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RESEARCH

Trajectories of long-term care entitlements in severely disabled older adults using nationwide Dutch data

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Abstract

Long-term care trajectories typically vary in care types, transitions and durations. Understanding these patterns can help optimize care provision. This study aimed at (1) identifying formal long-term care trajectories of severely disabled older individuals, and (2) assessing the relationships between individual characteristics and these trajectories.

Nationwide administrative data from the Centre for Care Needs Assessment were used. The sample included all 140,973 individuals older than 65 and with institutional care entitlements for somatic or psychogeriatric problems on July 1, 2015. The study period was from January 2010 to June 2019. Latent class growth analysis was performed to derive distinct care trajectories. Multinomial logistic regression analysis was used to examine the relationships between individual characteristics and these trajectories.

Five trajectories were identified, varying in complexity and duration of needs in long-term care. Two were characterized by mostly mild (somatic) institutional care and three by (psychogeriatric) institutional care with increasing duration and intensity. Men and younger individuals were more likely to require intensive (psychogeriatric) institutional care.

This study highlighted clear divergences among formal long-term care trajectories of severely disabled older individuals. Though less generous entitlement criteria may result in relatively lower expenditures in formal (institutional) care, they also imply increased use of alternatives, such as informal and community care. These insights can be used to tailor the provision of long-term care services in the future, and inform policy related to the financial sustainability of long-term care systems.

Keywords Ageing · Trajectories in long-term care entitlements · Formal long-term care · Latent class growth analysis

Introduction

Expenditure on long-term care (LTC) is considerable in most high-income countries and has increased steadily over the past several decades. As the share of older individuals grows in these countries, LTC expenditure is expected to rise further in the future, which may challenge the financial sustainability of LTC systems (OECD 2023). LTC can be generally defined as "a range of medical and nursing care, personal care and assistance services for people dependent on others for activities of daily living" (OECD 2020). Broadly, there are three types of LTC: (1) institutional care (around-the-clock care provided in a residential setting) (2) formal home care (care provided at home by professionals) and (3) informal care (typically unpaid care provided by family, close relatives, friends and neighbours) (OECD 2005; Norton 2011). In high-income countries, there recently have been moves away from institutional care, which is increasingly reserved for individuals with the highest care needs. Instead, ageing in place has become the norm (OECD 2018; Pani-Harreman, 2021).

Within these broader trends, individuals develop their own LTC trajectories or their itineraries through the care system and interactions with different actors, from individuals'

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entrance into the care system until their exit (Defossez et al. 2014). In individuals' care trajectories, transitions from one type of care to another may occur (e.g. from informal care only, to a mix of informal and formal home care, to institutional care). Individuals use several types and amounts of LTC successively, in part because care needs increase as individuals age (OECD 2019). Equally, individuals' own demographic and health characteristics may influence their LTC trajectories. Understanding this relationship may help to predict future demand for LTC services, and to adjust the supply of LTC where required (Cloutier et al. 2019). Research into individual characteristics and care trajectories may also better-inform care providers and individuals, helping to ensure that care transitions occur as seamlessly as possible (Cloutier et al. 2019; Teraoka et al. 2021).

To our knowledge, there is scant research examining trajectories in LTC among older individuals. More frequently, studies have examined health care trajectories overall, and were not specifically related to LTC (e.g. Dilworth-Anderson et al. 2011; Campen et al. 2013; Krabbe-Alkemade et al. 2020). Among the studies that have assessed LTC trajectories among older individuals, most were either cross-sectional, had follow-up periods of under 5 years (Gaugler et al. 2007; Gianino et al. 2017; Penning et al. 2018; Cloutier et al. 2019) or did not examine the time before the LTC entitlement (Teraoka et al. 2021). This limited the ability to view care trajectories over time. In addition, sample sizes were relatively small, impacting studies' generalizability (e.g. Campen et al. 2017; Penning et al. 2018; Cloutier et al. 2019; Freedman et al. 2024).

Our study identifies trajectories in formal LTC of severely disabled older individuals and investigates the individual characteristics associated with those LTC trajectories. We contribute to the literature in several ways. First, we had access to nationwide, longitudinal data on entitlements for formal LTC. More specifically, the dataset covered the period 2010–2019 and provided detailed information on all types of formal care entitlements. Second, our paper focusses on individuals aged 65 and older with age-associated health problems (Eurostat 2019; OECD 2021). Health problems that become more severe with age include somatic illnesses and psychogeriatric conditions (Luppa et al. 2010). Third, we research the trajectories of those who had been granted institutional care. This is especially relevant since institutional care is the main driver of publicly-funded LTC costs in most OECD countries (OECD 2023). Fourth, we had data on eligibility for formal LTC. While exploring trajectories in use of LTC is important, assessing trajectories in what people need might provide additional insights to adjust the availability of care, as the process leading to the actual use of care and the one underlying the need of care involve different actors and different incentives. Looking at trajectories in entitlements allows to more accurately study the development of needs of formal LTC, than when focussing on use of care only.[1]

A large body of literature has examined characteristics that are related to transitions into LTC. For instance, several studies have shown that one of the most important determinants for using any type of LTC service is having physical limitations (e.g. Dilworth-Anderson et al. 2011; Callahan et al. 2012; Campen et al. 2017). Other determinants for admission to a nursing care facility are related to age, cognitive decline, partner loss, limited social network, and socio-economic status (SES) (e.g. Gaugler et al. 2007; Martikainen et al. 2009; Wong et al. 2010; Campen et al. 2017). Similarly, a systematic review by Luppa et al. (2010) found that the use of institutional care can be predicted by cognitive and/or functional impairment, with dementia being the strongest predictor. However, studies examining characteristics that are associated with different full LTC care trajectories are lacking. In this research, we had access to detailed longitudinal demographic and health data. This allowed to thoroughly investigate the individual characteristics associated with the derived LTC trajectories.

To sum up, our study identifies trajectories in formal LTC entitlements over a nearly decade-long observation window, of Dutch individuals aged 65 and older, who have severe somatic or psychogeriatric disorders requiring institutional care. This research uses nationwide data and also investigates the individual demographic and health characteristics associated with the derived LTC trajectories. As such, it significantly contributes to the existing literature.

