

From curing to caring

A sequence analysis exploring trajectories of multimorbidity and social care needs among older adults in twelve European countries

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1. Background

The consequences of multimorbidity on healthcare systems are widely discussed due to its implications on healthcare and social care provision (Calderón-Larrañaga et al., 2017; McGilton et al., 2018; Simpson et al., 2022; Warner et al., 2011). In this sense, available evidence suggests that multimorbidity affects individuals' healthcare and social care needs, firstly by demanding changes in traditional healthcare practice usually focused on dealing with acute or only one chronic condition (Bayliss et al., 2008; Kuluski et al., 2017), and secondly because individuals living with one or chronic condition are at higher chances of facing functional decline and dependency (Jackson et al., 2015; Marengoni et al., 2009), mobility limitations (Davies et al., 2022), and difficulties to perform Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs), that usually translate into increasing dependence and needs for social care (Bao et al., 2019).

The process from the onset of one chronic condition to experiencing multimorbidity and social care needs is commonly understood as a linear process known as the 'evolution of chronic disease' (Ruel et al., 2014). This assumed linear path initiates with gaining years, the onset of one chronic condition and the progressive rising of multimorbidity alongside with dependency and social care needs, which is followed, after some unknown amount of time, by death. Yet, this evolutionary process might be less straightforward, mainly because the trajectories of (multi)morbidity and social care needs are complex, but also due to the heterogeneous ways through which healthcare and social care systems in each country approach individuals' needs. Nevertheless, the relation between multimorbidity and social care needs has started recently to be studied (Simpson et al., 2023): while research on multimorbidity focuses mainly on healthcare needs, less attention has been paid to the social care needs that may emerge as a result of the onset of one or more chronic condition. Some studies have explored the relationship between multimorbidity and social care services utilisation (Henderson et al., 2021) and costs (Blawat et al., 2020; Kasteridis et al., 2014), but there are few longitudinal analyses on this subject (Cezard et al., 2021; Simpson et al., 2022).

Less is known about the trajectories of multimorbidity and social care needs. Nevertheless, studying the trajectories of multimorbidity and social care needs from a longitudinal approach is a way to contribute to the emerging literature on the relationship between these two phenomena, as well as an opportunity to provide a better understanding of the complex and heterogenous process of ageing. Therefore, this study aims to comprehend further the connection between the onset of multimorbidity with the rise of social care needs in European countries in three ways: First, by exploring the different trajectories related to experiencing chronic disease and the onset of social care needs. Second, by analysing the individual and contextual factors associated with the experience of various trajectories of multimorbidity and care needs. Finally, by conducting cross-country comparisons, useful to identify best practices in healthcare systems and provide evidence for future research on policy implementation.

2. Methodology

2.1 Data

The “Survey of Health, Ageing and Retirement in Europe” (SHARE) is a longitudinal study that focusses on individuals living in residential households who are older than 50 years and their partners. This survey is ex-ante harmonized, allowing cross-country comparisons. Between 2004 and 2020, SHARE collected eight waves from 26 European countries and Israel, generally within a two-year interval (Börsch-Supan, 2017). However, not all countries participated in every wave, nor were the same questions always included. Thus, our analysis focuses on all but waves 3 and 7, as the relevant variables to this study weren't available in these waves. The included countries are the ones that collected data for at least three of the six waves used: Austria, Belgium, Czech Republic, Denmark, France, Germany, Greece, Italy, Spain, Sweden, Switzerland and the Netherlands. The analytical sample comprises 42,100 individuals who were 50 years or older during the observation period, meaning those born in 1971 or earlier.

2.2 Analytical approach

Two primary methods were employed to analyse the data. Firstly, sequence analysis was utilized to explore different states and trajectories of multimorbidity and care needs. Secondly, using the best cluster solution to group individuals' sequences, multinomial regression models were fitted to explore the main factors that accounted for the diversity in individuals' trajectories. All the analyses were conducted using the statistical program R (version 4.2.3), with the *Traminer* package for the sequence analysis (Gabadinho et al., 2011).

2.3 Variables

2.3.1 From states and sequences to trajectories

To identify individuals having chronic conditions and social care needs two types of variables were constructed: a variable classifying individuals' (multi)morbidity (0 = no chronic condition, 1 = one chronic condition, 2 = two or more chronic conditions), and a dummy variable that measured if individuals were experiencing at least one or more mobility limitation or in ADL and/or IADL (no=0, yes=1). Based on these two variables, the following six states were created: having (a) no chronic condition¹; (b) one chronic condition without care needs; (c) one chronic condition with care needs; (d) two or more chronic condition without care needs; (e) two or more chronic condition with care needs; and, (f) being dead. Based on dissimilarity measures between the sequences, four trajectories of multimorbidity and social care needs were identified and used as the response variable in the multinomial models.

