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<Original Paper>

A Study on the Factors Determining Home Death of Patients during Home Care: A Historical Cohort Study at a Home Care Supporting Clinic

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Aim: Associations between markedly low activities of daily living (ADLs) at the start of home visit care and patient home death were analyzed using data from a home care supporting clinic in Japan that has a low rate of home death.

Methods: The study was a historical cohort study. It involved patients who began to receive home visit care from a home visit care support clinic between April 1, 2006, and March 31, 2011. Using home death as a dependent variable and presence/absence of markedly low ADLs and other parameters as independent variables(cancer, the patient's desire for home death,etc.), adjusted hazard ratio and 95% its confidence interval(CI) were calculated using the Cox proportional hazards model.

Results: Markedly low ADLs were associated with home death even after adjustment for factors that influence home death (adjusted hazard ratio 4.40; 95% CI 2.37-8.16). Cancer and the patient's desire for home death were statistically significant factors involved in home death. In subgroup analysis according to presence/absence of cancer, the association between markedly low ADLs and home death was stronger in the cancer-free group (adjusted hazard ratio 10.78; 95% CI 2.89-40.26) than in the cancer group (adjusted hazard ratio 5.58; 95% CI2.39-13.05).

Conclusion: Patients'desire for home death could be fulfilled if home care

supporting clinics provide home visit services to not only terminal-stage cancer patients but also bedridden cancer-free patients. We must establish systems to remain at home during the terminal period of their lives.

Key words: activities of daily living, Cox proportional hazards model, home death, home visit, Japan

Introduction

In 2010, over 21% of Japan's population was elderly; marking the advent of an ultra-aging society, and the annual number of deaths in Japan exceeded 1 million, marking an era of many deaths. Subsequently, the annual number of deaths has increased further. In 2010, 80.3% of all deaths in Japan occurred at hospitals/clinics, and 12.6%, at home [1]. Evidently, with this trend, hospitals will face increasing difficulties in providing a place for death.

A survey conducted by the Japanese Ministry of Health, Labour and Welfare showed that 63% of the people wished to remain at home during the terminal period of their lives. However, as many as 66% think it difficult to take care of their family member dying at home because "caring for the dying patient burdens to family members" (79%) and owing to their "inability to response to abrupt changes in their patient's condition" (54%; multiple answers accepted) [2].

Consequently, the long-term-care insurance system started in 2000, and the care burden began to be placed on society in general. In 2006, clinics for home care supporting were introduced, so that the number of medical facilities providing

24/7/365 care services at home began to increase.

Studies from countries other than Japan have identified factors related to healthcare/nursing care services for patients' family members; for example, determining home death [4–8]. Reduction in activities of daily living (ADLs) was likely to increase home death [9, 10].

A few reports have investigated the factors involved in home death in Japan. Rough analyses conducting before the start of the long-term-care insurance system in Japan revealed that home death was influenced by factors related to healthcare, nursing care, and family members [11–14]. After the start of the long-term-care insurance system, a few reports demonstrated that home death was determined by factors related to the healthcare system and the patient's family members (e.g. desire of patient/family, 24-hour healthcare service, large family, etc.)[15-18]. Some of the reports yielding significant results after adjustment for multiple variables. To date, however, an association between reduced ADLs and home death has not been shown in Japan, even in reports using data from home care supporting clinics.

We investigated whether low ADLs at the start of home care was associated with home death, using data from home care supporting clinics. Home care for patients with

low ADLs will be expected to facilitate home death because this form of care can increase the percentage of elderly patients who die at home despite of a still low percentage (12.6%) of such patients home at present. We also explored other factors determining home death.

Methods

Participating medical facility

This study involved patients receiving home visit care from the Inahokai Hidaka Clinic (a clinic with no beds), located in the suburbs of Miyazaki City, a "local core city" of Miyazaki Prefecture. This clinic has two full-time physicians who provide outpatient care on each weekday and Saturday morning and home visit care on each weekday afternoon. The clinic is officially specified as a home care supporting clinic, providing 24/7/365 services. In the year beginning July 1, 2007, 22 patients were managed by this clinic died at home. This number exceeded the Japanese average (about only 2% among all home care supporting clinics in Japan treated ≥20 patients' deaths at home annually)[19]. Therefore, this clinic can be viewed as an active clinic

enabling patients to remain at home until their deaths.

