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Receiving the home care service offered by certified care workers prior to a patients' death and the probability of a home death: observational research using an instrumental variable method from Japan

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ABSTRACT

Objectives To assess the association between receiving the certified care workers' home care service, which is provided by non-medical professionals prior to a patients' death and the probability of a home death.

Design Observational research using the full-time translated number of certified care workers providing home care service per member of the population aged 65 or above, during the year prior to patient's death per municipality as an instrumental variable.

Setting The certified care workers' home care service covered by the public long-term care insurance (LTCI) system in Japan.

Participants In total, 1 613 391 LTCI beneficiaries aged 65 or above who passed away, except by an external cause of death, between January 2010 and December 2013 were included in the analysis.

Primary outcome measures Death at home or death at other places, including hospitals, nursing homes and clinics with beds.

Results Out of all participants, 173 498 (10.8%) died at home. The number of patients who used the certified care workers' home care service more than once per each month during 1, 2 or 3 months prior to the month of death numbered 213 848, 176 686 and 155 716, respectively. This was associated with an increased probability of death at home by 9.1% points (95% CI 2.9 to 15.3), 10.5% points (3.3 to 17.6) and 11.4% points (3.6 to 19.2), respectively.

Conclusions The use of the certified care workers' home care service prior to death was associated with the increased probability of a home death.

Strengths and limitations of this study

► This is the first study that suggests the association between receiving the home care service by non-medical professionals and the increased probability of a patients' home death.
► The analysis is conducted using the combined nationwide large-scale data of the public long-term care insurance claims data and vital statistics in Japan.
► An instrumental variable analysis is performed to address confounding attributed to preferences for the death place of unobserved patients or patients' families, assuming the exclusion restrictions after the adjustments.
► Our estimates obtained by the instrumental variable regression might be the local average treatment effect.
► Although all the study participants received long-term care services, the home deaths in our study might have included some unintentional and un-attended deaths because of the limitation of vital statistics.

INTRODUCTION

Age structures across the world are expected to change significantly over the next few decades. In most regions of the world, nearly a quarter of the population will be 60 years of age or older by 2050.[1] Along with this change, long-term care systems are required in many counties to support the elderly who are spending the end of their lives in their preferred places for their satisfaction.[2 3] Most elderly people wish to die at home, and their families' satisfaction would be much improved if an environment that allows them to take care of themselves at the end of their lives in their preferred places is arranged.[4 5] However, they often die in other places, such as hospitals, due to the burden of care on the families and the uneasiness of the care recipients.[6–9] Social and health policies to ensure more elderly people can die at home are expected to develop in the near future.

Previous studies have reported that death at home was associated with patients' illness (long-term disease, low functional status and having cancer); individual factors (good socioeconomic conditions, preferences of care recipients) and environmental factors (use of home care services by physicians and nurses, the use of multidisciplinary home palliative care, the timing of the introduction of palliative care, living in a rural environment and the presence of informal caregivers including spouse and relatives, informal caregivers' coping and historical trends).[10 11] However, these associations do not necessarily indicate that using home care services leads to home death because unobserved patients' and their families' preferences for the place of death cannot be adjusted for appropriately.[10–12] Additionally, some previous studies suffered from a limited generalisability because they have focused only on patients with cancer.[10] With regard to the palliative care services at home, several randomised controlled trials have demonstrated its effectiveness on home death for adults with advanced illness.[13] However, in those studies, multidisciplinary home palliative care teams consisted mainly of physicians, nurses and medical social workers, and did not include care workers who were not medical professionals. Therefore, the effectiveness of home care services offered by care workers prior to home death remains unknown. During the end of life, the burden of care for informal caregivers is among a serious issue.[9] The home care service offered by care workers at the end of life could support informal caregivers, such as patients' families, as well as mitigate caregivers' burdens, and increase the possibility of death at home.

This research aimed to assess the association between receiving the home care service by care workers prior to a death and the probability of a home death. To address the endogeneity in the use of home care services caused by unobserved patients' and their families' preferences for the place of death, an instrumental variable (IV) method was used.