2.3.2 Explanatory variables of the regression model

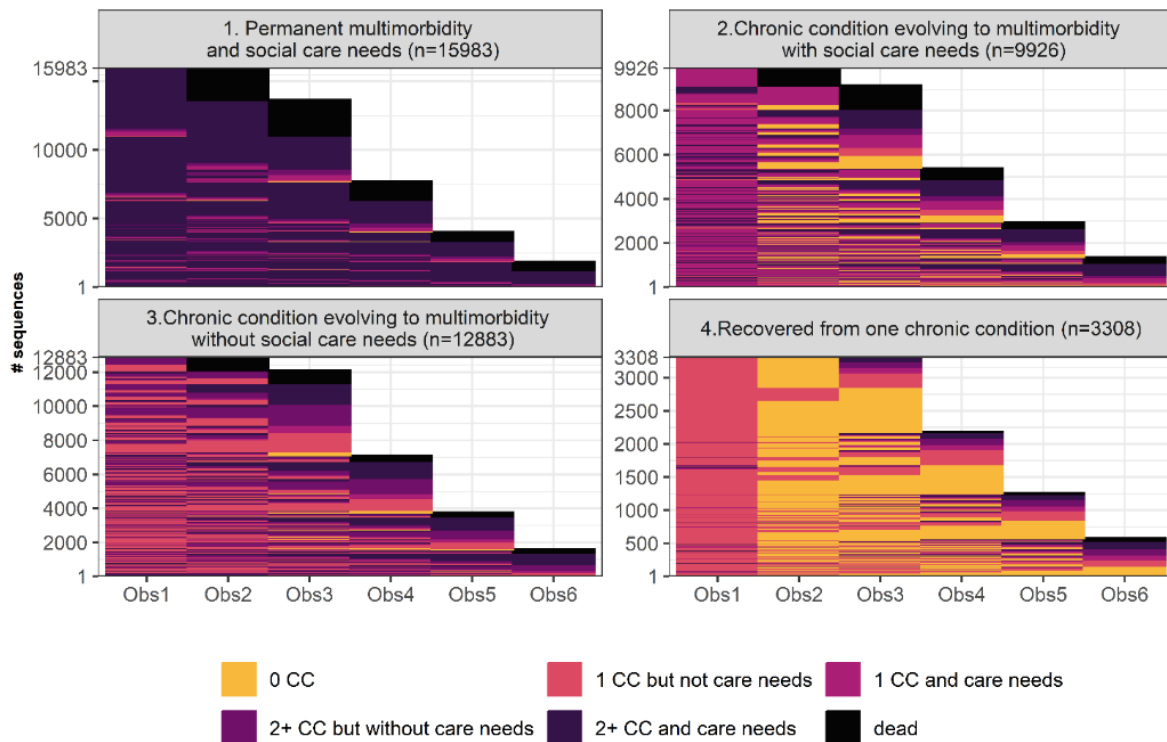
The regression models included demographic, socioeconomic, living arrangements and health-related dimensions. For the first dimension, the variables of country, sex, and age group (ages 50-64, 65-79 and 80+ in the first observation) were included. Regarding the socioeconomic dimension, the included variables were the educational level and housing tenure. Finally, the dichotomised chronic condition variable that was analysed in the multinomial regression model was operationalised as having experienced any or none of the chronic conditions that were included in the survey at any time during the observation period. Chronic conditions considered in this study were: heart attack or any other heart problem, high blood pressure or hypertension, high blood cholesterol, a stroke or cerebral vascular disease, diabetes or high blood sugar, chronic lung disease, cancer or malignant tumour, stomach or duodenal ulcer, Parkinson disease, cataracts, hip fracture or other fractures, Alzheimer's disease, dementia, organic brain syndrome, senility or any other serious memory impairment, other affective or emotional disorders, including anxiety, nervous or psychiatric problems, rheumatoid arthritis, osteoarthritis, or other rheumatism and others.

¹ Even though the analysis was focused on individuals that had at least one chronic disease, this category should be created to account for those that recovered from the chronic diseases during the observation period.

