Trajectories of Home Care Service Use among Older Swedes Affected by Severe Disease with and without Close Kin: Sequence Analysis of Nationwide Register Data

Anna C. Meyer (MSc)[1] and Karin Modig (Assoc. Prof)[1]

[1] Unit of Epidemiology, Institute of Environmental Medicine, Karolinska Institutet, Stockholm, Sweden

anna.meyer@ki.se

ABSTRACT

A growing proportion of older Swedes lives at home rather than in institutional housing. Although Swedish municipalities offer publicly funded home care services, these cannot compensate for the lack of care previously given within institutions. Family members take on an increasing share of care for older individuals, leaving those without next-of-kin in a vulnerable position. With this study, we aim to describe trajectories of home care utilization among individuals experiencing severe diseases and to examine how such trajectories are associated with the presence of close kin, specifically spouses and children.

This study is based on a linkage of population registers covering the entire Swedish population. We will visualize individual trajectories of granted home care hours during the time before and after experiencing a disease event. We focus on myocardial infarction, stroke, and hip fracture, which are among the most common and severe diseases in old age and often impact a person's care needs substantially. Using sequence analysis, we will identify clusters of common trajectories and compare these between diseases. We will then employ multivariable regression models in order to examine how the presence of children or spouses is related to the consumption of home care and to which extent other sociodemographic characteristics are associated with observed patterns.

Preliminary findings using the example of hip fracture indicate that sustaining a hip fracture is associated with increased utilization of home care, particularly among unmarried individuals. Individual trajectories of home care utilization are diverse, but sequence analysis is suitable to identify distinct clusters.

EXTENDED ABSTRACT

Background

In Sweden, population ageing has been accompanied by a changing structure of health- and elder care (1-4). During the past decades, hospital stays have become shorter and an increasing proportion of older men and women live at home rather than in institutional housing (1, 2, 4). Older individuals in need of care are supported by publicly funded home care services offered by the municipalities in which they reside. These services aim to provide help with personal care and hygiene or activities of daily living, such as grocery shopping and cleaning.

According to the Swedish National Board for Health and Welfare, approximately 15% of the Swedish population over the age of 65 received home care in 2018 (5). Little is, however, known about patterns of home care utilization among older individuals. Both a person's health status and the availability of support from other means may influence consumption of care services. Although the Swedish municipalities offer publicly funded home care services, research has shown that these do not manage to compensate for the lack of care previously given within institutions; family members take on an increasing share of the care for older individuals (2-4, 6). This puts men and women without close kin in a vulnerable position.

Experiencing a severe disease may affect a person's functional status and, consequently, their need for care and support. In this study, we examine trajectories of home care utilization among individuals experiencing a myocardial infarction, stroke, or hip fracture. These conditions are among the most common and severe diseases in old age; almost all affected individuals are hospitalized, often surgically treated and temporarily immobilized, and at elevated risk of complications such as infections and disease recurrence. Nevertheless, these diseases may impact patients' care needs in different ways. A stroke can result in both mental and physical impairment (7, 8), while sustaining a hip fracture almost always leads to physical limitations (9) but does not affect patients' mental capacities. Experiencing a myocardial infarction is associated with high mortality, but usually has less impact on functional limitations than experiencing a stroke (8).

Based on data from the entire Swedish population over the age of 65, this study aims to examine trajectories of home care utilization among individuals affected by these diseases and to investigate whether such trajectories are associated with the presence of next-of-kin, specifically spouses and children. Using sequence analysis, we will visualize these trajectories, identify clusters of common

trajectories, and analyze how having children or a spouse is related to the consumption of home care before and after disease occurrence. Moreover, we will investigate whether these trajectories are associated with individuals' sociodemographic characteristics, such as age, birth country, and educational level. By focusing on three conditions with diverse consequences, this study may facilitate a greater understanding of patterns of home care utilization among older individuals in poor health and contribute to identifying vulnerable population groups in need for support.