Subjects

This was a historical cohort study. The study involved 229 patients who began to receive home visit care services between April 1, 2006 and March 31, 2011. Eighty one patients were excluded from the analysis because they received care by visiting the facility rather than at home. Therefore, the final sample comprised 148 patients (Fig.1).

The beginning of observation and the duration of home visit care

The observation of each subject began at the first day of home visit care services. They were followed until March 31, 2011 or home death. Home death was analyzed as the outcome. Follow-up was censored before March 31, 2011 by completion of home visit care services other than death (for reasons such as hospitalization, accommodation in a facility for the aged, and referral to another facility). When home visit care continued until the end of the follow-up period, the follow-up was censored then. When home visit care stopped by hospitalization, but it began after discharge from the hospital, the duration of home visit care before suspension added to the duration of home visit care after resumption as the duration of home visit care.

Independent variables

The level of ADLs in each subject was rated in accordance with the “independence

degree of daily living for the disabled elderly" (see Appendix 1), which is used for assessment of the nursing care level needed under long-term-care insurance system and is known to correlate closely with the globally applied "Functional Independence Measure" [20]. Patients with markedly low ADLs were rated as having Rank C ADLs and the other than patients with Rank C did not have marked ADL reduction. Rank C corresponds to a "bedridden condition."

Referring to the previous papers [4–18], we analyzed several factors possibly affecting the death of patients at home (presence/absence of neurological, cerebral vascular, chronic respiratory, cardiovascular, musculoskeletal disease as home visit care ,presence/absence of intention for home death in the patient/family, age and sex of patient, presence/absence of cancer, presence/absence of dementia, presence/absence of a spouse capable of caring for the patient, and presence/absence of family) as additional independent variables.

Each patient's age was expressed as the calendar age at the start of home visit care services. Patients were divided into two groups according to age (<75 and ≥75 years). Presence/absence of dementia was determined using the "independence degree of daily living for the demented elderly" (see Appendix 2) to assess the daily assistance level

needed under long-term-care insurance system, which it is known to correlate closely with the Mini-Mental State Examination [21]. Patients rated as rank III, IV, or M (having dementia requiring nursing care) was classified as "demented," and all other patients were classified as "dementia-free." All data were obtained from individual medical records of the clinic.

Analysis

The Cox proportional hazards model was employed to elucidate factors possibly determining home death. Hazard ratio of home death and its 95% confidence interval (CI) were estimated. As a subgroup analysis was conducted according to presence/absence of cancer at the beginning of the observation, because it had been reported as a factor determining home death [4,5,9,10].The data of the two subgroups were also analyzed using the Cox proportional hazards model.

Epi Info Version 3.5.5. was used for these analysis. Hazard ratios were expressed with 95% CIs. P-value <0.05 was expressed to be statistically significant.

This study was conducted after its protocol was approved by the Ethics Committee on Epidemiologic Research of the Okayama University Graduate School of Medicine, Dentistry, and Pharmaceutical Sciences.

Results

Table 1 shows the characteristics of the 148 patients classified by sex and ADL reduction. The markedly low ADL group had a higher percentage of demented patients. The low ADL group in female had a significantly higher percentage of patients living with family and patients/family members desiring home death (intention home death), and a significantly shorter home visit care period (Table1).

Home death (i.e., the outcome) occurred during the follow-up period in 32 patients (54.2%) from the markedly low ADL group and 22 patients (24.7%) from the group without marked ADL reduction. Further, 3 patients in the markedly low ADL group and 6 in the group without marked ADL reduction died at home after resumption of home visits that had been suspended because of hospitalization, etc. Follow-up was discontinued (censored) for 27 (45.9%) patients in the markedly low ADL group and 67 (75.3%) in the group without marked ADL reduction .The reasons for censoring, continuation of home visits at the end of follow-up, death while hospitalized, accommodation in a facility for the aged and referral to another facility,etc., were not

so different between both groups (Table2).