3. Findings

This study presented complex trajectories of multimorbidity and social care needs after individuals' experience of at least one chronic disease: (1) Permanent multimorbidity and social care needs; (2) Chronic condition evolving to multimorbidity with social care needs; (3) Chronic condition evolving to multimorbidity without social care needs; (4) Recovered from one chronic condition (Figure 1). The existence of different trajectories highlights that instead of a "linear evolution of chronic disease" to multimorbidity and social care needs, this process is less straight forward and is affected by individual's characteristics including demographic, socioeconomic and country of residence aspects. Results also showed that women are at higher risks than men of being in a permanent state of multimorbidity and care needs, and that this usually is the case when sex is interacting with age, type of chronic disease and country (Figure 2).

Figure 1. Four-cluster solution composition by state and cluster



Note: CC refers to chronic conditions

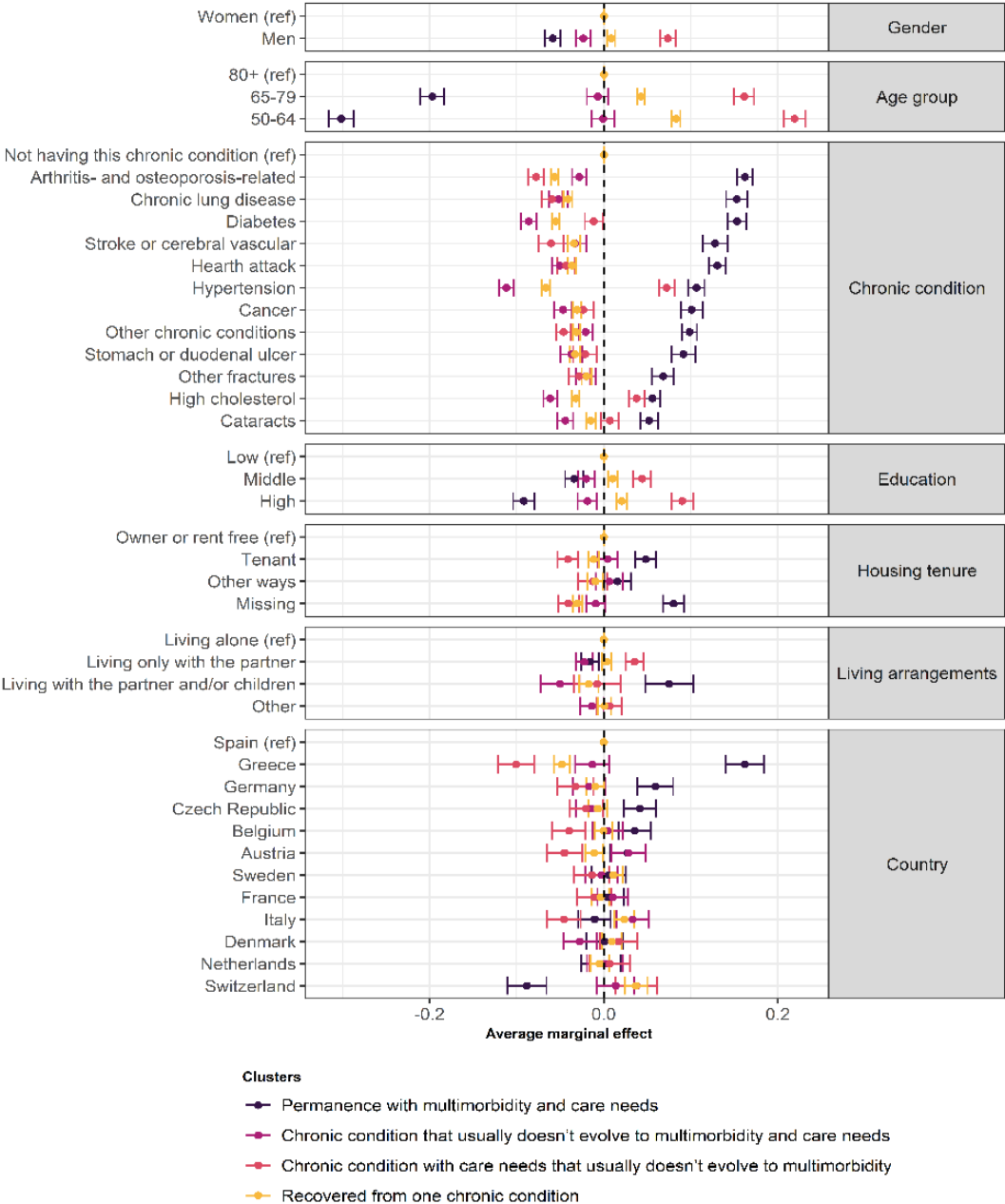
Source: Survey of Health Ageing and Retirement in Europe, waves 1-3, 4-6 and 8.