Study context

The Netherlands is an interesting setting to study LTC trajectories because of its well-developed national LTC system. Since 2005, access to LTC in the Netherlands has been administered by a nationwide independent committee, the Care Needs Assessment Centre (CNAC). The CNAC examines whether applicants are eligible for formal LTC and defines the type and amount of formal LTC an individual needs, using a set of nationwide, objective criteria (CNAC 2014). The CNAC provides access to LTC tailored to specific health conditions. These conditions are classified

[1] Note that having an entitlement for LTC does not necessarily coincide with individual needs. The amount and type of LTC individuals are entitled to, crucially depend on the eligibility rules used in the system and an individual may experience needs that differ from the support provided by the system. Moreover, being granted formal LTC does not automatically mean that individuals actually use care. Mostly because of supply restrictions, those with granted care may have to wait before they start using care. Information on waiting lists in the Netherlands is included in the section on "Study context".

into six sectors: somatic and psychogeriatric conditions, psychiatric disorders, and intellectual, physical and sensory handicaps. (CNAC 2013). Only individuals with a valid CNAC entitlement have access to formal LTC. After the granting process has been completed, regional care offices are required to ensure that individuals with an entitlement domiciled in their region are able to use the granted LTC. Therefore, the Dutch system makes it possible to distinguish between objective needs for LTC and the actual use of LTC.

However, the Dutch LTC system was costly. In 2014, the Netherlands spent 4.1% of its gross domestic product on LTC, the highest share of any Organisation for Economic Co-operation and Development (OECD) country (OECD 2018), while having an average share of older individuals. While the share of the Dutch population above 65 was not especially large, it was set to increase in the coming decades (OECD 2019). The Dutch LTC system was therefore forecast to become even more costly, potentially unsustainably so, as the Dutch population aged. As a result, the Dutch government implemented a large-scale reform of the LTC system in 2015 to support ageing in place (Maarse and Jeurissen 2016). Until 2015, entitlements for LTC were regulated by the Exceptional Medical Expenses Act (EMEA), which covered all Dutch individuals who needed formal LTC. EMEA included institutional care and most types of formal home care, both permanent and temporary. On January 1, 2015, the Long-Term Care Act (LTCa) replaced the EMEA. The LTCa covers intensive and permanent, to a large extent institutional, forms of LTC. Individuals entitled to LTCa care need permanent, around-the-clock supervision and care nearby (Penning et al. 2018; Rijksoverheid 2019). By law, only need factors are considered when assessing a LTCa application, and other factors such as social, material or supply conditions are not permitted to be taken into account. Since 2015, the CNAC is only responsible for access to LTCa care.

The Dutch LTC system remains fairly generous and offers universal access to comprehensive care. In the Netherlands, visiting the general practitioner and/or applying for care by the CNAC do not bring along any costs. Consequently, people in need of LTC face no meaningful barrier to enter the assessment process, which should to a large extent restrict latent demand.

Since 2015, Dutch individuals entitled to LTCa benefits have several options for receiving the care. Before the reform, individuals needing 24/7 care and supervision were most often institutionalized (i.e. moved to a residential home). In recent years, institutional care has been increasingly reserved for the most severely disabled older adults requiring round-the-clock assistance. An increasingly heterogeneous supply structure has gradually emerged, giving rise to new types of living arrangements for people with disabilities providing both own private space and access to (extensive) communal amenities and supportive (digital) services. Currently, those requiring round-the-clock assistance do not necessarily have to live in a nursing home, but may also receive the care in various home-like care settings. Note that access to privately owned LTC facilities also requires an approval (i.e. entitlement) from the CNAC. Without entitlements, clients have to pay all care and services out-of-pocket (which is costly and largely inaccessible to the vast majority of the older population). Exclusively private spending on LTC is virtually non-existent in the Netherlands.

Finally, in the last decade, individuals entitled to LTCa care have faced increasing waiting times before receiving the care needed due to supply shortages (Actiz 2024). For instance, in the first quarter of 2024, there are 24,297 individuals on the waiting list to receive institutional care from the LTC act, of whom 4,819 are urgent cases (Ministry of Health, Welfare, and Sport 2024b). Because of that, being granted formal LTC does not automatically mean that individuals actually use care.

Methods

Study design and sample selection

This study employed longitudinal, administrative data containing all entitlements in formal LTC administered by the CNAC in the period ranging from January 1, 2010 to June 30, 2019. The study sample was selected in a number of steps. First, all individuals were selected who had a valid entitlement for LTCa care (i.e. permanent institutional care) and who were aged 65 or older as of July 1, 2015 (N = 166,532).,[2][3] This date (hereafter baseline) was chosen to avoid the starting period after the LTC reform (namely January 1, 2015), which might differ from the standard business practice. Second, only individuals with an entitlement for somatic or psychogeriatric health problems were included in the sample (see Table A1, N = 142,324).[4] After

[2] Recall that an LTCa entitlement can only be received when a severe and permanent need for 24-h care or supervision due to a physical, intellectual, or psychological condition is present, as independently and objectively determined by the gatekeeper CNAC.

[3] This boils down to 5.4% of all Dutch individuals aged 65 and older, compared to 3.8% in OECD countries in 2014 (Wouterse, Bakx, Wong, 2023).

[4] Namely entitlements VV1-VV8. This boiled down to excluding 24,208 (14.5%) older individuals with a psychiatric disorder, an intellectual, physical or sensory handicap at July 2015. Handicaps or psychiatric disorders tend to occur/develop earlier in life, such as at birth. Therefore, individuals facing those disorders follow on average other LTC trajectories, compared to older disabled adults (for instance starting earlier in life and with fewer care transitions). Having included those health disorders as main health problem may have complicated the identification of clear LTC trajectories of older indi-

exclusion of individuals with temporary care at baseline ($N=897$; mainly those with palliative or rehabilitation care) and of duplicates ($N=454$), the final sample used in this study included 140,973 unique individuals.

These individuals were followed until June 30, 2019. Their LTC entitlements were searched retrospectively until January 1, 2010, which was chosen because digitalized data before this date were incomplete. June 30, 2019 was the most recent date with complete information at the time of the study and also precedes the COVID-19 pandemic. Given that individuals were assumed to experience a number of transitions in LTC needs, we collected information on valid entitlements and individual's characteristics every six months, which resulted in a dataset with 19 successive measurement points for each included individual. Note that the follow-up of each included individual may differ since many individuals had their first LTC entitlement after January 1st, 2010 and/or died before the end of observation period.

Long-term care entitlements categories

LTC entitlements were grouped into ten broader care categories.,[5,6] The ten categories encompass all possible LTC entitlements given between 2010 and 2019, and were iteratively developed in collaboration with experts from CNAC. The derived categorization is shown in Table 1.