The unadjusted hazard ratio for markedly low ADLs in terms of home death was significantly high (2.99; 95% CI 1.73–5.17).Excess crude hazard ratios also significantly elevated in cancer, a spouse capable of caring for patient, patient/family's intention for home death, and sex(female). Using cancer, dementia, a spouse capable of caring for patient, the patient/family's intention for home death, family, sex (female) and age (≥ 75 years), as independent valuable, adjusted hazard ratio was statistically significantly higher (4.40; 95% CI 2.37–8.16) among markedly low ADLs. In addition, a significantly high adjusted hazard ratio was observed for cancer (11.15; 95% CI 5.28–23.57), for a spouse capable of caring for the patient (2.89; 95% CI1.22–6.87) and for the patient/family's intention for home death (3.11; 95% CI 1.68–5.75) (Table3).

In the subgroup analysis, the markedly low ADL was adjusted for dementia, a spouse capable of caring for the patient, patient/family's intention for death at home, family, sex (female) and age (≥ 75 years).The adjusted hazard ratio for markedly low ADLs among cancer free group was 10.78 (95% CI 2.89–40.26). Age (≥ 75 years) had a significantly high adjusted hazard ratio (11.15; 95% CI 1.64–75.69). Among cancer

group, the adjusted hazard ratio for markedly low ADLs was 5.58 (95% CI 2.39–13.05). Effect modification by presence of cancer was observed (Table4).

Multivariate analysis was performed using the Cox proportional hazards model, with death at facilities (including death at hospitals) serving as a dependent variable and the above variables serving as independent variables. Unlike the data on home death, the adjusted hazard ratio for markedly low ADLs was not statistically significant (1.53; 95% CI 0.65–3.62). Cancer had a significantly high adjusted hazard ratio (9.81; 95% CI 4.46–21.6). The adjusted hazard ratio was significantly low for the patient/family's intention for home death (0.16; 95% CI 0.06–0.47) and for dementia (0.41; 95% CI 0.18–0.91) (not shown in the table).

Discussion

We investigated whether a low ADL level at the start of home care is likely to result in home death, using data collected at a home care supporting clinic. Our results indicate that a low ADL level at the start of home care is likely to correspond to home death. This association was also statistically significant after adjusting for the influence of

known factors determining the death of patients at home (cancer, the patient/family's intention for home death, dementia, a spouse capable of caring for the patient, etc.).

In a subgroup analysis dividing the subjects according to the presence/absence of cancer, the association between low ADLs and home death was stronger in the cancer-free group than in the cancer group. This finding suggests that home death is facilitated for cancer-free bedridden patients, although home visit care has tended to focus on patients in the terminal stages of cancer.

Furthermore, we adjusted the hazard ratio for markedly low ADLs in terms of home death by other disease as home visit care than cancer (neurological, cerebral vascular, chronic respiratory, cardio vascular, and muscle skeletal disease) (not shown as a table in this paper). The adjusted hazard ratio for markedly low ADLs was still high in approximately 3.0. These non-cancer diseases had unapparent effect the relationship between low ADL and the home death. On the relationship between non-cancer and the home death, cerebral vascular and muscle skeletal disease had apparent tendency of difficulty to die at home. After adjusted by markedly low ADLs in the cancer free group, the either relations were not statistically significant. Meanwhile, the adjusted hazard ratio for chronic respiratory disease was still statistically high about 5.56 after

adjusting by markedly low ADL (also not shown in a table). The result indicated that the home oxygen therapy and non-invasive positive pressure ventilation therapy for chronic respiratory disease at home influenced the increased home death.

