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9 Older adults living with cognitive and mobility-related limitations: social deprivation and forms of care received

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- ▶ Limitations in cognitive functioning in older adults are often related to dementia or similar conditions and may serve as a predictor in the absence of a clinical diagnosis
 - ▶ Social deprivation is significantly associated with cognitive and mobility related limitations
 - ▶ Cognitive and mobility-related limitations in older adults are both associated with the use of formal and informal help at home
 - ▶ Living alone is more unlikely for older people with severe cognitive limitations or dementia but not for those with mobility-related limitations
 - ▶ It is suggested to systematically examine the social environment of older adults who show early symptoms of cognitive impairment since they may be at risk of social deprivation
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9.1 Disability in old age and quality of life

Cognitive impairment and mobility-related limitations are two major risk factors for disability among older adults. In Europe, 9.95 millions of people aged 60 and over live with dementia (Alzheimer's Disease International-ADI 2010). The prevalence rate is estimated at seven per cent among individuals aged 60 and over. After age 65, the likelihood of developing dementia roughly doubles every five years: 22 per cent of people aged 85 to 89 and 43 per cent of people aged 90 and over suffer from dementia (ADI 2010). Mobility-related limitations concern about 20 per cent of persons aged 65 or older, increasing with age (Guralnik et al. 1996).

Both, cognitive and mobility-related limitations affect the ability of a person to carry out normal daily activities. Accordingly, older persons with moderate limitations may receive occasional help from informal or formal caregivers, or a combination of both, to enable them to continue to live at home (e.g. domestic tasks, personal care) and participate actively in the community. Older adults with more severe limitations require substantial help from a third party to fulfil daily activities. Therefore, care needs resulting from severe disability are often addressed by institutional long-term care over an extended period of time. Disability in old age is thus associated with adverse outcomes at the individual and societal level, such as diminished quality of life, increased costs for health and long-term care,

and social exclusion or the inability to fully participate in society (Van Bergen et al. 2014).

In order to develop effective support programs for older adults with disability and reduce social exclusion in this population, a fundamental step is to better understand their living conditions and how socioeconomic and demographic factors influence forms of care received. A large-scale population survey, such as SHARE, appears to be a helpful resource to study risk factors and consequences of cognitive and mobility-related disability among the 50+ in Europe. Concerning cognitive limitations, in addition to the self-reported diagnosis of dementia or related conditions, the cognitive module of SHARE allows the examination of intellectual capacities and how they change in old age. Mobility-related limitations are also examined in a specific module of the survey.

New SHARE Wave 5 data has been used to build a social deprivation index (see chapter 6 in this volume) that reflects the degree to which individuals are deprived of a basic social context covering domains such as social participation, social rights, and access to services. Regarding the forms of care received, SHARE also gathers basic data related to the source of help (i.e. formal or informal) received by survey respondents. With respect to informal care, SHARE examines separately if personal care is received from someone within or outside the household.

The main objective of this work was to use SHARE data to study socioeconomic factors and forms of care received by older adults living with cognitive and mobility-related limitations. Two hypotheses were formulated:

- 1) Both cognitive and mobility-related limitations increase social deprivation in older adults.
- 2) Both cognitive and mobility-related limitations increase the use of formal and informal care at home and limit the ability of disabled older persons to live alone.

This paper is structured in three sections. First, we explain how SHARE data can be used to identify people with cognitive or mobility-related limitations. Second, we study the relationship between living with cognitive or mobility-related limitations and being socially deprived based on the social deprivation index from chapter 6 in this volume. Then, we investigate whether the kind of care (i.e. formal or informal) received by older adults living with a disability differs according to the nature of the limitations (i.e. either cognitive or mobility-related). After discussing overall results obtained in this first analysis we review some methodological aspects and suggest further steps for our work.

9.2 Definition and measure of cognitive and mobility-related limitations

The selection of cognitive measures in population surveys is useful to study the impact of cognitive functioning on different domains of functioning in the life of an individual and in the use of economic and social resources. Over the last decades several large-scale population surveys have included assessment of cognitive function, for instance the English Longitudinal Study of Ageing, the National Social Life, Health, and Aging Project, Health and Retirement Study (Crimmins et al. 2011). At the European level, SHARE offers the possibility of examining cognitive functioning in the non-institutionalized population aged 50 and older and its association with other variables, such as life course occupation or macroeconomic conditions (Adam et al. 2007, Leist et al. 2014).

It is worth to remind that the diagnosis of dementia in older people is important in order to plan comprehensive and cost-effective care programs. However, underdiagnosis of this condition is very high leading to a delayed implementation of medical and social care or even to the absence of treatment. Underdiagnosis occurs when a disease is not recognised or is inaccurately diagnosed at the population level. It has been estimated that less than one-half of persons with dementia have actually received a clinical diagnosis (Connolly et al. 2011). Underdiagnosis for a given condition can be studied by measuring the variation in the difference between observed and estimated prevalence of dementia for a specific area or setting.

