevalence of neurodegenerative disorders are also a burdening concern (Ravindranath & Sundarakumar, 2021). These are not only having the impact on health but also have an impact on nation's social cohesion and economic prosperity (Kumar, George, & Kallivayalil, 2019; Sathianathan & Kantipudi, 2018).

With increasing global life expectancy (LE), recent literature observed a growing interest in whether the extra years gained are lived in good health. Dementia free Life Expectancy (DemFLE) can be defined as the number of years lived with and without dementia, providing information about the quantity and quality of life lived at a population level (Chang et al., 2013; Perenboom, Boshuizen, Breteler, Ott, & van de Water, 1996; Wu et al., 2020). Over the last decades, with increasing life expectancy, researchers have begun to explore whether these gains in years in life expectancy are

healthy years or years lived with disease and disability (Robine & Ritchie, 1991). Health expectancy combines morbidity and mortality estimates to provide healthy and unhealthy life expectancy indicators. These measures are generally independent of the population's age structure; therefore, they can be compared across the time and population subgroups. Since the risk of dementia is greatest in late life, it would be interesting to know how the number of years with this condition is likely to be affected by the reduction in old-age mortality.

The majority of research on Dementia health expectancies has come from high-income nations with longitudinal ageing studies and similar cultural heritage, such as the United Kingdom (UK), the United States (US), and Australia (Farina, Hayward, Kim, & Crimmins, 2020); (Ritchie, Mathers, & Jorm, 1994); (Wang et al., 2023). There are a few isolated findings from low and middle-income nations that extend knowledge in this field (Andrade, Corona, & Oliveira Duarte, 2019); (Ashby-Mitchell, Jagger, Fouweather, & Anstey, 2015); (Muangpaisan, Petcharat, & Srinonprasert, 2012). The comparative studies between high-income countries (HICs) and middle-and low-income countries (LMICs) has highlighted the disparities in the burden of dementia. Studies indicated that HICs tend to experience longer DemFLE compared to LMICs, which implied the differences in healthcare utilization, social factors and overall population health managements (Langa et al., 2008). According to (Prince et al., 2016), countries with higher income generally exhibit overall increased life expectancy due to better healthcare infrastructures, which results in improved cognitive health outcomes with longer DemFLE. In contrast the studies showed that LMICs encounter inadequate healthcare resources and socio-economic disparities, resulting into shorter DemFLE and higher burden of dementia. A study from the middle-income country Cuba (Llibre Rodriguez et al., 2008) reported that DemFLE at age 60 was lower than that in HICs. This suggests that individuals from LMICs may spend a greater portion of their lives in later years with dementia.

To date, dementia free life expectancy (DemFLE) has received much less attention in India, thus no studies have been done in this field. In recent years, literature on DemFLE has been increasing, but most is gathered from western countries. Although the Indian literature on various aspects of cognitive impairment and dementia is increasing, but still far short of assessment of the burden of cognitive loss in a population by highlighting whether additional years lived are spent cognitively healthy or in poor cognitive health. Thus, the present study will fill this research gap by providing estimates of Dementia-free Life Expectancy (DemFLE) at the national level. This study will investigate the specific dynamics of regional and social differences in DemFLE within the Indian context. Given the complexities of India's demographic diversity and its status as a lower-middle-income country, there is an urgent need of research that explores and delves into the intricate nature of dementia. It will enable the policymakers to more effectively prevent dementia, slow its progression, and narrow the gender differentials.

Research on life expectancy in India sheds light on the disparities that apparently exist in different regions and social groups of the country. According to (Gupta & Sudharsanan, 2022), individuals from marginalized castes (Scheduled caste, Scheduled tribe, Other backward classes) often face lower life expectancies compared to higher-caste groups. At the same time religious differences in life expectancy are also evident from the research conducted by (Kumari M, Mohanty S K, 2020) with higher life expectancy among Christians(68.1 years) than Muslims(66.0 years) and Hindus (65.0 years). There are some other studies in India which also highlight the substantial disparities in life expectancies across the Indian regions and social groups (Subramanian et al., 2006). The findings from these studies reveal that these disparities are indicative of the multifaceted socio-economic factors that influence the health outcomes in India. According to (Gupta & Sudharsanan, 2022), the religions and caste-based disparities in healthcare utilization, education contribute to the differences in life expectancy in India.