These results are novelty in our paper. In Japan, home deaths are not so popular despite many home death needs. Generally, it is difficult for family members to care for markedly low ADL patient. But our paper strongly suggested markedly low ADL patient could die at home by home visit care. It is necessary to establish and enhance systems for patients with markedly low ADL. Not only for cancer patients but also for cancer free patients, cares at home during the terminal period of their lives are also necessary to be promoted. Therefore, we need further research from many viewpoints.

Multivariate analysis revealed the presence of cancer and the patient/family's intention for home death as other significant factors determining the death of patients at home. These findings are analogous to those in past reports [9,13,17].

We analyzed the five-year data at a home care supporting clinic, and follow-up was possible on all subjects without any dropout. According to overseas reports, however, socioeconomic factors such as ease of inpatient bed utilization and income may also

determine home death. Despite being potential confounders, these factors were not incorporated in our study.

The participating facility is located in a local core city where resources for nursing care and healthcare are relatively easy to utilize. If utilization of such resources was difficult, home death would be difficult. This affects to generalizability of the present results.

The participating facility provides outpatient care in the morning and home visit services in the afternoon. This time schedule of service to have been adopted at many home care supporting clinics. However, other clinics provide only home visit services. The percentage of patients who die at home may differ at such clinics, so the inclusion of data from such clinics might have resulted in different findings. Two previous papers analyzed data from clinics providing only home visit services [17,18]. One of these papers did not include ADLs [17], and the other found no association between ADLs and home death [18]. We cannot compare these papers with our paper simply.

It is rational that patients with markedly low ADLs may be more likely to die at home than patients without marked ADL reduction when both groups receive home care. However, when analysis was conducted with death at facilities (including death

while hospitalized) as an outcome under similar settings and using similar variables, no association was found between markedly low ADLs and death at facilities. This result supports the conclusion that patients beginning to receive home care after marked ADL reduction are more likely to die at home.

In conclusion ,our results suggest that patients with markedly low ADL at the start of home visit care is likely to home death and home care supporting clinics can support home death among not only cancer patients but also cancer-free patients. An increase in home care supporting clinics is expected to provide a valid means of reducing healthcare costs .Because it may also increase the number of cancer patients desiring home death and their family members desiring to take care of the dying patient at home as well as cancer-free elderly patients with markedly low ADLs, this will reduce the proportion of patient death at facilities (including hospitals). And it is necessary to establish and enhance systems for patients with markedly low ADL. Therefore, we need further research from many viewpoints.

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Disclosure statement

The authors declare no conflict of interest.

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Figure Legend

Figure 1 Selection of subjects for the study

Table1 Background variable on 148 subjects

	Male n=72			Female n=76		
	Markedly low ADL[†] n=25	without marked ADL[‡] n=47	P value	Markedly low ADL[†] n=34	without marked ADL[‡] n=42	P value
Mean Age±SD	80.1±11.1	76.7±9.5	0.18	79.9±14.1	79.0±14.2	0.81
≥75 years old, n (%)	16(64.0)	32(68.1)	0.73	23(67.7)	32(76.2)	0.41
Spouse[§], n (%)	19(76.0)	27(57.4)	0.12	7(20.6)	4(9.5)	0.15
Family, n (%)	24(96.0)	39(83.0)	0.06	31(91.2)	28(66.7)	0.01*
Intention home death[¶], n (%)	15(60.0)	21(44.7)	0.22	17(50.0)	11(26.2)	0.03*
Home care period, days	42.0,median 2-1665range	86.0,median 2-1446,range	0.55	87.5,median 1-1387,range	334,median 5-1677,range	0.01*
Dementia, n (%)	17(68.0)	16(34.0)	0.01*	20(58.8)	14(33.3)	0.03*
Disease as home visit care						
Cancer, n (%)	13(52.0)	24(51.1)	0.94	7(20.6)	14(33.3)	0.22
Neurological disease, n (%)	1(4.0)	1(2.1)	0.58	2(5.9)	2(4.8)	0.61
Cerebral vascular disease, n (%)	4(16.0)	6(12.8)	0.48	4(11.8)	1(2.4)	0.12
Chronic Respiratory disease, n (%)	1(4.0)	4(8.5)	0.43	1(2.9)	3(7.1)	0.39
Cardio vascular disease, n, (%)	0(0)	1(2.1)	0.65	0(0)	0(0)	-
Musculoskeletal disease, n, (%)	2(8.0)	4(8.5)	0.66	6(17.6)	11(26.2)	0.27