The first category refers to individuals without a valid LTC entitlement at the beginning of our observation period. Two separate categories (mild and intensive) were used for formal home care. The costs per week of each home care entitlement were computed using the corresponding hourly wage (for 2011) published by the Dutch Healthcare Authority (Dutch: NZa) and the volume of granted care (see Appendix 2, Table A2). The average home care costs per week in the period from 2010 to 2014 equalled €351 (based on our calculations). This was used to discriminate between the mild and intensive categories. Remind that all individuals in the study sample have a valid entitlement for institutional care (i.e. LTCa care) at baseline, and therefore do not use any form of formal home care after January 1, 2015. Three main categories were used regarding permanent institutional care, namely mild, intensive, and intensive and complex care.[7] Alongside these categories, two categories for temporary institutional care were used: one for mostly geriatric rehabilitation care and recovery/respite care and another for other types of temporary LTC. The ninth category included palliative care and some other minor entitlements (such as short-term stays with a low intensity of care). The final category is for all measurement points after the individuals' death. One of these care categories was assigned to each individual at each of the nineteen observation moments between January 1, 2010 and June 30, 2019.

Individual characteristics

A number of individual characteristics were included in the analyses, and were selected based on the Andersen Behavioral Model of Health Service Use (Andersen 1995), other existing literature (e.g. Gaugler et al. 2007; Luppa et al. 2010; Martikainen et al. 2009; Wong et al. 2010), and availability in the dataset. Gender and age, as well as the interaction of gender and age, were included. Marital status was also included, and reflected whether someone was unmarried/divorced, widowed, married/partnered or whether the marital status was unknown. The average socio-economic status (SES) of an individual's neighbourhood was also included, and was derived from Statistics Netherlands (Statistics Netherlands 2022).[8]

In terms of individuals' health, the dominant health condition at baseline was characterized as either having a somatic or a psychogeriatric disorder. Secondary health conditions were also included, and were characterized as having a somatic disorder, a psychogeriatric disorder, a physical handicap, a psychiatric or mental handicap, or having no secondary health condition.

Footnote 4 (continued)

viduals. However, this does not preclude that individuals have handicaps or psychiatric disorder as secondary health problems.

5 The types of entitlements that could be given during our observation period changed. This resulted in a large number of different granted entitlements. Taking into account all these entitlements would have potentially resulted in numerous longitudinal LTC trajectories, which likely entailed difficulty in distinguishing among them and in analysing them. The EMEA (pre-2015) and LTC act (2015 and later) institutional care entitlements provided by the nursing sector are displayed in Appendix 1, Table A1. In terms of entitlement codes, lower numbers in care packages stand for lower intensity in care and higher numbers for more intensive forms of care. Entitlements for home care were provided using the types and volume of provided care, e.g. (combinations of) personal care, nursing care, guidance (individual or in group) (e.g. Rapport A4 (nivel.nl), in Dutch).

6 Mplus version 8.4 (Mplus User's Guide (statmodel.com)), the software used to identify the LTC trajectories, allowed a maximum of ten classes.

7 See Table 1 for a more detailed description of the categories.

8 The status score is computed using Principal Component Analyses for each four-digit postal code and is based on the financial prosperity, education level, and recent employment history of private households. The total score typically ranges from -2 (with the lowest status score) to 1 (with the highest status score). Four quartile dummy variables were used in the analyses.

Table 1 Newly developed categories LTC entitlements (January 1, 2010—June 30, 2019)

Newly developed categories of LTC entitlements	LTC entitlements	
	Until December 31, 2015	From January 1, 2015
No valid LTC entitlement	No valid entitlement for LTC care	n.a
Home care, Mild	€ 0 ≤ Costs per week ≤ € 351	n.a
Home care, Intensive	Costs per week > € 351	n.a
Permanent institutional care, Mild	Institutional care for individuals with reduced social self-reliance and/or light somatic, psychogeriatric, psychiatric problems and/or sensory impaired *,**	
Permanent institutional care, Intensive	Intensive institutional care for individuals with severe somatic and/or psychogeriatric disorders *	
Permanent institutional care, Intensive and complex	Intensive institutional care for individuals with severe somatic and/or psychogeriatric disorders with complex needs*	
Geriatric rehabilitation and respite care	(Unspecified) geriatric rehabilitation or respite care	Geriatric rehabilitation only for those with granted institutional care
Rest temporary institutional care	Unspecified institutional care or complex short-term stay**	n.a
Rest category	Palliative care Remaining entitlements	Palliative care*** Remaining entitlements
Deceased	n.a	Individual died between July 1, 2015 and June 30, 2019

*Newly developed categories LTC entitlements provided during observation window (January 1, 2010- June 30, 2019). Entitlements for institutional care were expressed using different care packages before and after the reform of 2015. The entitlements for care covered in the nursing sector are displayed in Appendix 1. Overall, lower numbers in care packages stand for lower intensity in care and higher numbers for more intensive forms of care

**After the reform, this type of institutional care was not granted anymore. Individuals received instead intensive formal home care. Individuals who were granted this care before the reform kept their entitlements after the reform

***Palliative care is no longer covered by the LTC-act (since January 1, 2018)

n.a. = not applicable

Statistical analyses

Descriptive statistics

Descriptive statistics were computed for the sample, which are reported in Table 2, as well as separately for the identified LTC trajectories.

Latent class growth analysis

Latent class growth analysis (LCGA) was used to identify homogenous subgroups of individuals with similar LTC entitlement trajectories (Jung and Wickrama 2008; Muthén 2002; Nylund et al. 2007; Tein et al. 2013; Zhang et al. 2018). A forward procedure was conducted, starting with a one-class solution (i.e. no subgroups) and investigating model fit criteria and clinical interpretability. One class at a time was added until model fit did not improve any further. The optimal number of classes was decided using several model fit criteria and a meaningful clinical distinction between the classes (Dziak et al. 2018; Jung and Wickrama 2008): the Akaike Information Criterion (AIC), Bayesian Information Criterion (BIC) and sample-size adjusted BIC (SABIC) were used (Kim 2014; Tein et al. 2013; Yang 2006). Lower values indicated better model fit. Classification quality, or fuzziness of classes was assessed by the entropy and the average class probabilities, scaled from 0 to 1. Higher values (> 0.8) indicate more distinct classes (Jung and Wickrama 2008; Nylund et al. 2007). The final decision on the number of classes was made in collaboration with a methodological expert (third author) and CNAC experts. Individuals were included into their best-fitting class.

Regression analyses

Multinomial logistic regression analyses were used to examine the relationships between the individual characteristics (independent variables) and the care trajectories (dependent variables) derived from the LCGA (Gray 2014). Average Marginal Effects (AME), confidence intervals and p-values were reported.

