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Original Study

Long-Term Care Use During the Last 2 Years of Life in Sweden: Implications for Policy to Address Increased Population Aging



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A B S T R A C T

Keywords:

Home care use
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gender differences
household type

Objectives: To map out the total use of long-term care (LTC; ie, home care or institutional care) during the last 2 years of life and to investigate to what extent gender differences in LTC use were explained by cohabitation status and age at death.

Design: The National Cause of Death Register was used to identify decedents. Use of LTC was based on the Social Services Register (SSR) and sociodemographic factors were provided by Statistics Sweden.

Setting and Participants: All persons living in Sweden who died in November 2015 aged ≥ 67 years ($n = 5948$).

Methods: Zero inflated negative binomial regression was used to estimate the relative impact of age, gender, and cohabitation status on the use of LTC.

Results: Women used LTC to a larger extent [odds ratio (OR) 2.17, 95% confidence interval (CI) 1.92–2.50] and for a longer period [risk ratio (RR) 1.14, 95% CI 1.11–1.18] than men. When controlling for age at death and cohabitation status, gender differences in LTC attenuated (OR 1.47, 95% CI 1.28–1.72) and vanished in regard to the duration. In the controlled model, women used LTC for 15.6 months (95% CI 15.2–16.0) and men for 14.1 months (95% CI 13.7–14.5) out of 24 months. The length of stay in institutional care was 7.2 (95% CI 6.8–7.5) and 6.2 months (95% CI 5.8–6.6), respectively.

Conclusions and Implications: A substantial part of women's greater use of LTC was due to their higher age at death and because they more often lived alone. Given that survival continues to increase, the association between older age at death and LTC use suggests that policy makers will have to deal with an increased pressure on the LTC sector. Yet, increased survival among men could imply that more women will have access to spousal caregivers, although very old couples may have limited capacity for extensive caregiving at the end of life.

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Long-term care is a key policy priority for governments as most countries face societal changes that imply a significant growth in the need for long-term care (LTC). Mortality is being postponed to older

ages, and most deaths in high-income countries now occur at ages around 85.¹ Although many people live well into advanced ages, deaths after age 80 years are often preceded by a period of functional loss, dependency, and need for LTC.^{2–5}

In response to increasing care needs, public responsibility for funding arrangements for LTC has expanded across the OECD, notably during the past few decades. In contrast, as part of the general expansion of the welfare state during the 1960s and 1970s, Sweden early developed a comprehensive, universal LTC system that is largely financed by local taxes and available for all inhabitants aged ≥ 65 years. The principle of “aging in place,” that is, to support older

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people in their own homes,⁶ became a political ambition as early as in the mid-1950s, when home care was introduced.⁷

The 290 municipalities are legally obliged to provide home care and institutional care, the main forms of LTC. Access to LTC is needs-based, not means-tested, and services are used by all socioeconomic groups. Although municipal need-assessors decide on social care needs based on individual needs-assessments, municipalities have a high degree of autonomy. On the country level, there are no uniform rules that specify the amount of help to which a person is entitled given a certain degree of dependency.⁸ Most people enter the LTC system through home care, and institutional care is only approved if an increase in home care would be insufficient.⁷ Individual income-related user fees are low, with a cap of currently ~\$225 per month, covering 4% to 5% of the actual costs.⁷ Family or household economic resources are not considered.

Home care covers personal care (eg, dressing, showering, toileting) and/or practical support with household chores. Home care can be offered around the clock and may be complemented with primary care providing nursing care in the homes. In 2015, 13% of the population aged ≥ 80 years lived in institutional care and 23% received home care.⁹

Age, gender, and household type are closely intertwined in old age and affect the use of LTC, in Sweden as in other countries.^{10,11} Generally, LTC is more common among women^{12,13}; woman also spend longer time in institutional care than men of the same age.^{10,14–17} The few studies that included cohabitation status concluded that individuals living alone were substantially more likely to use LTC, especially home care.^{12,13} Studies addressing the last years of life have often focused on the effect of age vs time-to-death on acute care and LTC.¹³ Results indicate that both proximity to death and age are associated with institutional LTC, while approaching death rather than age is the main determinant of hospital use.^{18,19}