Methods

This study is based on a linkage of several population registers covering the entire Swedish population. Individuals over the age of 65 with their first myocardial infarction, stroke, or hip fracture between January 2014 and June 2016 were identified in the Swedish National Patient Register (NPR) based on the International Classification of Disease, version 10 (ICD-10) codes I21-I22 (myocardial infarction); I61-I63 (stroke); and S72.0-S72.2 (hip fracture). We exclude individuals younger than 65 years, individuals living in institutional housing or care facilities prior to the disease event, and those with a previous disease occurrence in the NPR since 1998. Granted monthly home care hours are retrieved from the The Register for Care and Social Services for the Elderly. Other variables are extracted from the Multi-Generation Register, the Register of the Total Population, the Cause of Death Register, and the Longitudinal Integration Database for Health Insurance and Labour Market Studies (LISA).

We plot individuals' trajectories of monthly home care utilization, defined as sequences of the number of granted home care hours per month from 18 months before to 18 months after disease occurrence. Thus, each sequence has a length of 37 states, i.e., 37 months of which the 19th month reflects the time of disease occurrence. Home care hours are categorized into 6 states ranging from "no home care" to "full-time care (744 hours per month)" with death being a 7th state. Sequence analysis and the optimal matching algorithm (10) are employed to identify clusters of typical trajectories of homecare utilization. We then compare these clusters between diseases. Finally, we will use multivariable regression models to investigate whether these clusters are associated with having a spouse or having children while taking into account patients' sociodemographic characteristics. Sequence analyses are conducted using the packages TraMineR (11) and cluster (12) in R version 3.6.1.

Preliminary Results

We are currently exploring suitable algorithms and parameters for the clustering of sequences using data from individuals who experienced a hip fracture. In total, we have identified 20,561 individuals (68.1% women and 31.9% men) with first hip fracture between January 2014 and June 2016. The mean age at hip fracture was 83.1 years and 4 out of 5 individuals were granted home care at some point during the 18 months before and after their fracture. 35.5% were married and 83.9% had at least one child at the time of the fracture.
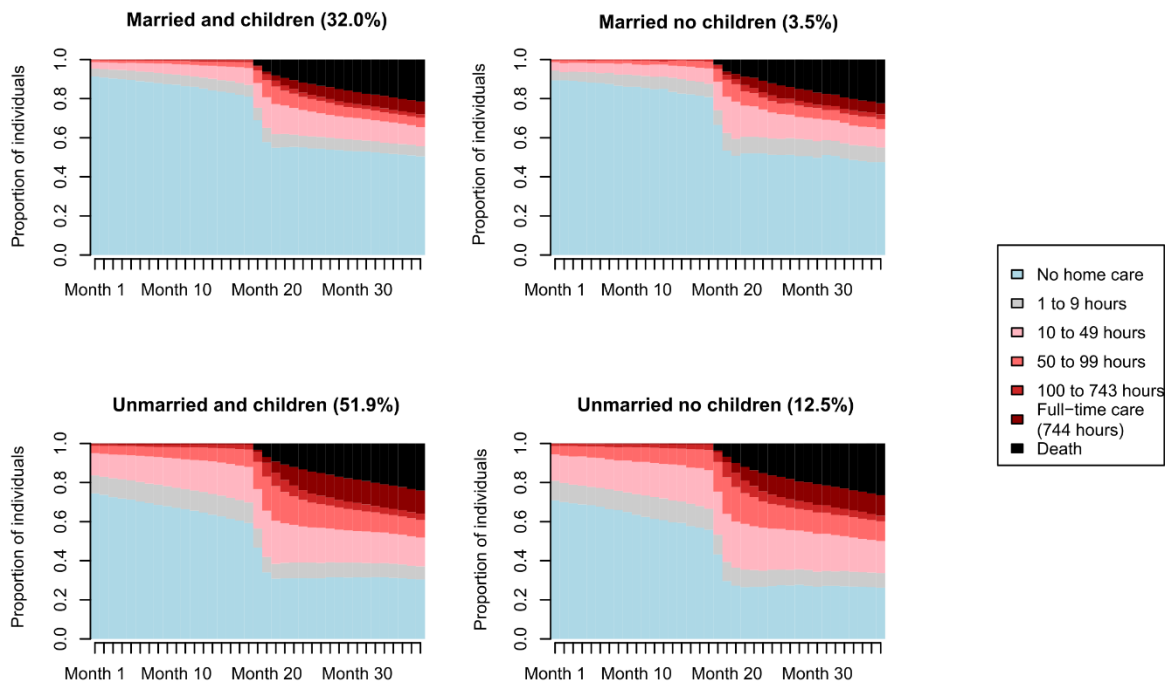