Table 2 Descriptive statistics of individual characteristics for total population and per derived care trajectory

		Trajectories in Long-Term Care Entitlements				
Variable at baseline July, 1st 2015	Total	A Mild institutional care	B Mild institutional care with high mortality rates	C Intensive institutional care, short trajectory	D Intensive institutional care, long trajectory	E Intensive and complex institutional care
Percentage of individuals	140,973	18.0	18.2	30.5	24.3	9.0
Female (%)	73.6	77.5	77,6	67.2	78.5	66.4
Age (mean, sd)	85.5 (6.98)	86.1 (6.3)	88.6 (5.9)	84.1 (6.7)	86.0 (7.0)	81.7 (8.2)
Marital status (%)						
Married / partnered	22.6	14.0	11.7	31.7	22.6	30.6
Unmarried / divorced	13.2	14.3	12.1	10.8	13.7	19.6
Widow(er)	60.4	67.4	73.3	53.2	60.4	44.9
Unknown	3.8	4.2	2.9	4.3	3.4	4.8
SES score 2014*	−0.19 (−1.04 −0.41)	−0.21 (−1.05 −0.37)	−0.22 (−1.04 0.37)	−0.16 (−1.02 −0.43)	−0.23 (−1.09 −0.37)	−0.07 (−0.93 −0.45)
Dominant health condition (%)						
Somatic disorder	45.2	83.6	65.1	30.1	29.5	21.1
Psychogeriatric disorder	54.8	16.4	34.9	69.9	70.5	78.9
Secondary health condition (%)						
None	51.4	73.4	62	43.8	42.8	34.3
Somatic disorder	33.6	10.2	23.5	45.0	41.7	39.7
Psychogeriatric disorder	2.4	2.4	3.3	1.8	2.0	2.9
Mental handicap	8.1	8.3	8.0	7.1	9.5	8.2
Physical and sensory handicap	4.6	5.5	3.2	2.3	4.0	14.9

* The total score typically ranges from -2 (with the lowest status score) to 1 (with the highest status score)

Sensitivity analyses

First, we ran comparable analyses using a slightly different categorization of LTC entitlements in which three different categories of formal home care were distinguished (mild, medium and intensive) and only two categories of permanent institutional care (mild and intensive). Highly comparable results regarding home care were found when using two or three separate categories and using three distinct categories for permanent institutional care enhanced the clinical interpretability of our results. Second, we ran separate analyses for individuals aged 65–84 and for those aged 85 and older. Four different care trajectories were identified for individuals aged 65–84 and five for those aged 85 and older. The four trajectories for those aged 65–84 overlapped to a large extent those identified for those aged 85 and older. The results of the sensitivity analyses are available upon request by the authors.

Statistical analyses were performed using R (version 4.4.1, R Core Team, 2024) and Mplus version 8.4. (Muthén and Muthén 1998–2017).

Results

Descriptive analyses

Sample characteristics at baseline (July 1, 2015) are displayed in Table 2, Column 2. Most importantly, 73.6% of the included individuals were female, they were on average 85.5 years old and the majority of them was widowed (60.4%). 45.2% had a somatic disorder as dominant health condition while the remaining 54.8% had a psychogeriatric disorder. In addition, around half of the sample had a secondary health problem. Finally, the full care trajectory is observed for 37.7% of the included individuals (i.e. they got their first entitlement after January 2010 and died before the end of our observation window) and 57.2% have deceased before the end of our observation window (not shown in Table 2).

Analyses of the care trajectories

Latent class growth analyses

Five distinct care trajectories (A-E), displayed in Fig. 1, were derived from the LCGA. Appendix 3 shows the technical output of the LCGA. Columns 2–6 of Table 2 present the descriptive characteristics of individuals in each trajectory.

Trajectory A is characterized by mild institutional care at July 1, 2015, and a relatively long and stable trajectory in mild institutional care (about 8–9 years). About 40% of individuals in trajectory A had been entitled to LTC since 2010 and around 20% had been granted home or rehabilitation care. Only 30% of these individuals had died by the end of the observation period. 18.0% of all individuals had been allocated to this trajectory.

In trajectory B, individuals were entitled to mild and intensive institutional care at baseline. Before moving to permanent institutional care, some individuals were granted temporary institutional care or formal home care. Of these individuals, 60% were already entitled to LTC at the beginning of our observation window. About 85% of the individuals had died by June 30th, 2019, generally after a short period of intensive institutional care. Of all included individuals, 18.2% were allocated to this trajectory.

Trajectory C is characterized by intensive institutional care at July 1, 2015, and a relatively short care trajectory. Only 10% of these individuals had LTC entitlements in January 2010, and these entitlements were generally for mild home care. These initial entitlements tended to change within a period of about one year (around 2014) to intensive institutional care. About 70% of these individuals had died by June 30th, 2019. The largest share of individuals (30.5%) were assigned to this care trajectory.

Trajectory D is characterized by entitlements for intensive institutional care at baseline, and long, stable trajectories in intensive institutional care (about 8–9 years). As with trajectory B, before moving to permanent institutional care, some individuals were granted temporary institutional care. Of these individuals, 70% were already granted LTC as of January 1st, 2010 and about 80% had died at the end of the observation period. Roughly a quarter (24.3%) of all individuals included in our sample, had care trajectories that were comparable to this one.

In trajectory E, individuals were entitled to intensive and complex institutional care at baseline, and had relatively long care trajectories (also about 8–9 years). Of these individuals, 70% had died by June 30th, 2019, and 55% were already entitled to various types of LTC at January 1, 2010. This care trajectory included the smallest share of individuals (9.0%).

Figure 2 shows the identified trajectories by individual age (and not by calendar time as in Fig. 1) as it may provide additional insights on the care paths.

As expected the percentage of those without granted care decreases with age and the percentage of deaths increases with age. Second, only 3.3% of the selected individuals had a LTC entitlement at age younger than 69 and those with granted care were mostly in trajectories C, D and E. Third, the vast majority of our respondents are aged 80–95 (68.2%). Fourth, the trajectories C, D, and E start on average at earlier ages than trajectories A and B. Finally, especially those in C and E die at earlier ages than others (namely the shares of individuals older than 85 in those categories become smaller as people age).

Table 2 (Columns 3–7) reports the descriptive statistics of the individuals per identified trajectory. As expected, there are more women in all categories since they on average become older and tend to develop severe somatic or psychogeriatric disorders more often than men. Trajectory D included most women, but there are relatively more men in trajectories C and E. Individuals in trajectory E were the youngest (on average 81.7 years old at baseline), those in C are also relatively young (84.1 years old at baseline) and those in trajectory B the oldest (88.6 years old at baseline). Regarding marital status, individuals in A and B are more often unmarried or widowed, whereas those in C, D and E are more often married of with partners. Turning to SES, there is no much difference between SES scores in trajectories A, B and D. However, higher SES scores characterize individuals in C and E. Those in trajectories A and B often had a somatic condition (83.6% and 65.1%, respectively) and those in class C, D and E a psychogeriatric condition (69.9%, 70.5% and 78.9%, respectively).