These socio-economic factors responsible for differences in life expectancies, are intertwined with the socio-economic risk factors of dementia. Education, as a prime determinant of cognitive resilience, explains substantial disparities across the various Indian demographic groups. According to (Lee et al., 2023; Mathuranath et al., 2010), there is a correlation between lower education levels and increased risk of dementia and these discrepancies are apparent by socio-religious factors (Muhammad, 2022; Muhammad, Pai, Kumar, & Sekher, 2023). Additionally, (Chandra et al., 1998) also highlighted that the variations in healthcare infrastructure, accessibility and quality between social groups can impact the early detection and management of Dementia. It can be concluded from the studies by (Raina et al., 2013; Verma & Dash, 2020)that religious differences in healthcare access can ultimately affect the dementia outcomes. Moreover, diabetes is a well-established risk factor for dementia among older adults in India. The research findings from (Ahmed Shaikh, Bhuvan, Thet Htar, Gupta, & Kumari, 2019; Cukierman, Gerstein, & Williamson, 2005) suggested that individuals with diabetes are approximately 1.5 times more likely to develop dementia compared to those without

diabetes. In India there are differences in diabetes prevalence among the older adults by, caste and religious factors. According to the data from Indian National Family Health survey (NFHS), the southern states like Kerala, Tamilnadu reported the higher prevalence of diabetes among older adults (Corsi & Subramanian, 2012; Maiti, Akhtar, Upadhyay, & Mohanty, 2023). Caste and religion based disparities in diabetes prevalence are also notable from the research by (Maiti et al., 2023). These findings underscore the significance of diabetes as a risk factor of dementia among Indian older adults. Additionally, alcohol and tobacco consumption patterns among those aged 45 and older also exhibit the variations in risk of developing dementia (Kawakami et al., 2023; Letenneur, Larrieu, & Barberger-Gateau, 2004) among older adults in India (Khan, 2022; Muhammad, Govindu, & Srivastava, 2021).

It is evident from the previous research that the variations in risk factors for dementia such as education, healthcare, lifestyle, are intricately linked to life expectancy, which can directly contribute to the disparities in DemFLE in India. So, this study specifically aims to investigate the research question: Are the significant variations in social aspects of dementia (DemFLE) similar to the disparities observed in the life expectancies among the older population in India? By addressing this question, we seek a deeper emphasize on the importance of estimating DemFLE for older adults, as it reflects not only the length of life but the quality of life accounting for burden of dementia. Understanding the correlation between life expectancies and DemFLE allows for assessment of healthcare needs and the quality of life of elder population.

## **Hypotheses**

H<sub>1a</sub>: Higher life expectancy within certain caste groups are more likely to have greater DemFLE (Positive association)

H<sub>2a</sub>: The religious groups across India with higher life expectancy are expected to have a greater DemFLE (Positive association)

## **Data & Methods**

### ***Data***

Our study is based on two types of data, the LASI- Diagnostic Assessment of Dementia data from the first wave of the Longitudinal Aging Study in India (LASI) for the prevalence of dementia and fifth round of the National Family Health Survey (NFHS 5) for estimating mortality:

LASI is a nationally representative longitudinal survey conducted between 2017 and 2019 that provides data on cognition, mental and physical health, and social networks of the aging population in India. LASI sample comprises over 72000 individuals aged 45 and older across all states and union territories. LASI survey is conceptually similar to the United States Health and Retirement Study (HRS) and other HRS-type surveys in different countries, including China Health and Retirement Longitudinal Survey (CHARLS) in China, Indonesia Family Life Surveys (IFLS) in Indonesia, and English Longitudinal Study of Ageing (ELSA) in England. LASI data was utilized to assess the prevalence of dementia in older Indian adults. From LASI, a sample of adults aged 60+ were administered the neuropsychological tests and informant interview in 2018 through 2020, to get the subsample study on dementia assessment (LASI-DAD) for older adults in India.

NFHS-5 is a large-scale cross-sectional and nationally representative conducted between 2019 and 2021. It collects data from 636,699 households and encompasses 825,954 individuals residing within them. Regarding mortality, NFHS-5 aimed to capture overall mortality, and data were collected at the national and district levels. During the survey, participants were asked for information about any deaths that occurred among household members within a 2-year reference period. A total of 80,667 deaths were recorded. In addition to that a separate woman's questionnaire was asked to the ever-married woman in the household between the age of 15-49 which asked health and fertility related questions including a full birth history. Women reported details about their children they ever had and the survival of the children. Data on sex, caste, religion, place of residence, and various socio-economic dimensions were collected in this survey.