Background in Japan
Gaps in the place where people die
In 2012, a nationwide survey conducted in Japan, one of the most rapidly ageing societies in the world, revealed that elderly people are more likely to expect spending their life's last moments at home instead of hospitals and facilities; 34.9% of elderly people wanted long-term care delivered at home and 54.6% wanted to die at home.[14] In 1951, the proportion of home deaths was 82.5% and the proportion of hospital deaths only 9.1%. However, in 2017, the proportion of home deaths had reduced to 13.2% and the proportion of hospital deaths had increased to 73.0%.[6] Thus, there is a huge gap between the preferred place and actual place of death.

Home care services in Japan
In Japan, certified care workers' home care service has provided assistance to care recipients with the activities of daily living (ADL) and the instrumental ADL (IADL). Care workers need to complete a 130-hour training programme to obtain certification. Certified care workers' home care service is covered by public long-term care insurance (LTCI). LTCI was initiated by the Japanese government in 2000, with compulsory participation.[15] Those aged over 40 and are suffering from intractable diseases and those aged over 65, requiring care, are eligible to receive long-term care services with small copayments (10% of actual expenses). LTCI covers various services other than the certified care workers' home care service; including day-care services, a home nursing service by qualified nurses, a home physiotherapeutic service and residential care services.

METHODS
Data
We targeted LTCI beneficiaries aged 65 or above who passed away, excluding deaths caused by external factors such as accidents or suicide (V01–Y89 on the International Classification of Diseases 10 (2003)), between January 2010 and December 2013. A pooled cross-sectional study was deployed. With official approval to use the secondary data from the Statistics and Information Department of the Japanese Ministry of Health, Labour and Welfare (MHLW) under Tohatsu-1218–1 as of 18 December 2015, we used the individual data from the Survey of Long-term Care Benefit Expenditures, the death records from Vital Statistics, the Survey of Medical Institutions and the Survey of Institutions and Establishments for Long-term Care.[16] In addition, we also used the aggregated data from the population census and municipal taxation published by the Japanese government.[17 18] Since all individual data were anonymised by the MHLW, we could not identify a specific individual. As individual data did not include the common number for each person, we conducted a deterministic linkage between the Survey of Long-term Care Benefit Expenditures and the death records from Vital Statistics using five items of demographic data to identify death for each LTCI beneficiary; prefectures, municipalities, sex, month and year of birth and month and year of death. Although the date of death is not included in the Survey of Long-term Care Benefit Expenditures, the eligibility for LTCI expires exactly 1 day after the date of death on the death certification. Thus, we matched the data indicating the month and year of the patient's death to the month and year of the day before LTCI eligibility expiry's date. The deterministic linkage revealed that 15.3% of the five items of demographic verification data were overlapped between all expiry dates of LTCI eligibility because the exact date of the patient's birth and death were not included in the data of each of the Survey of Long-term Care Benefit Expenditures and death record. We excluded those samples from the analysis. Also, the expiry of LTCI eligibility includes those who have moved to other municipalities, as well as death. Thus, the linkage between the Survey of Long-term Care Benefit Expenditures and Vital

Statistics was 81.3% (18.7% of LTCI eligibility expiry did not match 1:1).[19] We excluded the unmatched samples from the analysis. Finally, we extracted the data for those LTCI beneficiaries who passed away at the age of 65 or more between January 2010 and December 2013.

Outcome, exposure and IV

The outcome was patients' death at home. The other places of death included hospitals, nursing homes and clinics with beds. The primary exposure was the use of certified care workers' home care service more than once during the month prior to the month of death. This service is included in home nursing care services in the classification of healthcare products of the System of Health Accounts 2011 and was revised by Organisation for Economic Co-operation and Development, European Union and World Health Organization in 2017.[20] To cope with the endogeneity of the primary exposure, we conducted an IV regression analysis. The full-time translated number of certified care workers providing home care service per member of the population aged 65 or above, during the year prior to death per each municipality, was used as an IV. The number of full-time conversions was calculated by adding the number of full-time home care workers, full-time converted number of concurrent home care workers and full-time converted number of part-time home care workers for each municipality. Unemployed home care workers, who are still seeking job opportunity, were excluded. It was expected that the use of home care services would increase if the patient lived in a municipality with many certified care workers because care recipients would have more opportunities to use the home care service. It was further expected that patients would live in a municipality irrespective of patients' or their family's preference for a place of death. The number of home care workers within a municipality in the year before patient's death was supposed to be exogenous to the relationship between the primary exposure and the outcome through adjustments in individual-level and municipality-level factors as proxies of the unobserved municipality-level preference for death at home. Namely, it was assumed that the number of home care workers within a municipality in the year before patient's death would increase the probability of a home death through the use of the home care service, after adjusting for the covariates shown below (an exclusion restriction). In the next section, we explain in detail the potential confounders adjusted for.