Regression analyses

Table 3 presents the results of the multinomial logistic regressions, examining individual characteristics' relationships to the probability of being in a given LTC trajectory, derived from the LCGA. The regression results confirm to a large extent the descriptive results of Table 2.

Most importantly, our statistical results show that there are relatively more men in trajectories C and E than in A (AMEs equal to -0.02 and -0.03 and p-values $= 0.06$ (borderline significant) and < 0.001, respectively) and that comparable shares of women are found in A, B and D. Individuals in B are on average older than those in A, whereas those in C, D and E are younger. In addition, females in D and E are more likely to survive longer than males and females in B and C die earlier than males. Overall, less care-intensive trajectories (A–B) were associated with being unpartnered. Those in C, D and E are more often widowed than those in A. Higher SES scores are associated with a

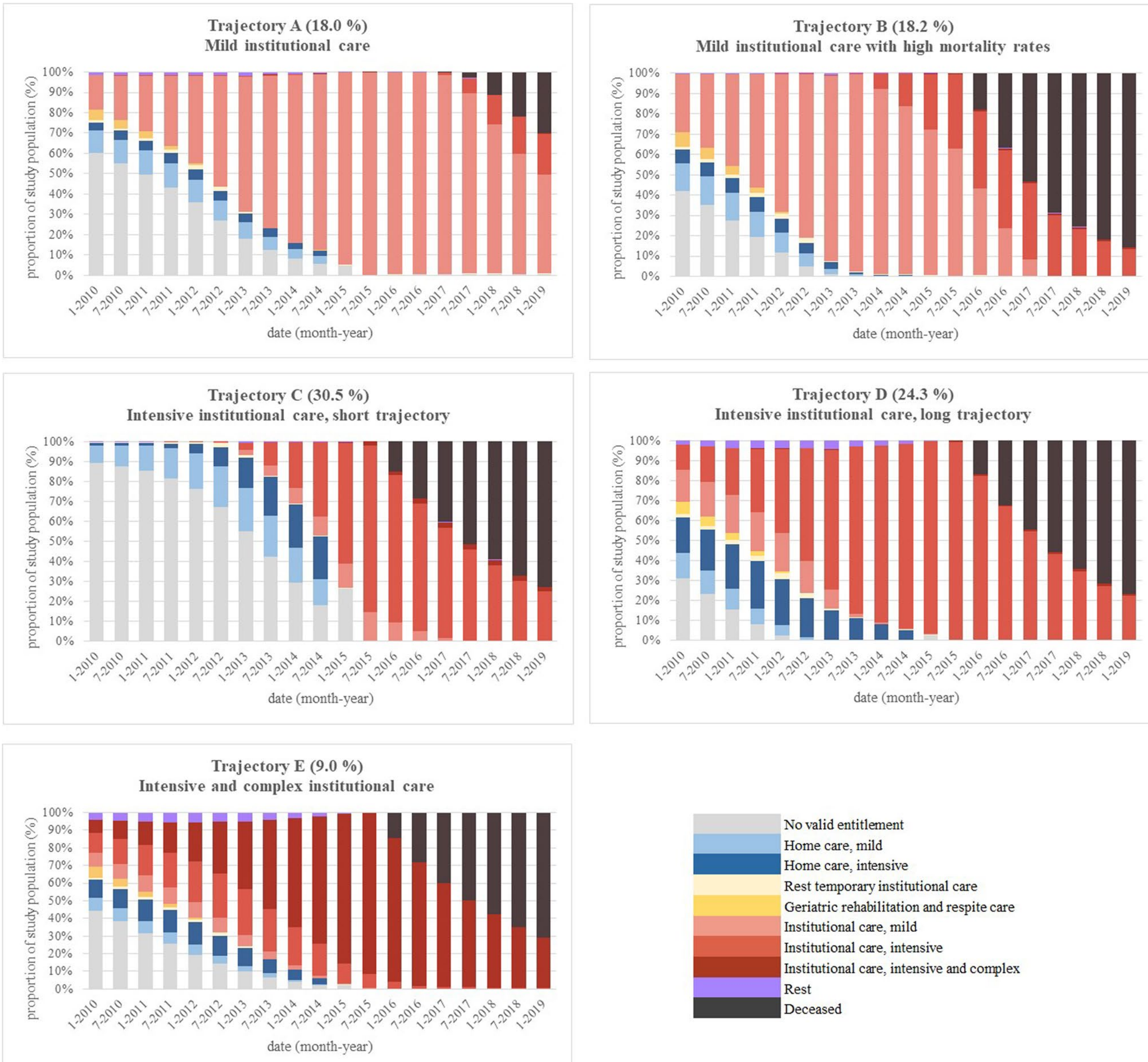

Fig. 1 Derived Long-term care trajectories with the latent class growth analyses

lower probability of being in trajectory D and a higher probability of being in trajectory E. Across the board, having a psychogeriatric disorder as a dominant health condition, relative to having a somatic disorder, is progressively associated with more intensive care needs. For instance, having a psychogeriatric disorder relative to a somatic disorder is associated with a decreased probability of being in B than in A (AME = − 0.14, *p*-value = 0.01), the least care-intensive trajectory. In contrast, having a psychogeriatric disorder relative to a somatic disorder is associated with an increased probability of being in trajectory D, an intensive trajectory, relative to trajectory A (AME = 0.18, *p*-value = < 0.001). Trajectories C and E are also characterized by substantially higher probabilities of having psychogeriatric disorders than A (AME = 0.14 and 0.10, *p*-values = < 0.001, respectively). Finally, the presence of a comorbidity also relates with the probability of being in a given trajectory. Trajectories B and C are more likely to have a secondary somatic health condition than those in A whereas those in E are much more likely to have a mental handicap.