## Methods

### *Assessing dementia*

For the dementia assessment we have used the LASI- Diagnostic Assessment of Dementia data, which is subsample study from Longitudinal Aging Study (LASI) in India. Out of 72,262 respondents in LASI survey around 4000 participants of aged 60 and older took part in this in-depth dementia assessment( (Lee, Banerjee, Khobragade, Angrisani, & Dey, 2019). To maintain national representation and to ensure sufficient numbers of respondents with cognitive impairment, the survey used a two-stage stratified random sampling approach and oversampled respondents at a higher risk of cognitive impairment (Lee et al., 2019). The survey used Clinical dementia rating(CDR) (Lee et al., 2023; Morris, 1993) to assess dementia among the participants. Then employing the imputation models on the subset of LASI-DAD participants with a CDR score. The probabilistically dementia status were predicted for all LASI respondents aged 60 and older without a clinical dementia classification(Lee et al., 2023). The CDR total score of 1 or higher was classified as indicator of dementia.

We estimated the prevalence of dementia by age, caste and religion groups from the imputed model, which is the weighted mean of the imputed dementia status. Sampling weights provided in the data were incorporated in the prevalence estimation to ensure the representativeness of the same to the national level.

### *Life Table Approach*

We utilized NFHS-5 data to compute the Age-Specific Death Rate (ASDR) and life expectancy at age 60 by caste, and religion. The advantage of NFHS data is that, unlike SRS data, it enables the calculation of death statistics according to socioeconomic characteristics such as caste, religion and region. Caste data has been collected for Scheduled Caste (SC), Scheduled Tribe (ST), Other Backward Classes (OBC), and others. Similarly, in the 'religion' variable consist of seven categories: Hindu, Muslim, Christian, Sikh, Buddhist, Jain, Other religion and religion not stated. Due to sample size constraints, we recoded this variable into four categories: Hindu, Muslim, Christian, and others.

The following steps are employed to compute the Age-Specific Death Rate (ASDR), life expectancy at birth by caste, and religion, and Dementia Free Life Expectancy (DemFLE) by region, caste and religion.

1. **Estimation of ASDR:** In the NFHS-5 dataset, we consider the adult age-specific death rates aged from 60 to age 85. NFHS 5 data contains information on individuals who were usual residents and died according to the household questionnaire. We use the information on recent household deaths for estimating mortality at age 60 until age 85. For adult mortality, we only consider the deaths within the two years prior to the interview in order to minimize the potential recall bias (Gupta & Sudharsanan, 2022).

we estimate the mortality for individuals ages 60 and above from household data using the information on recent household deaths. Survey participants were asked if any regular household member had died since January,2016 for NFHS 5. For each deceased individual, participants were asked to provide sex, date of death and age at death of the deceased.

At first, we have calculated the single year deaths from Household file and the single year population from the file of household members. Then to get the single year person-years at risk of death, we assumed that, for two-year period, a person aged  $x$  at the time of the interview contributed on average one-half of a person-year of exposure at age  $x$ ; one whole person-year by the person aged  $x + 1$  and one-half of a person-year of exposure at age  $x + 2$ , symbolically (Dhakad & Saikia, 2023),

$$\text{Person-years at risk at age } x \text{ at the time of survey} = P_x * 0.5 + P_{x+1} * 1 + P_{x+2} * 0.5$$

where  $P_x$  = Number of usual residents at age  $x$  at the survey time.

Age-specific death rates are then calculated by dividing the number of deaths by the corresponding person-years at risk. The resulting rate is multiplied by 1000 to obtain the death rate per 1000 person-years.

2. **Simulation of age pattern of mortality rates:** After getting the death rates for age between 60-85 from NFHS 5 data, we use Gompertz-Makeham model to provide a good empirical fit and simulate the age pattern of death rates for each social groups from age 60 and older (moultrie et al, 2013; Missov & Lenart, 2013) . As the NFHS was not driven to estimate national level mortality rates, we used UN life tables for India for the year 2019-2020 (“UN- Model Life Tables- 2019-2020”) and we adjusted the fitted death rates from the NFHS 5 to the fitted death rates from UN life tables. For the adjustment we calculated a calibration factor performing the following calculation:

$$C_{60-85} = \frac{M_{60-85}^{UN}}{M_{60-85}^{NFHS}}$$

Here, M signifies the fitted mortality rates from the specified dataset and C signifies the specific calibration factor for different ages. We then multiply the fitted death rates from NFHS 5 by this calibration factor in order to get the calibrated death rates from NFHS 5 to use in our lifetables:

$$M_{60-85} = C_{60-85} \times M_{60-85}^{NFHS}$$

We assumed this calibration factor to be constant across each social group. Using the same Calibration Factor, we repeated the same step for each group of caste and religion- we fitted the Gompertz-Makeham model to the death rates among different caste and religious groups from NFHS 5 data, in order to simulate the data. And then multiplied the fitted death rates by the same calibration factor we calculated from the UN data.