In this work, in order to identify people aged 65 or older who have cognitive limitations, two elements from SHARE are used: (a) a global composite score of cognitive functioning and (b) the self-reported diagnosis of dementia variable, in which the respondent declares if a doctor has ever told him/her having Alzheimer's disease, dementia, organic brain syndrome, senility or any other serious memory impairment (PH006).

For computing the composite score of cognitive functioning we used a set of measures from the Cognitive Functioning Module from SHARE Wave 5. We have focused our analysis on 29,036 people aged 65 and over who completed the four cognitive tests described here:

- *Verbal fluency*: the respondent is asked to name as many animals as possible in one minute. Fluency is a measure of executive function. Scores for this measure range from 0 to 100.
- *Immediate free-recall*: the respondent is asked to recall as many words as possible from a 10-word list that had been read out loud once by the interviewer immediately before. For this measure of short-term memory scores range from 0 to 10.

- *Delayed free-recall*: the respondent is asked to recall the same 10-word list after a standardised interval of time. For this measure of episodic memory scores range from 0 to 10.
- *Serial 7's*: the respondent is asked to subtract 7 from 100, and continue subtracting 7 from each subsequent number for a total of five trials. For this measure of working memory scores range from 0 to 5.

A general examination of mean scores showed a wide variability in the number of correct answers to the different cognitive tests; therefore, it was decided to create a standardised score. For doing so, we used the aforementioned cognitive measures to build a cognitive indicator using averaged z-scores for the four tests. The final indicator (“z-cognitive limitations score”) is a reversed and standardised score ranging from 0 to 10 (10 = worst cognitive performance, 0 = best cognitive performance).

We next examined whether the “z-cognitive limitations score” was a good indicator of respondents’ general cognitive functioning, using as reference their self-report on having received a dementia diagnosis from a physician or not (PH006). The mean z-cognitive limitations score was 5.5 for persons who did not declare having received a dementia diagnosis, whereas it was 6.8 for people who have reportedly been diagnosed. These findings show that people clinically diagnosed with dementia appear to have worse cognitive functioning than those undiagnosed. Consequently, it can be suggested that SHARE respondents who declared having received a dementia diagnosis had a good awareness of their diagnosis, since the cognitive limitations score reflected well the generalized cognitive decline expected in dementia.

Nevertheless, it is important to take into account that 64 per cent of persons who reported having received a diagnosis of dementia did not respond to the four cognitive tests. This high proportion of non-respondents in this section might be explained by the cognitive module being a non-proxy section, which is skipped if the respondent does not have enough cognitive resources to understand the meaning of the information or to respond alone. Thus, the z-cognitive limitations score for respondents with reportedly diagnosed dementia and, consequently, also the difference in cognitive scores between those with and without diagnosed dementia might be underestimated.

Mobility-related limitations, in SHARE, are defined by one or more affirmative answers on a list of 10 activities:

- (a) Walking 100 meters
- (b) Sitting for about two hours
- (c) Getting up from a chair after sitting for long periods

- (d) Climbing several flights of stairs without resting
- (e) Climbing one flight of stairs without resting
- (f) Stooping, kneeling, or crouching
- (g) Reaching or extending your arms above shoulder level
- (h) Pulling or pushing large objects like a living room chair
- (i) Lifting or carrying weights over 5 kilos, like a heavy bag of groceries
- (j) Picking up a small coin from a table.

Respondents are asked to declare if they experience any difficulty executing any of these activities, excluding those for which difficulties were expected to last less than three months.

The mobility-related limitation was calculated by summing the number of activities in which the respondent encountered some difficulty (10 = worst mobility performance, 0 = best mobility performance).

9.3 Social deprivation and disability in older adults

In order to estimate the impact of mobility-related and cognitive limitations on social deprivation, adjusting for country, sex, age, having a partner, number of children, and education level, we used the method of ordinary least squares (OLS). Figure 9.1 shows a clear association between cognitive and mobility-related limitations and social deprivation. Interestingly, the explanatory power of each kind of limitation is almost identical. The introduction of quadratic terms shows nevertheless that cognitive limitations have a non-linear effect on social deprivation whereas the effect of mobility-related limitations is linear. This suggests that, while the onset of cognitive decline is barely accompanied by increased social deprivation, consequences get more pronounced with progressive dementia. However, despite controlling for a set of observable possible confounders, causality of this relationship cannot be warranted; probably causation is bidirectional and occurs through many different pathways. Further research is needed to better understand the corresponding underlying mechanisms.