Although elder care in most countries is being shifted from institutional to home-based care, few longitudinal studies have included both forms of LTC and addressed the relative importance of age, gender, and cohabitation status for use of care. Most Swedish research following older decedents for the last years of life used data from the 1990s or early 2000s, is restricted to institutional care, and is based on smaller local samples.^{10,12,19–21}

Unique to this study, we use nationwide registers comprising all Swedes aged ≥ 67 years who died in November 2015. The objectives were to (1) map out the total use of LTC (ie, home care and institutional care) during the last 2 years of life in a country with a long-established and comprehensive public LTC system and (2) to investigate if gender differences in the use and duration of LTC were dependent on cohabitation status and age at death.

Methods

Study Population

Using individually linked nationwide Swedish registers, all persons who died in November 2015 aged ≥ 67 years were followed retrospectively for 2 years. The National Cause of Death Register was used to identify decedents ($n = 6329$) and LTC use was collected from the Social Services Register (SSR). Eight individuals were excluded because they immigrated after November 30, 2013; 373 individuals were excluded because they lived in a municipality with incomplete LTC data.

Data

The Social Services Register (SSR) is a routinely collected administrative register that includes information on all LTC provided by the municipalities. According to the register holder (National Board of

Health and Welfare), reliable monthly information on individual LTC use has existed for most municipalities since late 2013. We excluded 25 (7%) smaller and mostly rural municipalities that reported unreliable information, that is, did not report data for at least 2 of the 24 months or reported large variations in LTC use ($>30\%$ between 2 of the 24 months). Information on age, sex, municipality of residence, and cohabitation status was based on registers held by Statistics Sweden. Date of death was available from the National Cause of Death Register.

This study was approved by the Regional Ethics Review Board in Stockholm (Dnr2016/4:6).

Outcomes

Long-term care

Home care use was defined as receipt of services in ordinary dwellings, beyond meals on wheels and/or digital security alarm.

In accordance with the methods used by the register-holder, institutional care was considered to be permanent from the first month of institutionalization. In Sweden, a move to institutional care is almost always permanent because it requires a needs assessment.

Covariates

Age at death was categorized into quartiles: 67 to 77 years, 78 to 84 years, 85 to 90 years, and 91 to 109 years.

Cohabitations status was categorized as living alone or cohabiting. Cohabiting people were registered as married or shared the household with someone in 2014, according to Statistics Sweden. In total, 114 persons lost their spouse during the follow-up. These individuals were treated as cohabiting, as we did not know the date of bereavement.

Statistical Analyses

In order to describe the study population, we summarized socio-demographic characteristics and LTC use as percentages, means, and standard deviations, and calculated the median duration of home help use and institutional care with accompanying 10th, 25th, 75th, and 90th percentile. All individuals had 24 months of contributing time. To account for the many nonusers and the skewed distribution of the number of months with LTC, zero inflated negative binomial (ZINB) regressions were used to estimate the relative impact of age, gender, and cohabitation status on use of institutional care and on the overall use of LTC (home care or institutional care). ZINB regressions consist of a logistic part, estimating the probability of use (0/1), and a Poisson part estimating the number of months with LTC (1–24 months). Average marginal effects (AMEs) were calculated to estimate the average number of months with LTC. All analyses were performed with Stata, version 14 (StataCorp, College Station, TX).

Results

Half of the 5948 decedents (52%) died at an age ≥ 85 years, 44% of the men and 59% of the women. Eighty percent of the women lived alone, compared with about half of the men (52%) (Table 1). A majority received home care during the 2 years preceding death. Institutional care was more common among women (46%) than among men (30%), and more men (29%) than women (16%) died without having used any LTC. On average, women used LTC for a longer time (17.0 out of 24 months) than men (12.5 months).