3. **Estimation of life expectancy:** Then the age-specific calibrated death rates and population-at-risk data from NFHS 5 is being used to compute life expectancy at age 60 by caste, religion using the Chiang method (Veron, Preston, Heuveline, & Guillot, 2002);(Chiang, 1972); (Schoen, 1978). The Chiang method is an advanced and accurate approach for constructing life table, where the  ${}_n a_x$  (the number of years lived in the x to x+n age interval by those dying in the interval) is estimated. We close the life table at age 85 and above by assuming that in this open-age interval, everybody dies at some time point i.e.  ${}_n q_x = 1$ . So, for the last interval at older ages, we could conclude:

$$L_{85+} = d_{85+} / m_{85+}$$

And since the  $d_{85+}$  group is as same as the  $l_{85+}$  group:

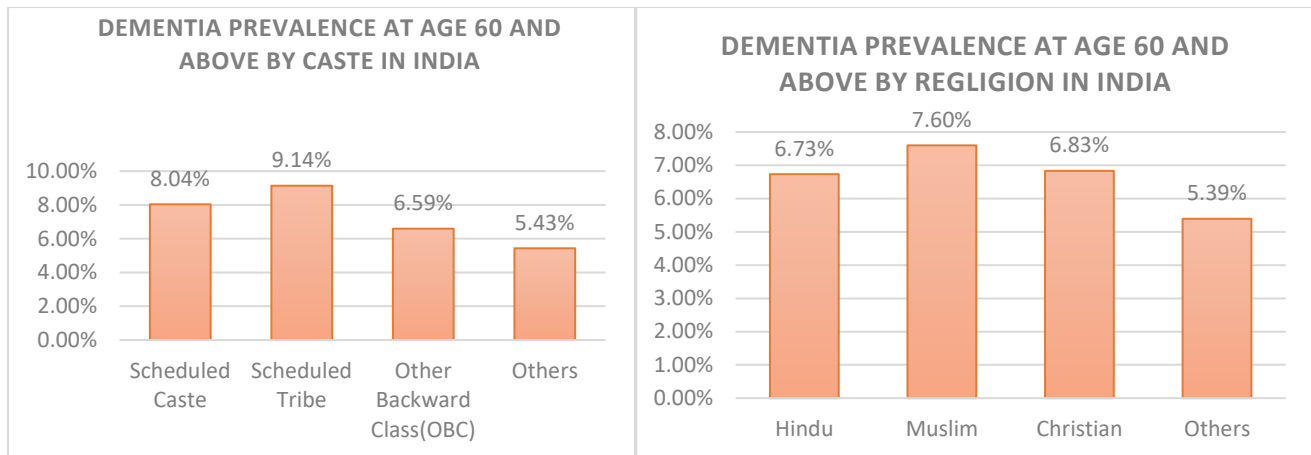
$$L_{85+} = l_{85+} / m_{85+}$$

This is how we close the life table and proceed to the  $T_x$  column (Veron et al., 2002).