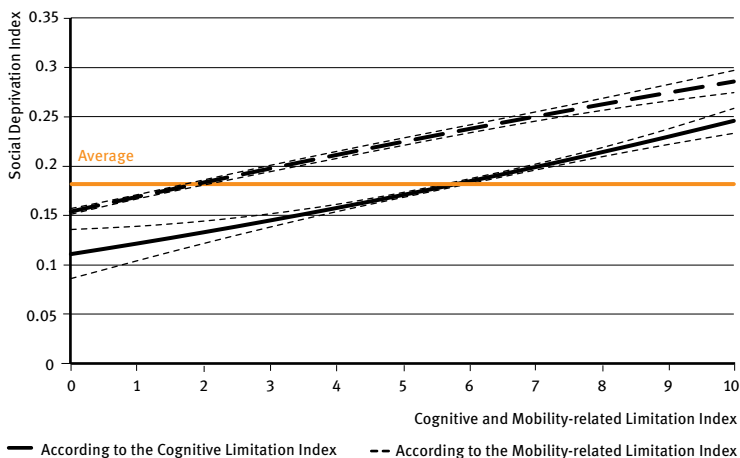


Figure 9.1: Predicted social deprivation conditional on cognitive limitation index and mobility-related limitation index

Notes: Controlled for country, sex, age, having a partner, number of children, and education level; N=29,036

Source: SHARE Wave 5 release 0

9.4 Forms of care received and disability in older adults

A majority of people with functional limitations need assistance to perform activities of daily living. Based in particular on the Social Support module of the questionnaire, previous literature using SHARE data (Bonsang 2009, Fontaine et al. 2009) has contributed to a better description of care received by older people with disabilities and a better understanding of socioeconomic determinants of the kind of care received. Traditional methods to measure care needs do not clearly identify care needs resulting from cognitive limitations because most daily life activities have an important physical component. To overcome this limit, we propose to measure care needs through an indirect approach based on functional limitations using the mobility-related limitation index and the cognitive limitation index in order to disentangle cognitive and mobility related limitations. We investigated the specific effect of cognitive and mobility-related limitation on three outcomes:

- the propensity to live alone
- the propensity to receive informal care by non-co-residents (at least weekly)
- the propensity to receive formal care.

Note that we did not consider in our empirical analysis information available in SHARE on care received from co-residents because this information is limited to personal care (such as washing, getting out of the bed, or dressing). Practical household help from co-residents is known to be underestimated. The information is thus not collected. Because they may substitute or complement each other, we assumed that common unobserved factors are likely to influence each outcome. To deal with this issue, we specified a Trivariate Probit Model where the residual of each equation is assumed to be correlated. The specific effect of cognitive and mobility-related limitations was investigated controlling for country dummies, age, age squared, education level, living with a partner, number of sons, number of daughters and two dummy variables allowing to identify among those not having completed the cognitive tests whether or not they have received a diagnosis of dementia.

Both cognitive and mobility-related limitations are significantly associated with the propensity to receive care. Predicted probabilities in Figures 9.2 and 9.3 show that the propensity to receive (informal or formal) care from outside the household is much more sensitive to mobility-related limitations than to cognitive limitations. Moreover, the use of home-care services is more dependent on care needs than informal care from non-co-residents. People suffering from severe cognitive limitations are significantly more unlikely to live alone. This is also true for those not having completed the cognitive tests but having received a diagnosis of dementia. They are less likely to live alone and are more liable to receive formal care. Mobility-related limitations do not have any significant effect on the disposition to live alone. This shows the importance to distinguish between cognitive and mobility-related limitations to understand household composition in the older population. The results allow suggesting that the specific care needs of people with dementia, such as companionship or regular supervision, limit the ability of these individuals to live alone to a greater extent than in those with mobility-related limitations.

Estimation results further reveal that the form of care received is also associated with traditional social and demographic characteristics (not shown). Women are more likely to live alone but tend to receive more formal and informal care. As could be expected, having a partner is negatively associated with the likelihood of living alone. In addition, as the partner is traditionally the main care provider, his or her presence significantly reduces the probability of receiving both formal and informal care. With regard to number of children, our results confirm previous findings: an additional daughter significantly increases the probability of receiving informal care from outside the household whereas an additional son does not have any significant effect. Also, the number of children reduces the disposition of living alone in older adults, probably because it increases the pos-

sibility of (re)forming an intergenerational household. More interestingly, only the number of sons is significantly associated (negatively) with the propensity to receive formal care. This gender effect was not expected and requires further investigations. Education level is positively associated with formal care use, probably because it captures an income effect. It is nevertheless not significantly associated with informal care.