The proportion of people using LTC increased with approaching death (Figure 1). Among women, 62% used LTC 2 years before death and 82% in the month before death; among men, LTC use increased from 41% to 69%. Proportions of LTC users were higher for men and women who lived alone compared with those cohabiting. The

Table 1
Use of LTC During the Last 2 Years of Life, Age at Death and Cohabitation Status Among People Who Died in Sweden in November 2015 Aged ≥67 Years

	Age at Death, Mean (SD)	Total (n = 5948)	Men (n = 2808)	Women (n = 3140)
Cohabiting	81.15 (7.68)	33.39	48.15	20.19
Living alone	85.23 (8.35)	66.61	51.85	79.81
Age at death (quartiles)				
67-77		24.92	31.30	19.20
78-84		23.37	25.14	21.78
85-90		27.03	26.46	27.55
91-109		24.68	17.09	31.46
No LTC	77.36 (7.23)	21.81	28.70	15.64
Only home care	83.71 (7.94)	39.85	41.38	38.47
Both home care and institutional care	87.15 (6.77)	17.06	14.81	19.08
Only institutional care	88.19 (6.99)	21.28	15.10	26.82
Months with LTC				
Mean (SD)		14.86 (10.53)	12.53 (10.71)	16.95 (9.92)
Median (IQR)		23 (24-2)	13 (24-0)	24 (24-6)
0	77.36 (7.23)	21.81	28.70	15.64
1-6	80.13 (7.52)	11.85	13.78	10.13
7-12	82.91 (7.51)	5.83	7.26	4.55
13-18	84.10 (7.43)	4.98	5.66	4.36
19-24	87.30 (7.13)	55.53	44.59	65.32
Months with home care				
Mean (SD)		8.12 (9.66)	7.52 (9.31)	8.66 (9.94)
Median (IQR)		2 (18-0)	2 (15-0)	3 (20-0)
0	82.71 (8.94)	43.09	43.80	42.45
1-6 (10th percentile)	81.88 (7.85)	16.56	18.30	15.00
7-12 (25th percentile)	84.77 (7.69)	8.66	9.12	8.25
13-18 (75th percentile)	85.89 (7.29)	7.67	7.87	7.48
19-24 (90th percentile)	86.33 (7.34)	24.02	20.90	26.82
Months in institutional care				
Mean (SD)		6.74 (9.91)	5.01 (8.92)	8.29 (10.49)
Median (IQR)		0 (16-0)	0 (6-0)	0 (24-0)
0	81.46 (8.27)	61.65	70.09	54.11
1-6	86.84 (6.89)	6.39	5.80	6.91
7-12	87.12 (6.61)	5.06	4.45	5.61
13-18	87.24 (7.19)	3.80	2.92	4.59
19-24	88.19 (6.89)	23.10	16.74	28.79

IQR, interquartile range; SD, standard deviation. Unless otherwise noted, values are %.

incidence of institutional care accelerated during the last 3 months of life (Figure 2).

LTC was more common among individuals who died at older ages compared with those who died at younger ages (Figure 3). More than 86% of all decedents aged 91 to 109 years used LTC during the month before death (not shown). Among the youngest decedents, proportions of LTC ranged between 35% (cohabiting men) and 60% (women living alone) 1 month before death, and the proportion of individuals living in institutional care remained less than 20% over the whole 2-year period.

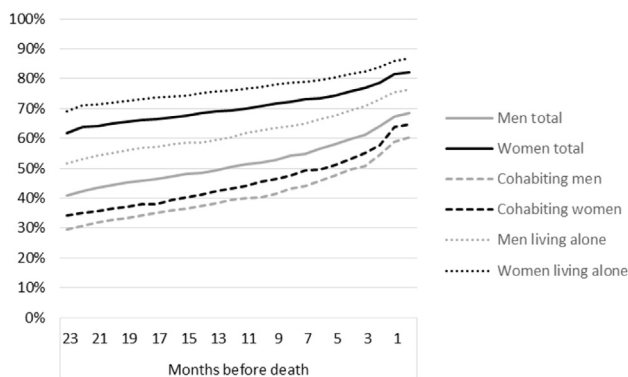


Fig. 1. Proportion of women and men with LTC (home care or institutional care) during the last 2 years of life, by household type.