The average marginal effects of the multinomial regression model (see Figure 3) showed that men face a lower relative probability than women of being in the cluster of permanent multimorbidity and care needs (first cluster) and chronic disease evolving to multimorbidity with social care needs (second cluster) with respectively average marginal effects (AME) of -0.05 and -0.02, and at the same time a higher probability of being part of the third and fourth cluster (AME 0.07 and 0.00), corresponding to having chronic disease evolving to multimorbidity without social care needs and recovered from one chronic disease. Analysis by country showed a heterogeneous panorama. Even though not all the included countries have statistically significant results, it is noticeable that Greece has the highest probability of individuals experiencing the first cluster of a permanent multimorbidity and care needs (AME 0.16) and that Switzerland has the lowest (AME -0.08).

Previous research on multimorbidity trajectories has similarly found that there are different paths and that the risks of being in one of these are related to individuals' characteristics, including socio-demographic ones and type of chronic disease (Ashworth et al., 2019; Cezard et al., 2021). The main contribution of

this study is to combine multimorbidity and social care needs in the study of these trajectories, which is aligned with current debates about ageing, multimorbidity and long-term care provision. Therefore, it must be stated that these results are not fully comparable with previous studies because of this inclusion of the experience of social care needs as part of this trajectories, however, it is aligned with an approach that understands multimorbidity as a continued process. Europe, as a leading region the ageing process, offers the opportunity to increase our understanding of older individuals' needs and demands, in this sense, we tried to show the complex paths from curing to caring challenging both social care regimes and healthcare systems and calls attention on the need of care integration (Johri et al., 2003; Ouwens et al., 2005).

Figure 2. Average Marginal effect of the multinomial regression model explaining individuals' trajectories



Source: Survey of Health Ageing and Retirement in Europe, waves 1-3, 4-6 and 8.

References

- Ashworth, M., Durbaba, S., Whitney, D., Crompton, J., Wright, M., & Dodhia, H. (2019). Journey to multimorbidity: longitudinal analysis exploring cardiovascular risk factors and sociodemographic determinants in an urban setting. *BMJ Open*, *9*(12), e031649. <https://doi.org/10.1136/bmjopen-2019-031649>
- Bao, J., Chua, K.-C., Prina, M., & Prince, M. (2019). Multimorbidity and care dependence in older adults: a longitudinal analysis of findings from the 10/66 study. *BMC Public Health*, *19*(1), 585. <https://doi.org/10.1186/s12889-019-6961-4>
- Bayliss, E. A., Edwards, A. E., Steiner, J. F., & Main, D. S. (2008). Processes of care desired by elderly patients with multimorbidities. *Family Practice*, *25*(4), 287–293. <https://doi.org/10.1093/fampra/cmn040>
- Blawat, A., Green, E., Belloni, A., Jaccard, A., Adomako-Mensah, V., de Preux, L., Thiebaut, S., Sassi, F., Webber, L., & Retat, L. (2020). *The health and social care costs of a selection of health conditions and multi-morbidity*.
- Börsch-Supan, A. (2017). Survey of Health, Ageing and Retirement in Europe (SHARE). In N. A. Pachana (Ed.), *Encyclopedia of Geropsychology* (pp. 2343–2350). Springer Singapore. https://doi.org/10.1007/978-981-287-082-7_243
- Calderón-Larrañaga, A., Vetrano, D. L., Onder, G., Gimeno-Feliu, L. A., Coscollar-Santaliestra, C., Carfí, A., Pisciotta, M. S., Angleman, S., Melis, R. J. F., Santoni, G., Mangialasche, F., Rizzuto, D., Welmer, A.-K., Bernabei, R., Prados-Torres, A., Marengoni, A., & Fratiglioni, L. (2017). Assessing and Measuring Chronic Multimorbidity in the Older Population: A Proposal for Its Operationalization. *The Journals of Gerontology: Series A*, *72*(10), 1417–1423. <https://doi.org/10.1093/gerona/glw233>
- Cezard, G., McHale, C. T., Sullivan, F., Bowles, J. K. F., & Keenan, K. (2021). Studying trajectories of multimorbidity: a systematic scoping review of longitudinal approaches and evidence. *BMJ Open*, *11*(11), e048485. <https://doi.org/10.1136/bmjopen-2020-048485>
- Davies, L. E., Mercer, S. W., Brittain, K., Jagger, C., Robinson, L., & Kingston, A. (2022). The association between multimorbidity and mobility disability-free life expectancy in adults aged 85 years and over: A modelling study in the Newcastle 85+ cohort. *PLOS Medicine*, *19*(11), e1004130. <https://doi.org/10.1371/journal.pmed.1004130>
- Gabardinho, A., Ritschard, G., Müller, N. S., & Studer, M. (2011). Analyzing and Visualizing State Sequences in R with TraMineR. *Journal of Statistical Software*, *40*(4), 1–37. <https://doi.org/10.18637/jss.v040.i04>
- Henderson, D. A. G., Atherton, I., McCowan, C., Mercer, S. W., & Bailey, N. (2021). Linkage of national health and social care data: a cross-sectional study of multimorbidity and social care use in people aged over 65 years in Scotland. *Age and Ageing*, *50*(1), 176–182. <https://doi.org/10.1093/ageing/afaa134>
- Jackson, C. A., Jones, M., Tooth, L., Mishra, G. D., Byles, J., & Dobson, A. (2015). Multimorbidity patterns are differentially associated with functional ability and decline in a longitudinal cohort of older women. *Age and Ageing*, *44*(5), 810–816. <https://doi.org/10.1093/ageing/afv095>