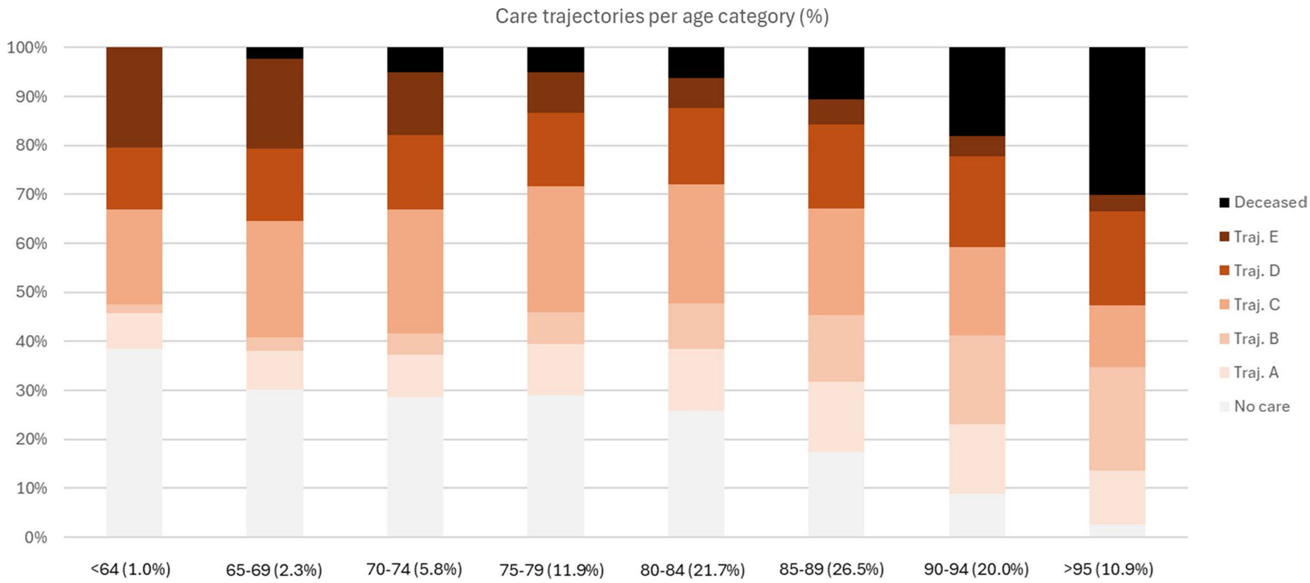

Fig. 2 Long-term care trajectories per age category (%)

Discussion

This paper aimed (1) at identifying trajectories in formal LTC entitlements over a nearly decade-long observation window, of Dutch individuals aged 65 and older having severe somatic or psychogeriatric disorders requiring institutional care. (2) at assessing the demographic and health characteristics of individuals in those trajectories. We had access to unique data, comprising the universe of Dutch administrative data of 2010–2019 on access to all formal LTC care (and not only on use). Because we use nationwide data, this study presents a complete and likely very accurate picture of the formal LTC trajectories in the Netherlands of older individuals having severe somatic and psychogeriatric disorders.

We assessed LTC trajectories retrospectively, from January 1, 2010, and prospectively, until June 30, 2019 of all Dutch individuals having a valid entitlement for institutional care at July 1, 2015. We used LCGA and multinominal logistic regression analysis. This is unique among studies examining LTC trajectories, which are either cross-sectional or have shorter observational periods (Gaugler et al. 2007; Gianino et al. 2017; Penning et al. 2018). From the LCGA, five distinct LTC trajectories were identified. Trajectories A and B were characterized by mild (especially somatic) institutional care, with the former being on average milder and longer (up to 9 years) than the latter. Around one third of all individuals were allocated to these classes. Trajectories C and D were characterized by intensive (mostly psychogeriatric) institutional care, with trajectory C shorter than trajectory D (about three years). 54.8% of all individuals were assigned to these categories. Trajectory E was characterized by intensive and complex care, with individuals generally starting using this sort of care at relatively young ages (often having mental handicaps) and using it on average for 6 years of time. 9% of all individuals were allocated to this trajectory.

Some common characteristics were present across trajectories. Within each trajectory, the LTC intensity increased over time. In most trajectories, individuals started with home or rehabilitation care and moved gradually to entitlements for institutional care. This increasing LTC intensity was also found in previous studies (Penning et al. 2018; Campen et al. 2017). Nonetheless, there were key differences among care trajectories. Most importantly, some of the care trajectories were relatively short (up to 3 years) whether others were exceptionally long (about 9 years). In addition, the intensity of the required LTC varies a lot between the trajectories. The