In Table 2, we estimated the use of “any form of LTC” and “institutional care” using zero-inflated negative binomial regression models, adjusting for gender and cohabitation status.

Any Form of LTC

In the crude model 1, women had 2.17 times higher odds than men to use any form of LTC. Considering users only, women used LTC for 14% more months than men. When accounting for cohabitation status and age at death, gender differences attenuated (model 2); women had 47% higher odds to use any form of LTC and used LTC for 4% more months than men. Living alone and a higher age at death increased the

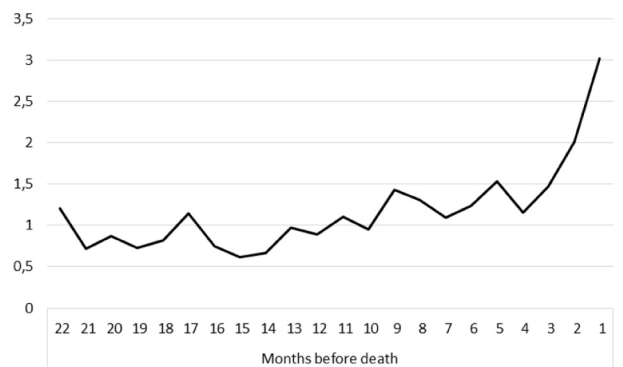


Fig. 2. Incidence rate of institutional care during the last 2 years of life.