- Johri, M., Beland, F., & Bergman, H. (2003). International experiments in integrated care for the elderly: a synthesis of the evidence. *International Journal of Geriatric Psychiatry*, 18(3), 222–235. <https://doi.org/https://doi.org/10.1002/gps.819>
- Kasteridis, P., Street, A., Dolman, M., Gallier, L., Hudson, K., Martin, J., & Wyer, I. (2014). *The Importance of Multimorbidity in Explaining Utilisation and Costs Across Health and Social Care Settings: Evidence from South Somerset's Symphony Project*.
- Kuluski, K., Ho, J. W., Hans, P. K., & Nelson, M. L. A. (2017). Community Care for People with Complex Care Needs: Bridging the Gap between Health and Social Care. *International Journal of Integrated Care*. <https://doi.org/10.5334/ijic.2944>
- Marengoni, A., Von Strauss, E., Rizzuto, D., Winblad, B., & Fratiglioni, L. (2009). The impact of chronic multimorbidity and disability on functional decline and survival in elderly persons. A community-based, longitudinal study. *Journal of Internal Medicine*, 265(2), 288–295. <https://doi.org/https://doi.org/10.1111/j.1365-2796.2008.02017.x>
- McGilton, K. S., Vellani, S., Yeung, L., Chishtie, J., Commisso, E., Ploeg, J., Andrew, M. K., Ayala, A. P., Gray, M., Morgan, D., Chow, A. F., Parrott, E., Stephens, D., Hale, L., Keatings, M., Walker, J., Wodchis, W. P., Dubé, V., McElhaney, J., & Puts, M. (2018). Identifying and understanding the health and social care needs of older adults with multiple chronic conditions and their caregivers: a scoping review. *BMC Geriatrics*, 18(1), 231. <https://doi.org/10.1186/s12877-018-0925-x>
- Ouwens, M., Wollersheim, H., Hermens, R., Hulscher, M., & Grol, R. (2005). Integrated care programmes for chronically ill patients: a review of systematic reviews. *International Journal for Quality in Health Care*, 17(2), 141–146. <https://doi.org/10.1093/intqhc/mzi016>
- Ruel, G., Lévesque, J.-F., Stocks, N., Sirois, C., Kroger, E., Adams, R. J., Doucet, M., & Taylor, A. W. (2014). Understanding the Evolution of Multimorbidity: Evidences from the North West Adelaide Health Longitudinal Study (NWAHS). *PLOS ONE*, 9(5), e96291-. <https://doi.org/10.1371/journal.pone.0096291>
- Simpson, G., Kaluvu, L. M., Stokes, J., Roderick, P., Chapman, A., Akyea, R. K., Zaccardi, F., Santer, M., Farmer, A., & Dambha-Miller, H. (2022). Understanding social care need through primary care big data: a rapid scoping review. *BJGP Open*, 6(4), BJGPO.2022.0016. <https://doi.org/10.3399/BJGPO.2022.0016>
- Simpson, G., Stokes, J., Farmer, A., & Dambha-Miller, H. (2023). Social care need in multimorbidity. *Journal of the Royal Society of Medicine*, 116(4), 124–127. <https://doi.org/10.1177/01410768231168382>
- Warner, L. M., Ziegelmann, J. P., Schüz, B., Wurm, S., Tesch-Römer, C., & Schwarzer, R. (2011). Maintaining autonomy despite multimorbidity: self-efficacy and the two faces of social support. *European Journal of Ageing*, 8(1), 3–12. <https://doi.org/10.1007/s10433-011-0176-6>