Other covariates
Illness and individual factors

By referring to determinants of the place of death in previous studies, the patients' age at the time of death, sex, presence of spouse (presence, unmarried, bereavement and divorce), the underlying cause of death (dummy variables of cancer (C00–C97), cerebrovascular disease (I60–I69), cardiovascular disease (I01, I020,

I05–I09, I20–I25, I27 and I30–I52), senility (R54) and pneumonia (J12–J18)), the year of death, the degree of care need were adjusted as illness and individual factors. The underlying cause of death was based on the International Classification of Diseases 10 (2003).[21] In Japan, the degree of care needed is classified into seven stages. It includes two stages that require support of the IADL (levels 1 and 2) and five that require long-term care of the ADL (levels 1–5). The higher the level is, the more is the need for care.[22] We used the dummy variable of care needed and divided them into the three categories: a low degree including level 1 and 2 requiring IADL support, a moderate degree including level 1 and 2 requiring support for a part of the ADL, and the high degree including levels 3–5 requiring support for all ADLs. The database used to identify each variable is indicated in online supplementary table S1.

Environmental factors

Adjustment variables related to environmental factors included the following data from municipal area as well as administrative districts: the population, the proportion of population aged over 65, the crude death rate of those aged over 65 years, the proportion of solitary elderly households, the proportion of elderly couple households and the annual income per capita and the number of beds in hospitals, clinics, home care support clinics, home-visit nursing stations and beds of nursing homes per member of the population aged over 65. The crude death rate was calculated by dividing the number of deaths of those over 65 by the number of people aged 65 or over. The proportion of solitary elderly households was the proportion of households where an elderly aged over 65 lives alone, occupying the total number of general households. In addition, the proportion of elderly couple households referred to the proportion of households with one male aged over 65 and one female aged over 60 per the total number of general households. The home care support clinic runs 24 hours and provides home medical care from doctors and qualified nurses, in collaboration with other hospitals and clinics in the area. The database used to identify each regional variable is indicated in online supplementary table S1. These data were linked to the extracted target individual data by the municipal code of the place of residence. In addition, as a patient's behaviour may differ depending on the presence of secondary medical areas, the dummy variables of 330 secondary medical areas were adjusted. Definitions of secondary medical areas are set by the Japanese government to secure patients' access to inpatient services. Most of them are based on a complex of adjacent municipalities. We assumed that these adjustments would resolve the instrument-outcome confounders. There were no missing values in any of the variables. However, there were some unknown codes indicating the care level and the presence of the spouse. They were excluded from the analysis.

Statistical analysis

We conducted a two-stage least squares (2SLS) regression analysis.[23] We supposed the following two equations:

$$y_{1i} = x_{1i}\pi_1 + x_{2i}\pi_2 + \varepsilon_i \qquad (1)$$

$$y_{2i} = y_{1i}\beta_1 + x_{1i}\beta_2 + \mu_i \qquad (2)$$

Here, y_{1i} indicates use of certified care workers' home care service 1 month prior to the month of death, which becomes 1 if i-th person used the service and 0 if person did not use the service; y_{2i} is an indicator of home death, which becomes 1 if i-th person died at home and 0 if person died in another place; x_{1i} indicates i-th person's age, sex, degree of care need, presence of spouse, underlying cause of death, year of death, secondary medical area dummy variables and data from the living municipality; including the population, proportion of population of those aged over 65, crude death rate of those aged over 65, the proportion of solitary elderly households, the proportion of elderly couple households, annual income per capita, the number of beds in hospitals, clinics, home care support clinics, home-visit nursing stations and beds of nursing homes per member of the population aged over 65. Meanwhile, x_{2i} is an IV, which indicates the full-time translated number of certified home care workers in a living municipality a year prior to the patient's death. β and π are coefficients of each variable. ε and μ are error terms.