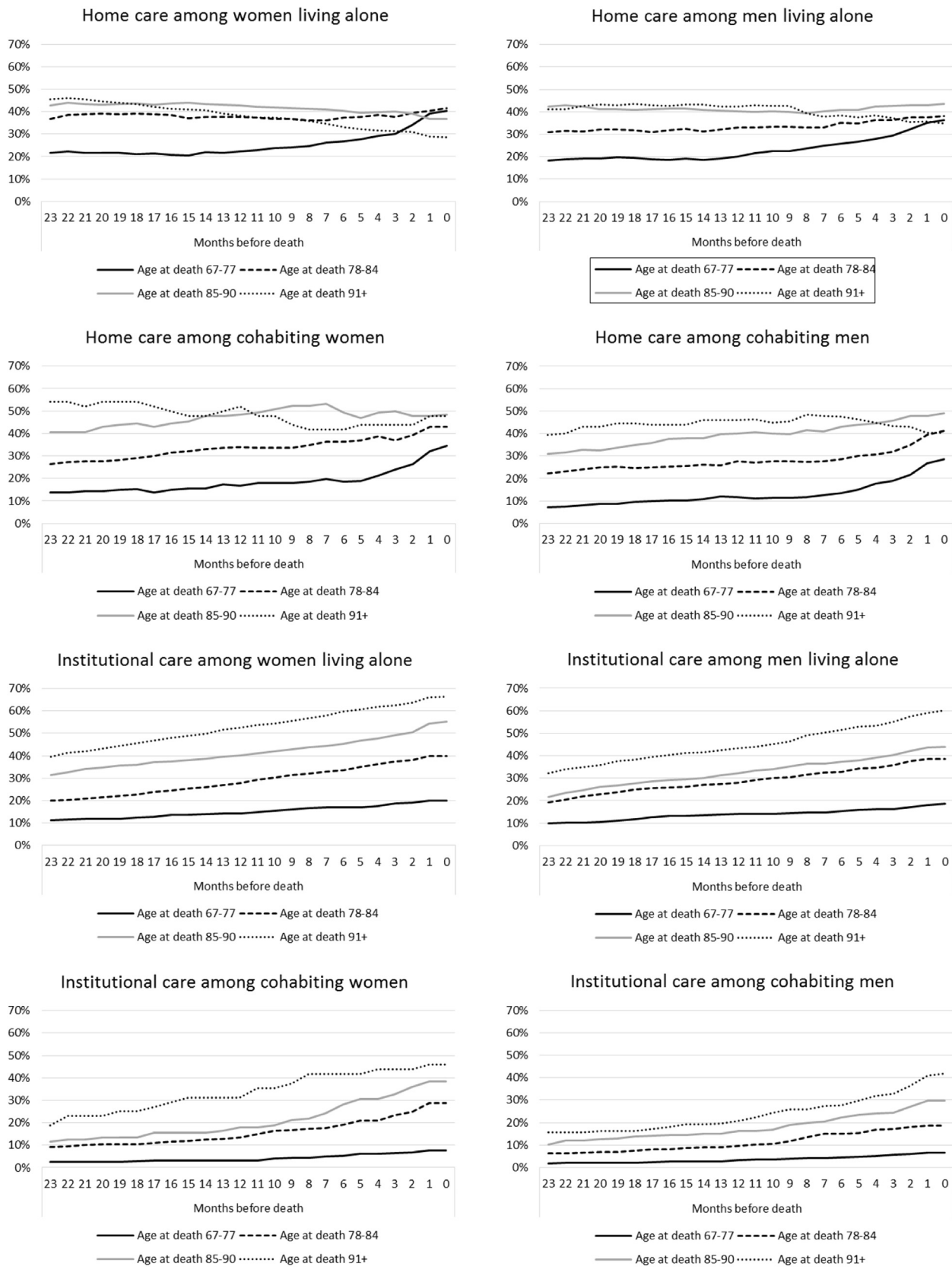


Fig. 3. Proportions of women and men with LTC (institutional care; home care) during the last 2 years of life, by age at death, gender, and household type.

Table 2
Estimated Use of LTC and Duration of LTC During the Last 2 Years of Life, Bivariate Associations and Controlled for Gender, Age at Death, and Cohabitation Status

	Any Form of LTC		Institutional Care	
	Model 1*	Model 2 [†]	Model 1*	Model 2 [†]
	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)
Estimate of use				
Women	2.17 (1.92, 2.50)	1.47 (1.28, 1.72)	2.00 (1.79, 2.22)	1.31 (1.16, 1.49)
Living alone	2.94 (2.63, 3.44)	2.08 (1.81, 2.38)	3.13 (2.78, 3.57)	2.22 (1.96, 2.56)
Age at death				
67-77	ref	ref	ref	ref
78-84	2.94 (2.50, 3.45)	2.86 (2.44, 3.45)	3.03 (2.56, 3.70)	2.94 (2.44, 3.57)
85-90	8.33 (6.67, 10.00)	7.14 (6.25, 9.09)	5.26 (4.55, 6.25)	4.76 (4.00, 5.88)
91-109	16.67 (14.29, 25.00)	14.29 (11.1, 20.00)	10.00 (8.33, 12.50)	8.33 (6.67, 10.00)
	RR (95% CI)	RR (95% CI)	RR (95% CI)	RR (95% CI)
Estimate of number of months				
Women	1.14 (1.11, 1.18)	1.04 (1.01, 1.07)	1.08 (1.03, 1.13)	1.01 (0.96, 1.06)
Living alone	1.29 (1.25, 1.34)	1.23 (1.18, 1.27)	1.30 (1.23, 1.38)	1.28 (1.20, 1.37)
Age at death				
67-77	ref	ref	ref	ref
78-84	1.29 (1.23, 1.36)	1.29 (1.23, 1.36)	0.99 (0.90, 1.09)	1.00 (0.91, 1.11)
85-90	1.45 (1.38, 1.52)	1.42 (1.36, 1.49)	1.03 (0.94, 1.12)	1.02 (0.93, 1.12)
91-109	1.60 (1.52, 1.67)	1.52 (1.45, 1.60)	1.09 (1.0, 1.19)	1.06 (0.98, 1.16)
	AME (95% CI)	AME (95% CI)	AME (95% CI)	AME (95% CI)
Average months				
Men	12.5 (12.1, 13.0)	14.1 (13.7, 14.5)	5.01 (4.7, 5.4)	6.2 (5.8, 6.6)
Women	17.0 (16.5, 17.4)	15.6 (15.2, 16.0)	8.29 (7.9, 8.7)	7.2 (6.8, 7.5)

AME, average marginal effects; ref, reference category; CI, confidence interval; OR, odds ratio; RR, rate ratio.