Finally, correlations between residuals suggest that after controlling for the main sociodemographic characteristics, cognitive limitations and mobility-related limitations, living alone is positively associated with informal care from outside the household. Moreover, informal care provided by non-co-residents is *ceteris paribus* positively associated with formal care use. This suggests that formal care and informal care from non-co-residents are frequently used together and tend to be a substitute to care from co-residents.

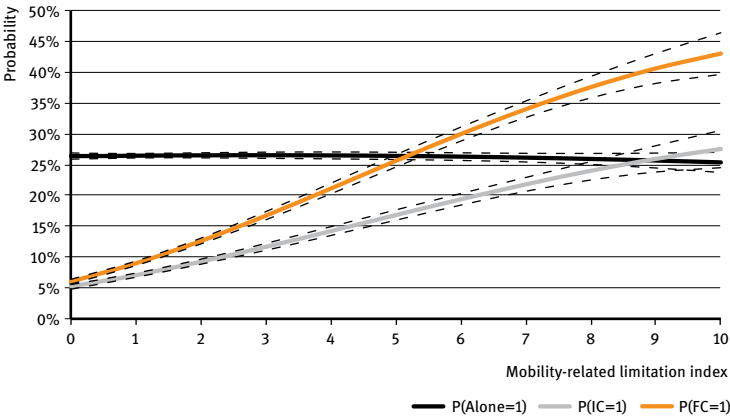


Figure 9.2: Average predicted probabilities of living alone, receiving informal care from outside the household and receiving formal care, according to the mobility-related limitation index

Notes: N=29,036

Source: SHARE Wave 5 release 0

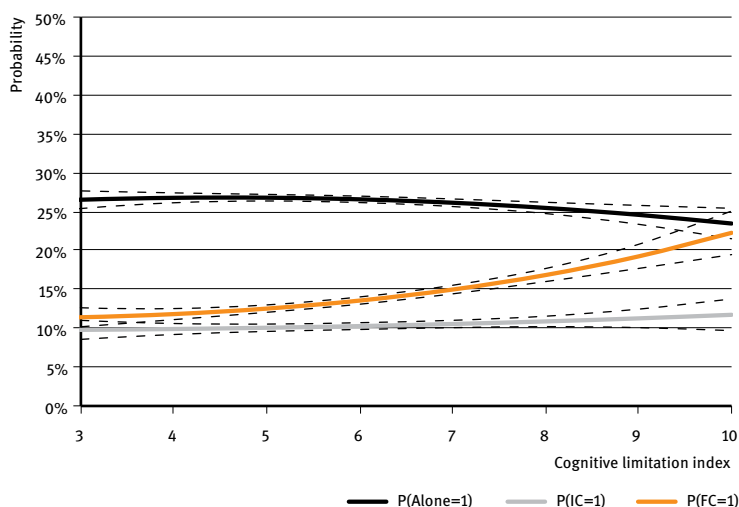


Figure 9.3: Average predicted probabilities of living alone, receiving informal care from outside the household and receiving formal care, according to the cognitive limitation index

Notes: N=29,036

Source: SHARE Wave 5 release 0

9.5 Disability in old age and increased risk of social deprivation: areas for further investigation and suggested preventive measures

Existing literature highlights the negative impact of physical disability on social inclusion of older adults leading to a high risk of marginalization of this group in their community context. A number of studies have shown that participation in social activities prevents cognitive decline in older persons. However, the specific impact of cognitive impairment, and particularly of dementia, on social inclusion has received less attention from researchers.

The present analysis offers a first focus on the risk of social deprivation and on the need for social support of older adults in particular when they face cognitive or physical limitations. Two results can be highlighted after this preliminary analysis. First, both cognitive and physical limitations seem to be a risk factor for social deprivation. Second, cognitive limitations reduce individuals' capability of living alone, while this is not the case for physical limitations.

Complementary analyses are needed to go beyond these first results. Indeed, the cognitive impairment definition that we have used for this analysis should

only be understood as a starting point. A valid dementia diagnosis involves a thorough clinical and medical examination. A validation of the proposed cognitive functioning score using SHARE data has yet to be done. Moreover, exploiting of the longitudinal dimension of SHARE offers important research perspectives to better understand the dynamics of cognitive disorders and their interplay with individuals' economic and social environment. It is indeed critical to consider that dementia develops over several years and that the notion of change, or decline, between previous and current level of cognitive functioning is fundamental. A natural next step would thus be to use panel data to follow respondents through time. This is also true for following cognitive performance of persons that have been reportedly diagnosed with dementia. The measure of change in cognitive function is particularly important because the rate of decline, rather than the absolute level, is a critical indicator of dementia onset.

In terms of public policy, the examination of the social environment of older adults who show early symptoms of cognitive impairment should be done systematically, since they may be at risk of social deprivation. The present study highlights the need of developing measures to prevent and deal with the effect of cognitive and mobility-related limitations on social inclusion in old age.

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