During the first stage, we estimated $\hat{y}_{1i}$ (the fitted values of y_{1i}) by an ordinary least squares (OLS) estimation using the equation (1). During the second stage, we regressed y_{2i} on $\hat{y}_{1i}$ and x_{1i} by the following OLS estimation:

$$y_{2i} = \hat{y}_{1i}\beta_1 + x_{1i}\beta_2 + \left\{ \left(y_{1i} - \hat{y}_{1i}\right)\beta_1 + \mu_i \right\} \qquad (2)'$$

which was transformation of the equation (2). The resulting estimator $\hat{\beta}_1$ is consistent for β_1 if x_{2i} is uncorrelated with μ_i conditioned by x_{1i}. This implies that if the exclusion restriction stated above is valid, the resulting estimator is consistent for β_1. Since we had a large number of observations through 2SLS, a linear probability model could be practically used even for a dichotomous variable such as an indicator of home death, the distribution of which would be normal asymptotically.[24] Robust SEs were estimated. $\hat{\beta}_1$ indicated the effect of the use of home healthcare prior to death based on the probability of death at home, and is reported in the results section.

The Kleibergen-Papp Wald rk F statistic checked the weak identification of IV. In this study, since an endogenous variable was exactly identified by an IV, overidentification test of IV was not conducted. The endogeneity of the exposure variable was assessed by the Wooldridge's robust score χ^2 test and robust regression-based F test. An OLS estimation for equation (2) with robust SEs was also conducted for comparison with the 2SLS approach result. The analyses were repeated using 'at least one use of the home care service every month during the 2 or 3 months prior to the month of death' as the exposure.

Data management and analysis were all conducted using Stata V.14 MP with the ivreg2 package.[25]

Patient and public involvement

This research was done without any patient involvement. Patients were neither invited to comment on the study design nor consulted to develop patient-relevant outcomes or interpret the results. Further, patients were not invited to contribute to the writing or editing of this document for readability or accuracy.

RESULTS

There were 1 716 065 LTCI beneficiaries who passed away between January 2010 and December 2013. After excluding patients with those aged under 65, extrinsic death, unknown care levels and those whose spouse's presence remained unknown, 1 613 391 patients were analysed. This totalled 37.7% of all deaths of those aged over 65 in Japan, throughout the 4 years studied.

Table 1 shows the characteristics of illness and individual factors of the participants by place of death. The proportion of home deaths was around 10.8% irrespective of the year of death. The number of those who used home care services at least once prior to the month of death totalled 213 848 patients or 13.3% of the population. The proportions of home death were 8.2% for those who did not use the home care service and 27.3% for those who used it prior to the month of their death. A summary of the municipal data used as an IV and covariates is presented in table 2.

In the first stage, Kleibergen-Paap Wald rk F statistic was 752.7, which was much higher than 10 (the 'rule of thumb' value).[26] The results of the first stage of the 2SLS are presented in online supplementary table S2. As expected, the higher the number of certified home care workers per member of the population aged over 65 in a municipality, the likelihood for the use home care services increased.

Table 3 presents the results of the association between the certified care workers' home care service use prior to death and the probability of a home death, using the OLS and the 2SLS. The use of home care services 1 month prior to death was associated with an increased probability of home death in either analysis: $\hat{\beta}_1 = 0.180$; 95% CI 0.178 to 0.182 in the OLS; $\hat{\beta}_1 = 0.091$; 95% CI 0.029 to 0.153 in the 2SLS. The use of the home care services 1 month prior to the death increased the probability of death at home by 9.1% points according to the IV regression. The 2SLS analyses were repeated for the use of services during 2 and 3 months prior to the month of death as exposures. The $\hat{\beta}_1$ s were slightly higher than for home care service use during the month prior to death as an exposure ($\hat{\beta}_1=0.105$; 95% CI 0.033 to 0.176 for 2 months use prior to the month of death; $\hat{\beta}_1=0.114$; 95% CI 0.036 to 0.192 for 3 months use prior to the month of death, respectively). The differences between the OLS estimates