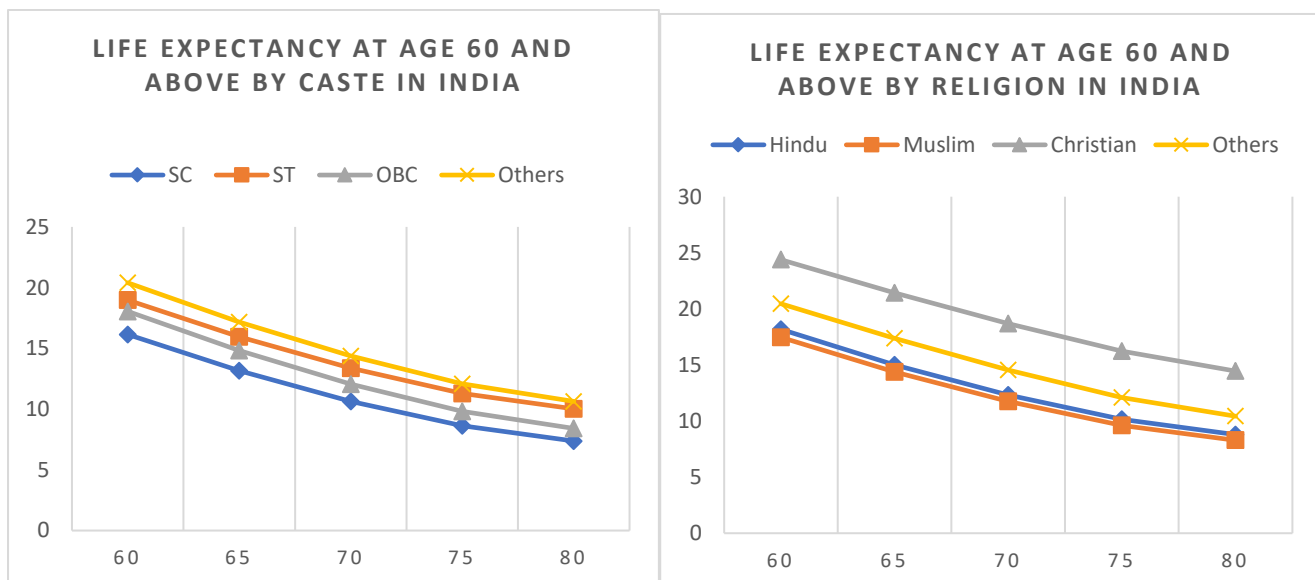
4. **Computation of Dementia-Free Life Expectancy (DemFLE):** We utilize the Sullivan method to estimate Dementia-free Life Expectancy (DemFLE) and Life Expectancy with Dementia (DemLE) for individuals aged 60 years and older (Sullivan,1971). The Sullivan method requires the age-specific prevalence (proportions) of dementia, which is obtained from LASI-DAD data, and age-specific mortality information from NFHS 5 data. This approach incorporates the prevalence of health problems according to socioeconomic characteristics into the constructed life tables, thereby partitioning life expectancy into the expectation of life with and without problems. The Sullivan method offers several advantages, as it is recommended for its relative accuracy and ease of interpretation.

## Preliminary findings

### Figures for Dementia prevalence at age 60 and above by caste and religion in India



### Figures for Life Expectancy at age 60 and above by caste and religion in India



From the preliminary figures for dementia prevalence and life expectancy at age 60 and above by caste and religion groups in India for combined sexes (Male-Female), we can see that dementia prevalence among older adults age 60 and above varies across the caste and religious groups in India. For different caste and religious groups, the dementia prevalence is the highest among Scheduled Tribe (ST) (9.14%) caste-group, Muslims (7.60%) religious-group and lowest for other caste (NO CASTE) (5.43%) and Others (5.39%) religious group. For the different caste groups life expectancy at age 60 is highest for other caste (NO caste) (20.4) followed by ST and OBC then lowest in Scheduled caste (SC) (16.14). Finally, Christians have the highest life expectancy at age 60(24.38) in India and Muslims have the lowest (17.46) one.

## Next steps & brief discussion

For the advance analysis for our study we will delve into investigating our three hypotheses mentioned previously, those are:

Whether higher life expectancy within certain caste groups are more likely to have greater DemFLE (Positive association)?

If the religious groups across India with higher life expectancy are expected to have a greater DemFLE (Positive association)

In this preliminary stage we have estimated the dementia prevalence and remaining life expectancy at age 60 across the social groups. Subsequently, in the second stage of our study, we will integrate these estimates with the prevalence data for dementia which is obtained from LASI-DAD imputed data. In order to integrate these data, we will use Sullivan method to estimate the proportion of years are expected to live without dementia. And finally, we will compute the confidence interval (CI) for DemFLE using the Sullivan Method, in order to examine whether these proportion of years without dementia at remaining age can be lived significantly by the older adults in India.

This study will be the first study in India that brings forth the noteworthy findings on the complex interactions of dementia and its disparities. The preliminary findings from our study suggest that there are social differences in life expectancy at age 60 and above in India. This allows us to investigate the question that whether these disparities can tend to the disparities in proportion of years lived without dementia burden. In India, the caste system still has a significant influence due to its social segregation and limitations (Borooah, Dubey, & Iyer, 2007). And caste and religion are inextricably related and also apparent as a proxy for socioeconomic status in India. The lower socioeconomic status is significantly associated with lower healthcare utilization and eventually ends with poor health outcomes such as lower life expectancy and burden of dementia. Only the better-offs within the deprived caste avail the benefits from caste-based employment, education and health facilities.

In conclusion, this study is a critical step towards understanding and addressing the adverse impact of neurodegenerative diseases in a diverse and dynamic society like India. However, this study has several limitations which can be emphasized for further comprehensive studies. This study will help in developing targeted interventions and policies to eradicate the encumbrances of dementia in India.

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