Figure 1: State distribution of granted home care hours per month during 18 months before hip fracture to 18 months after hip fracture stratified by parenthood and marital status (n=20,561)

Figure 1 visualizes sequences of home care utilization stratified by parenthood and marital status. Note that state distribution plots do not reflect individual trajectories. Instead, the plot visualizes the distribution of home care categories in each month separately. The impact of sustaining a hip fracture on home care utilization is evident in all strata. Furthermore, it is evident that unmarried individuals consume considerably more home care than married men and women. This may be, at least partly, explained by the higher average age among widowed (and therefore unmarried) individuals.

State-distribution plots for 5 clusters identified through cluster analysis using an optimal matching algorithm are shown in Figure 2. The most common cluster, for instance, comprises individuals who are

consistently independent from public home care or utilize home care only in brief episodes. Another cluster, to which 22% of individuals belong, is characterized by independence before fracture and moderate utilization of home care after the fracture. Future analyses will examine the sociodemographic composition of each cluster and associations between cluster-membership and presence of spouse or children.
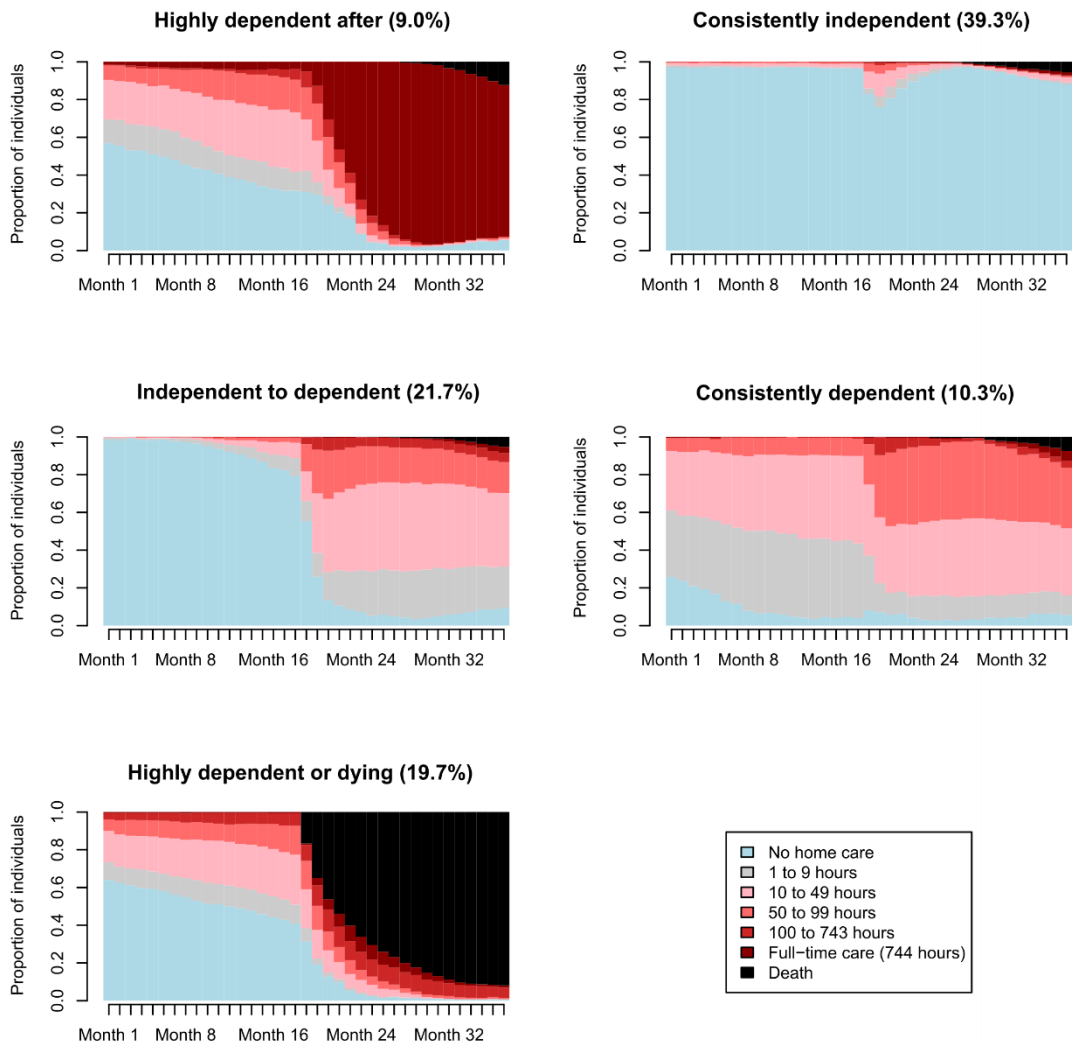