Table 1 The characteristics of illness and individual factors of long-term care beneficiaries (<65 years old) who died, excluding death by external factors, between 2010 and 2013 by place of death

Characteristics	Home		Other places*		Total
No of death	173 498	10.8%	1 439 893	89.3%	1 613 391
Median (IQR) age, years	86 (80–91)		86 (80–92)		86 (80–92)
Sex					
Male	77 443	10.8%	641 915	89.2%	719 358
Female	96 055	10.7%	797 978	89.3%	894 033
No of death by year					
2010	44 564	10.8%	368 721	89.2%	413 285
2011	41 589	10.6%	351 673	89.4%	393 262
2012	45 583	10.9%	372 223	89.1%	417 806
2013	41 762	10.7%	347 276	89.3%	389 038
Degree of care need					
Low	11 071	13.9%	68 451	86.1%	79 522
Moderate	40 643	12.8%	278 066	87.2%	318 709
High	121 784	10.0%	1 093 376	90.0%	1 215 160
No of the use of certified care workers' home care service prior to death					
No use	115 078	8.2%	1 284 465	91.8%	1 399 543
1 month	58 420	27.3%	155 428	72.7%	213 848
2 months	47 026	26.6%	129 660	73.4%	176 686
3 months	41 618	26.7%	114 098	73.3%	155 716
Presence of spouse					
Present	72 677	11.4%	566 300	88.6%	638 977
Unmarried	5000	9.1%	50 044	90.9%	55 044
Bereavement	89 471	10.4%	766 788	89.6%	856 259
Divorce	6350	10.1%	56 761	89.9%	63 111
Underlying cause of death					
Cancer	49 083	13.2%	323 426	86.8%	372 509
Pneumonia	7054	3.2%	212 692	96.8%	219 746
Cerebrovascular	15 886	8.5%	170 040	91.5%	185 926
Senility	24 850	19.8%	100 346	80.2%	125 196
Cardiovascular	21 828	24.2%	68 421	75.8%	90 249
Others	54 797	8.8%	564 968	91.2%	619 765

*Other places include the deaths at the hospitals, clinics with beds and nursing homes.

and 2SLS estimates and the Wooldridge's robust score χ^2 test 8.03 (p=0.018) and robust regression-based F test 8.03 (p=0.005) showed the endogeneity between exposure and outcome. Online supplementary table S3 presents these results including the covariates of the OLS regression and IV regression.

DISCUSSIONS
Principal findings
This study demonstrated that the use of the certified care workers' home care service prior to death was positively associated with the probability of a home death among LTCI beneficiaries. When the IV can address the

endogeneity in the relationship between the use of home care services and home death, our findings suggest that at the individual level, the use of home care services for 1, 2 or 3 months prior to the month of death increase the probability of death at home by 9.5%, 10.9% and 11.9%, respectively. The estimates might be essential when considering the current proportion (13.2% in 2017) of home deaths in Japan.

Comparison with other studies and strengths of this study
Most previous studies in various countries, including Japan, have examined the association between home care services provided by medical professionals such as physicians, nurses and medical social workers and home

Table 2 Summary of municipal data used as an instrument variable and covariates (n=1695)

	25th percentile	Median	75th percentile
Population*	8.815	25.419	67.197
Proportion of population aged over 65	0.223	0.272	0.322
Crude death rate of those aged over 65 years†	0.030	0.035	0.039
Proportion of solitary elderly household	0.074	0.096	0.130
Proportion of elderly couple household	0.096	0.118	0.148
Annual income per capita‡	24.728	26.770	29.821
No of beds in hospitals§	0.010	0.037	0.062
No of clinics¶	1.906	2.557	3.226
No of home care support clinics¶	0	0.267	0.519
No of home-visit nursing stations¶	0	0.132	0.229
No of beds in nursing homes§	0.021	0.030	0.040
Full-time translated no of certified home care workers§**	0.015	0.026	0.039

*Per 1000 people.
†Calculated by dividing the number of deaths of those over 65 by the number of people aged 65 or over.
‡Per 100 000 JPY (about €750, US$1000).
§Per population aged over 65 years.
¶Per 1000 population aged over 65 years.
**Calculated by adding the number of full-time home care workers, full-time converted number of concurrent home care workers and full-time converted number of part-time home care workers for each municipality.