*Model 1: bivariate associations.

[†]Model 2: controlled for gender, age at death, and cohabitation status.

likelihood of using LTC. When calculating the overall marginal effects in the adjusted model 2, women used LTC for 15.6 (95% CI 15.2-15.9) and men for 14.1 (95% CI 13.7-14.5) of the studied 24 months.

Institutional Care

In the crude model 1, women had 2 times higher odds than men to live in institutional care in the 2 years prior to death. When accounting for age and cohabitation status, the gender difference decreased to 31% higher odds of institutional care for women (Model 2). According to the unadjusted analyses, among those living in institutional care, women lived there for 8% more months than men; when cohabitation status and age were introduced, the gender differences vanished.

Living alone and higher age at death increased the odds of institutional care, but only living alone was associated to the duration (RR 1.28, 95% CI 1.20-1.37). Adjusted for cohabitation status and age at death, on average, women lived in institutional care for 7.2 months (95% CI 6.8-7.5) and men for 6.2 months (95% CI 5.8-6.6) out of the studied 24 months.

Discussion

Using Swedish national registers covering all decedents aged ≥ 67 years, this study showed that women used LTC more often and for a longer period than men during the last 2 years of life. Although age, gender, and household type are closely intertwined in old age, few studies have addressed these factors simultaneously. Considering that women died at higher ages and more often lived alone, results showed that gender differences in LTC use attenuated but remained statistically significant, possibly due to women's generally higher level of disability.^{2,22,23} With regard to the duration of LTC, gender differences almost disappeared.

Individuals living alone were twice as likely to use LTC as those cohabiting. This is in line with earlier local Swedish studies^{10,12} as well

as a nationwide Dutch study.¹³ The results suggest that cohabiting people postpone formal LTC by informal care. As shown previously, the potential availability of a cohabiting partner seemed to influence LTC use similarly for men and women.^{24,25}

The finding that older age at death was associated with more LTC use is mirrored in other studies that found institutional care to be more prevalent with increasing age, even when adjusting for closeness of death, in Sweden,^{11,19} other European countries,^{13,16,17,26,27} and the United States.¹⁸ Given that survival is still increasing, the increase of LTC with older age highlights the importance of policies addressing strategies for optimizing the use of limited public resources.

Although increasing care needs in aging populations has been the main policy driver of the development of LTC systems across the OECD since the early 1990s, Sweden was a forerunner in providing formal LTC, especially home-based care. The comprehensive needs-based LTC system covers all citizens aged ≥ 65 years under the same program and expanded rapidly during the 1960s and 1970s, before aging populations were a concern.

Since coverage rates peaked in the mid-1980s, focus has been on cost containment to sustain a system that is used by all socioeconomic groups. Besides organizational reforms and efforts to increase cost-efficiency, the most salient strategy for system adaption to contain costs has been to further strengthen the home-oriented approach. Despite unchanged legislation, institutional care and hospital beds drastically decreased. Although institutional beds decreased by 30% during the past 2 decades, currently reaching 13% of people aged ≥ 80 years, the overall home care coverage has remained at around 21% to 23%.^{9,28} Yet, Sweden is still one of the biggest public spenders in LTC with 3.2 % of GDP compared with the OECD average of 1.7% and 0.5% in the United States.²⁹

As a consequence of reduced institutional care, eligibility thresholds for access have risen and the length of stay has decreased.²⁰ Although municipalities have a high degree of autonomy in their

need assessments, in general, institutional care is only approved when increased home care is considered to be insufficient.⁷

As most users in Sweden enter LTC through home care, our result that older age at death was associated with a longer total period of LTC is in line with other Swedish studies, showing that older age was the main driver of home care use and costs, whereas time to death had a greater impact on institutional care.^{11,19} The latter is also indicated in the present study by the steeper increase in the incidence rate of institutional care during the last 3 months of life.