Figure 2: State distribution of granted home care hours per month during 18 months before hip fracture to 18 months after hip fracture in 5 different clusters (n=20,561)

References

1.   Sundström G, Johansson L, Hassing LB. The Shifting Balance of Long-Term Care in Sweden. The Gerontologist. 2002;42(3):350-55.

2.   Dahlberg L, Berndt H, Lennartsson C, Schön P. Receipt of Formal and Informal Help with Specific Care Tasks among Older People Living in their Own Home. National Trends over Two Decades. Social Policy & Administration. 2018;52(1):91-110.

3.   Larsson K. The social situation of older people (Chapter 8). International Journal of Social Welfare. 2007;16:S203-S18.

4.   Ulmanen P, Szebehely M. From the state to the family or to the market? Consequences of reduced residential eldercare in Sweden. International Journal of Social Welfare. 2015;24(1):81-92.

5.   Socialstyrelsen. Statistik om socialtjänstinsatser till äldre 2018. Socialstyrelsen; 2019.

6.   Socialstyrelsen. Tillståndet och utvecklingen inom hälso- och sjukvård och socialtjänst - Lägesrapport 2014. Socialstyrelsen; 2015.

7.   Wolfe CDA, Crichton SL, Heuschmann PU, McKevitt CJ, Toschke AM, Grieve AP, et al. Estimates of Outcomes Up to Ten Years after Stroke: Analysis from the Prospective South London Stroke Register. PLOS Medicine. 2011;8(5):e1001033.

8.   Levine DA, Davydow DS, Hough CL, Langa KM, Rogers MAM, Iwashyna TJ. Functional disability and cognitive impairment after hospitalization for myocardial infarction and stroke. Circ Cardiovasc Qual Outcomes. 2014;7(6):863-71.

9.   Dyer SM, Crotty M, Fairhall N, Magaziner J, Beaupre LA, Cameron ID, et al. A critical review of the long-term disability outcomes following hip fracture. BMC Geriatr. 2016;16:158.

10.   Abbott A, Tsay A. Sequence Analysis and Optimal Matching Methods in Sociology: Review and Prospect. Sociological Methods & Research. 2000;29(1):3-33.

11.   Gabadinho A, Studer M, Mueller N, Buergin R, Fonta P-A, Ritschard G. Trajectory Miner: a Toolbox for Exploring and Rendering Sequences (TraMineR). R package version 2.0-12 ed2019.

12.   Maechler M, Peter R, Struyf A, Hubert M, Hornik K, Studer M, et al. Finding Groups in Data: Cluster Analysis Extended. R package verion 2.1.0 ed2019.