Table 3 The results of the association between the certified care workers' home care service use and the probability of a home death by each term of continuous use prior to death, using ordinary least squares (OLS) regression and two-stage least squares (2SLS) regression (n=1 613 391)

	Coefficient	Robust SE	95% CI
1 month			
OLS	0.1796	0.0010	0.1777 to 0.1815
2SLS	0.0908	0.0315	0.0291 to 0.1525
2 months			
OLS	0.1672	0.0011	0.1651 to 0.1693
2SLS	0.1049	0.0364	0.0334 to 0.1763
3 months			
OLS	0.1661	0.0011	0.1639 to 0.1683
2SLS	0.1138	0.0396	0.0362 to 0.1915

death.[10–13] However, there have been few investigations of the health outcomes of services provided by non-medical professionals.[27] A study in Japan reported the association between the use of welfare services, including home care services by non-medical professionals and home death in 1990.[28] This study would not be suitable for the current situation in Japan as it was conducted 10 years prior to the introduction of LTCI. In addition, several studies have reported an association between the use of certified care workers' home care services and an improvement of the patients' and families' satisfaction and maintenance of patients' ADL,[29–32] but they did not include the place of death as an outcome. This study can claim originality due to the examination of the association between the use of the certified care workers' home care service by non-medical professionals and the place of patients' death, using nationwide large-scale data extracted from the public LTCI system. Although this was an observational study, we managed to address endogeneity in the use of care services attributed to unobserved patients' or patient families' preferences for the place of death by using the IV method.

Possible mechanism

According to a survey conducted in 2017, over 70% of the elderly people in Japan worry that their families will be burdened should they receive long-term care at home.[9] A few studies have demonstrated that the use of the certified care workers' home care service is associated with a reduction in the psychological caregiving burden of patients' families,[29] and made patients feel secure and confident about their lives, by providing physical assistance with their ADL and IADL.[32] Thus, the use of certified care workers' home care services prior to death might assist terminal patients to die at home, both by reducing families' caregiving burden and by relieving care recipients' uneasiness.

Limitations

Some limitations should be noted. First, the home deaths recorded in this study might have included some unintentional and unattended deaths. Although we could not detect such situations from death records, we supposed that most patients and their informal caregivers in this study were in receipt of the appropriate medical and long-term care services at the end of life because they had applied to the LTCI, were using the long-term care services to some degree and were not deaths caused by external factors.

Second, the IV method used in the current study was based on the assumption of exclusion restriction. To justify this assumption, we adjusted for as many factors that could confound between the IV and patients' place of death as possible, as shown in the Methods section. Nevertheless, if our analyses still suffered from the

violation of exclusion restriction caused by insufficient adjustment for the factors that connected the IV and the outcome, our estimates might be biassed to some degree.

Third, the estimates obtained by the IV regression might be the local average treatment effect. Namely, our IV estimates suggested the average effect of change in the use of home care services induced by a change in the number of home care workers employed in the municipality. Thus, we cannot conclude the effectiveness of the certified care workers' home care service on home death of always takers, never takers and defiers, even if the number of certified care workers in the municipality increases.[33] Moreover, the estimates might include the interaction effects with other home care services. Considering the heterogeneity of service effect on the place of death, it would be necessary to study each demographic.

Implications
Our findings suggest that the use of certified care workers' home care service prior to death is associated with the increased probability of death at home. Policy-makers should ensure that elderly patients who wish to die at home have sufficient opportunities to use the care workers' home care service at the end of life.

CONCLUSION AND FUTURE RESEARCH
The use of the certified care workers' home care service prior to death was associated with the higher likelihood of patients' home death. Future research should investigate the effectiveness of other long-term care services on the place of death in a super-ageing society; including physiotherapeutic services, day-care services and residential care services, such as respite care services.

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