Our finding that living alone, but not older age at death, increased the length of stay in institutional care may be interpreted as evidence for the rather strict eligibility criteria, where cohabiting people enter institutional care closer to death compared with those living alone. This indicates that even the needs-based Swedish LTC system strongly builds on informal caregiving among older couples.

Swedish municipalities use a range of measures in order to avoid or postpone the more expensive option of institutional care, eg, heavily subsidized housing adaptations, assistive devices, and an increased supply of welfare technologies (eg, digital security alarms, medication reminders, nighttime monitoring using web cameras, electronic rostering tools). In order to enable older people with complex care needs to remain in their own homes, developmental projects have been provided with earmarked resources to develop new models of integrated care and improved cooperation and coordination between providers of medical and social care. Day care and respite care, where the older person alternately lives at home and in institutional care, are also widely used strategies to support especially older community-dwelling couples. Moreover, in 2009, support of informal caregivers was introduced into the social service legislation.

Although in international comparison formal care for older people in Sweden is still extensive and people aged ≥ 65 years typically live alone (32%) or just with their partner (64%), informal carers provide the bulk of support to community-dwelling older people and their role is increasing.^{25,30–32} As a result of declining publicly financed LTC, older persons with lower education especially increasingly receive family care from outside the household, mostly adult children, whereas those with higher education are more likely to pay out of pocket for services, mostly practical help.^{25,33} Also, different forms of accessible “senior housing” have appeared more recently as part of the private housing market in urban regions. Yet, privately purchased help with personal care is still almost nonexistent.

Strengths and Limitations

A main strength of this study is the nationwide data covering all decedents during 1 specific month. Previous studies on LTC use during the last year(s) of life were often based on local samples or focused on institutional care. The inclusion of home care in analyses of LTC is of particular importance because social policies increasingly prioritize home-based care, in Sweden and other European countries.^{9,13,29}

Register data overcome biases related to self-reporting and high nonresponse that often exist in hard-to-reach populations. On the other hand, register data are limited to formal LTC use and do not include indicators of disability. Yet, universally accessible LTC approved according to need implies that LTC use in Sweden most probably reflects need for care rather than economic resources. However, because individuals who only rely on informal care are not part of the register, this implies an underestimation of the total care needs.

The main limitation is the limited available study period of 2 years. Because of the left-censoring, 52% of the decedents already received LTC at the start of the study, implying an underestimation of the duration of LTC in general, as well as gender differences and differences between individuals living alone and those cohabiting.

Conclusions and Implications

In conclusion, despite the decline of LTC in Sweden during the past 2 decades, almost 70% of the men and about 85% of the women used LTC before death. A substantial part of women's greater use of LTC during the last 2 years of life was due to their higher age at death and because they more often lived alone—factors that were strongly related to LTC use.

As survival continues to increase and a rapid growth in the number of very old people in Sweden is expected from the 2020s, these developments will increase the pressure on the LTC sector in general. If survival continues to increase faster among men than among women, this may imply an increase of men's use of LTC. On the other hand, an increase in male survival is expected to result in longer marriages or partnerships and changing household structures where more women will have potential access to informal care from a partner toward the end of life.³⁴ Indeed, no difference between men and women in caregiving for partners has been shown in couple-only households,^{24,34} a rapidly increasing household-type in many countries and altogether prevailing in Sweden.³⁴ Yet, when relationships last into advanced old age, the capacity of caring for a partner toward the end of life, when care needs often are extensive, may be limited among very old couples. Against the background of recent developments in the Swedish LTC system, it may be expected that support from family members outside the household will gain importance,^{25,35} as well as services paid out of pocket, indicating a narrower definition of public responsibility.^{25,33,36}

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