Table 3 Multinominal logistic regression results long-term care trajectories

	Long-term care trajectories*			
	B Mild institutional care with high mortality rates	C Intensive institutional care, short trajectory	D Intensive institutional care, long trajectory	Intensive and complex institutional care
	AME** [95% CI] p-value	AME** [95% CI] Rvalue	AME** [95% CI] p-value	AME** [95% CI] p-value
Female	0.02 [−0.01 to 0.04] 0.12	− 0.02 [-0.03 to 0.00] 0.06	0.02 [−0.00 to 0.03] 0.09	−0.03 [−0.04 to 0.02] 0.00
Age				
65–74 (ref.cat.)				
75–79	0.09 [0.06 to 0.13] 0.00	−0.02 [-0.03 to 0.00] 0.07	−0.03 [−0.05 to 0.02] 0.00	−0.05 [−0.05 to 0.04] 0.00
80–84	0.15 [0.13 to 0.18] 0.00	−0.04 [-0.05 to 0.02] 0.00	−0.06 [-0.07 to 0.04] 0.00	−0.09 [−0.10 to 0.08] 0.00
85–89	0.22 [0.20 to 0.25] 0.00	−0.07 [-0.09 to 0.06] 0.00	−0.07 [-0.08 to 0.05] 0.00	−0.09 [−0.10 to 0.08] 0.00
90–94	0.31 [0.28 to 0.34] 0.00	−0.12 [-0.14 to 0.11] 0.00	−0.06 [-0.08 to 0.05] 0.00	−0.10 [−0.10 to 0.09] 0.00
95 plus	0.38 [0.35 to 0.42] 0.00	−0.16 [-0.18 to 0.15] 0.00	−0.06 [-0.08 to 0.04] 0.00	−0.08 [−0.09 to 0.08] 0.00
Female*Age				
Female*Age 65–74 (ref.cat.)				
Female*Age 75–79	−0.01 [-0.04 to 0.02] 0.36	−0.02 [−0.04 to 0.01] 0.15	0.00 [−0.02 to 0.03] 0.79	0.02 [0.00 to 0.03] 0.01
Female*Age 80–84	−0.03 [-0.05 to 0.00] 0.03	−0.04 [−0.06 to 0.02] 0.00	0.03 [0.00 to 0.05] 0.02	0.02 [0.01 to 0.03] 0.00
Female*Age 85–89	−0.04 [-0.06 to 0.01] 0.00	−0.06 [−0.07 to 0.04] 0.00	0.06 [0.04 to 0.09] 0.00	0.03 [0.02 to 0.04] 0.00
Female*Age 90–94	−0.05 [-0.07 to 0.02] 0.00	−0.07 [−0.09 to 0.05] 0.00	0.08 [0.06 to 0.10] 0.00	0.04 [0.03 to 0.06] 0.00
Female*Age 95 plus	−0.04 [-0.07 to 0.01] 0.00	−0.10 [−0.12 to 0.07] 0.00	0.11 [0.07 to 0.14] 0.00	0.06 [0.03 to 0.09] 0.00
Partner status				
Married / partnered (ref.cat.)				
Unmarried /divorced	0.08 [0.07 to 0.09] 0.00	−0.11 [−0.12 to 0.10] 0.00	−0.01 [-0.02 to 0.00] 0.01	−0.00 [−0.00 to 0.00] 0.83
Widow(er)	0.08 [0.07 to 0.08] 0.00	−0.07 [−0.08 to 0.07] 0.00	−0.03 [-0.04 to 0.02] 0.00	−0.02 [−0.03 to 0.02] 0.00
SES score				
Low (ref.cat.)				
Low-medium	0.01 [0.00 to 0.01] 0.02	0.00 [−0.00 to 0.01] 0.47	−0.01 [0.02 to 0.00] 0.00	-0.00 [-0.00 to 0.00] 0.86
Medium-higri	−0.00 [-0.01 to 0.00] 0.61	0.00 [−0.00 to 0.01] 0.24	−0.02 [-0.02 to 0.01] 0.00	0.01 [0.01 to 0.02] 0.00
High	−0.00 [-0.01 to 0.00] 0.19	0.02 [0.01 to 0.02] 0.00	−0.02 [-0.03 to 0.02] 0.00	0.01 [0.01 to 0.02] 0.00
Dominant health condition				
Somatic disorder (ref.cat.)				
Psychogeriatric disorder	−0.14 [−0.15 to 0.14] 0.01	0.14 [0.14 to 0.15] 0.00	0.18 [0.17 to 0.19] 0.00	0.10 [0.10 to 0.10] 0.00
Secondary health condition				
None (ref.cat.)				
Somatic disorder	0.03 [0.02 to 0.04] 0.00	0.02 [0.01 to 0.02] 0.00	−0.02 [−0.03 to 0.02] 0.00	−0.02 [−0.02 to 0.02] 0.00
Psychogeriatric disorder	−0.03 [-0.04 to 0.02] 0.00	−0.04 [-0.05 to 0.02] 0.00	0.01 [-0.00 to 0.03] 0.12	0.15 [0.13 to 0.17] 0.00
Mental handicap	−0.03 [-0.04 to 0.02] 0.00	−0.14 [-0.16 to 0.14] 0.00	0.01 [-0.01 to 0.02] 0.31	0.18 [0.17 to 0.19] 0.00
Physical and sensory handicap	−0.01 [-0.02 to 0.00] 0.03	−0.04 [-0.05 to 0.03] 0.00	0.08 [0.07 to 0.09] 0.00	0.02 [0.01 to 0.02] 0.00
#	135,543			
Nagelkerke Pseudo *R*-square	0.31			

* Reference category long-term care trajectory A (Mild institutional care) ** AME; Average marginal effects

heterogeneity in duration of LTC trajectories has also been found in e.g. Collingridge Moore et al. 2020.

Individual characteristics differ between the identified care trajectories. Most importantly, two of the most intensive care trajectories (C and E) are characterized by having psychogeriatric disorders and having relatively more males. Having more males may partly explain the observed shorter lifespans and higher SES (Marais et al. 2018; Autor et al. 2023). Conversely, relatively more cognitively impaired females are in trajectory D, and, as expected, those survive longer and have on average lower SES. Individuals in the most intensive categories are more likely to be partnered, compared to individuals in other categories, which may be related to their younger ages at baseline (July 1, 2015).

When interpreting this study's findings, several limitations are important to consider. First, this study was based on valid LTC entitlements and not on the actually used care. Individuals could have used less care than their entitlement gave them (Bakx et al. 2021). In the future, using data on entitlements and invoice data on use of LTC may help to further distinguish care trajectories. Conversely, as earlier mentioned, our approach provides valuable insights into the development of actual needs for formal care, as trajectories in use may be confounded by supply conditions. Second, we had no information on informal care, and for this reason, the identified trajectories only include transitions in granted formal LTC. Third, some caution is also warranted when interpreting the results of the multinomial regressions. Based on the results of the pseudo-R^2, only a small part of the variation in LTC trajectories (Nagelkerke Pseudo R-square = 0.31) could be explained by individual characteristics. This implies that not all relevant characteristics were taken into account (for instance availability of informal care or more precise information on diseases). Future research could consider more individual characteristics. Given the earlier findings about predictors of institutional care, the relationship between individual SES and LTC trajectories could be further analysed (our analyses only control for differences in SES at municipality level) (Martikainen et al. 2009).

In this study, we disentangled clear distinct trajectories of LTC entitlements of those with needs in institutional (somatic and psychogeriatric) LTC. Knowledge on LTC trajectories and associated characteristics is relevant, in the context of ageing populations, and with likely larger cohorts of individuals in need of (expensive) institutional care. This study has implications for both policy and practice. First, this study found that many individuals (quickly) transition care entitlements, which indicates a need for cooperation among the different LTC providers to smoothly facilitate these transitions. Second, insights into current LTC trajectories can be used to tailor LTC services provision in the future and better-anticipate future individuals' needs.

What do our results mean for cohorts of older individuals in other countries? As discussed in the section on "Study context", individuals with granted care in the Netherlands can be regarded as those having objective needs for LTC. As such, the paper identifies the most prevalent trajectories in formal LTC needs of individuals aged 65 and older, having severe somatic or psychogeriatric disorders. We therefore believe that the identified trajectories in LTC needs are not unique to the Netherlands and are likely to be observed in other ageing populations as well.

What do our results mean for future cohorts of Dutch older individuals? Remind first that the Dutch eligibility criteria used after 2015 are stricter than the ones used before the reform. This implies that part of the individuals who were granted (light) institutional care in the period preceding the reform would not be granted this type of care using the 2015 criteria. Because of that, the derived LTC trajectories would likely become shorter (A, B, and D) and/or involving less intensive types of institutional care (e.g. D). Moreover, the current Dutch eligibility criteria are only based on health needs and not on the availability of informal care (e.g. partner and children) or other material conditions. About one third of all older severely disabled older individuals have long trajectories in mild (mostly somatic) institutional care which do not evolve in intensive care (trajectories A and B). Using additional eligibility criteria (for instance based on the social network of the applicants) would likely result in fewer individuals in A and likely in B and D, as part of the care could be provided in home-like settings, by formal or informal providers. Studies have consistently shown that spouses and adult children, especially women aged 50–75, predominantly provide informal care (e.g. Rocard and Llena-Nozal 2022). For individuals in A and B, care from adult children or community care could provide some assistance and allow them to remain at home for as long as possible. This may also likely hold true for those in C, D and E since a substantial share of individuals in those care-intensive trajectories still have their partner. However, the required care (mostly intensive and some also complex) may be more difficult to provide (informally) at home.

To conclude, using less generous entitlement criteria, e.g. based on needs and on the availability of informal care or other material support, and/or reserving institutional care only to those with intensive needs, may result in relatively lower expenditures for formal (institutional) care. However, this may also result in the increased use of alternatives, such as formal and informal home care and community care. Investigating whether and to which extent this is feasible would be the topic of future studies.

Appendix 1

See Table 4.

Table 4 Health care packages for institutional care in the nursing sector before and after the Dutch LTC reform of 2015

EMEA (until December 31, 2014)		*LTC-act (from January 1, 2015)*	
Codes description		Codes description	
VV01	Light care for individuals with reduced social self-reliance	VV1	Light care for individuals with reduced social self-reliance*
VV02	Light care for individuals with early-stage health problems	VV2	Light care for individuals with early-stage health problems*
VV03	Light care for individuals with somatic disorders	VV3	Light care for individuals with somatic disorders*
VV04	Light care for individuals with psychogeriatric or psychiatric problems, combined with physical limitations or sensory impaired	VV4	Light care for individuals with psychogeriatric or psychiatric problems, combined with physical limitations or sensory impaired
VV05	Intensive care for individuals with psychogeriatric disorders	VV5	Intensive care for individuals with psychogeriatric disorders
VV06	Intensive care for individuals with somatic disorders	VV6	Intensive care for individuals with somatic disorders
VV07	Intensive care for individuals with complex psychogeriatric needs	VV7	Intensive care for individuals with complex psychogeriatric needs
VV08	Intensive care for individuals with complex somatic needs	VV8	Intensive care for individuals with complex somatic needs
VV09	Unspecified geriatric rehabilitation**		
VV09A	Geriatric rehabilitation for individuals without LTC entitlement**		
VV09B	Geriatric rehabilitation for individuals with granted institutional care	VV9B	Geriatric rehabilitation for individuals with granted institutional care
VV10	Palliative care for individuals with or without granted long-term care	VV10	Palliative care for individuals with or without granted long-term care***

*Entitlements not given after December 31, 2014. However, individuals who had been given those entitlements before the reform and who were alive after the reform were also included in our study's dataset. ** Entitlements not given after January 1, 2012. *** Entitlements not given after January 1, 2018

Appendix 2 Weighted rates home care 2011

See Table 5.

Table 5 Weighted rates home care 2011

Type of care	Weighted rates	Type of rate
Personal care	€ 49.04	hourly rate
Nursing care	€ 70.55	hourly rate
Guidance (individual)	€ 58.32	hourly rate
Guidance (group)	€ 47.67	rate per day
Treatment (group)	€ 56.70	rate per day

The weighted rates of home care are calculated on agreed volume and tariffs of Dutch Health Care Authority for 2011 derived from Cognos database.

Appendix 3 Technical output of the Latent Class Growth Analyses

Intermediary steps: The clinical interpretability and the fit criteria were examined at each step of the forward procedure. The distinction in care categories was not clearly defined in a 2-class solution. In a 3-class solution, one of the classes consisted of mainly mild institutional care. However, the other two classes were highly similar and consisted of a mix of care categories. In a 4-class solution, one class consisted of mainly mild institutional care, one of mainly intensive institutional care and one of mainly intensive and complex institutional care. One of the classes had a mix of mild and intensive institutional care. In a 5-class solution, there were two classes with mainly mild institutional care. These trajectories had different lengths: while one remained mild institutional care, the other changed into intensive institutional care. There were also two classes with mainly intensive institutional care (one relatively short and the other relatively long). Finally, there was one category with mainly intensive and complex institutional care. The 6-class solution was similar to the 5-class solution, with the only difference that one of the classes with intensive institutional care was split into two different classes.

Model fit criteria: The model fit criteria for the different class solutions are shown in Table A3. Regarding the information criteria (AIC, BIC, SABIC), lower numbers were found in higher number of classes, indicating a more optimal number of classes. Fewer parameters were observed in lower numbers of classes. The classification quality was good for each of the class solutions, which is indicated by the high entropy values which are all above 0.8. The entropy value and class probabilities were the highest for a 2-class and a 4-class solutions. However, as mentioned, the clinical interpretability was low. The distinction of the classes was clear and meaningful in a 5- and 6-class solution. A 5-class solution was therefore chosen as the optimal number of classes, because, with similar model fit criteria and interpretability, a lower number of classes is preferred. The output from the5-class solution is descriptively presented and interpreted in the results section.

See Table 6.

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Author contributions Portrait, Krabbe-Alkemade and Thompson wrote the main manuscript text. Portrait, Krabbe-Alkemade, Hoekstra and Rusticus performed the analyses and prepared Fig. 1 and Tables 1–4. All authors reviewed the manuscript.

Availability of data and materials No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate According to the Dutch law, a study like this does not require approval from an Ethics Review Board, as the study does not fall within the scope of the Medical Research Involving Human Subjects Act (WMO).

Competing interests The five authors did not receive any financial grants to conduct this study. The first author has an appointment as a researcher with the CNAC of one day a week. In addition, we would like to emphasize that this study does not necessarily reflect the view of the CNAC on Dutch social care policy.

Table 6 Latent class model fit indices

Number of classes	AIC	BIC	SABIC	Free paranieters	Entropy	Class probabilities	Percentage of subjects per class
1	7,399,760.70	7,401,150.40	7,400,702.30	141	–	1	100
2	6,313,385.90	6,316,175.30	6,315,275.90	283	0.976	0.995 / 0.990	62.2 37.8
3	5,726,843.30	5,731,032.20	5,729,681.50	425	0.968	0.990 / 0.981 / 0.985	33.5 1 37.3 29.2
4	5,392,196.10	5,397,784.60	5,395,982.70	567	0.974	0.991 / 0.981 / 0.984 / 0.987	31.4 31.21 / 28.3 / 9.0
5	5,167,139.10	5,174,127.20	5,171,874.00	709	0.971	0.984 / *1* 0.973 / 0.980 / 0.983 / 0.987	18.0 18.2/ 30.5 / 24.3 / 9.0
6	4,963,715.00	4,972,102.80	4,969,398.20	851	0.97	0.963 / 0.984 / 0.984 / 0.972 / 0.981 / 0.988	14.7 / 19.0 / 23.4 / 16.8 / 17.7 / 8.4

AIC, Akaike's information criterion; BIC, Bayesian information criterion; SABIC, Sample-size adjusted BIC; Class probabilities, the average class probabilities

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