[†]Markedly low ADL group, [‡]Group without marked ADL reduction, [§]Spouse is capable of caring for the patient, [¶]Patient/family's intention is for death at home, *P-value<0.05

Table 2 The number of deaths and censored, and the reasons of censored

	Markedly low ADL group n = 59			Group without marked ADL reduction n = 89		
Death at home, n (%)	32 (54.2)[†]			22(24.7)[‡]		
		Situation at end of follow-up n=27			Situation at end of follow-up n=67	
Follow-up ended (censored), n (%)	27(45.8)	Home visits[§] continued, n (%)	10(37)	67(75.3)	Home visits[§] continued, n (%)	23(34.3)
		Death at Hospital, n (%)	7(25.9)		Death at Hospital, n (%)	19(28.4)
		Accommodated, n (%)	7(25.9)		Accommodated, n (%)	13(9.4)
		In hospital, n (%)	1(3.7)		In hospital, n (%)	5(7.5)
		Referral, etc., n (%)	2(7.4)		Referral, etc., n (%)	7(10.4)

[†]Including 3 patients who died at home after home visit services had been suspended for reasons of hospitalization, etc., then resumed, Including 6 patients who died at home after home visit services had been suspended for reasons of hospitalization, etc., then resumed,

[§]Home visit care

Table 3 Hazard ratio for each variable in terms of home death

	Monovariate analysis			Multivariate analysis[†]		
	cHR[‡]	95% CI [§]	P-value	aHR[¶]	95% CI [§]	P-value
Markedly low ADL	2.99	1.73-5.17	<0.001	4.40	2.37-8.16	<0.001
Cancer	7.60	4.21-13.73	<0.001	11.15	5.28-23.57	<0.001
Dementia	1.19	0.70-2.03	0.52	0.91	0.51-1.61	0.74
Spouse capable of caring for the patient	2.76	1.61-4.74	<0.001	2.89	1.22-6.87	0.02[*]
Patient/family's intention for death at home	3.19	1.80-5.68	<0.001	3.11	1.68-5.75	<0.001
Family	2.47	0.98-6.21	0.05	0.66	0.23-1.86	0.43
Sex(Female)	0.56	0.33-0.96	0.04[*]	1.99	0.91-4.31	0.08
≥75 years old	0.90	0.50-1.62	0.73	1.50	0.75-3.01	0.26

[†]Adjusted for cancer ,dementia, a spouse capable of caring for the patient ,patient/family's intention for death at home, family, sex and age (≥75 years old).[‡]Unadjusted hazard ratio,[§]95% confidence interval,[¶]Adjusted hazard ratio, [*]P- value<0.05.

Table 4 Hazard ratios and their 95%CIs in the subgroup analysis in terms of home death

	Cancer-free group n = 90 (60.8%)			Cancer group n = 58 (39.2%)		
	aHR[†‡]	95%CI[§]	P-value	aHR[†‡]	95%CI[§]	P-value
Markedly low ADL	10.78	2.89-40.26	<0.001	5.58	2.39-13.05	<0.001
Dementia	1.42	0.48-4.18	0.52	0.77	0.35-1.69	0.51
Spouse capable of caring for the patient	0.89	0.11-7.07	0.91	3.87	1.17-12.77	0.03[*]
Intention for death at home[¶]	1.54	0.53-4.47	0.42	3.55	1.49-8.50	<0.001
Family	1.07	0.28-4.11	0.92	0.47	0.08-2.86	0.42
Sex(female)	1.71	0.44-6.68	0.44	1.22	0.41-3.62	0.72
≥75 years old	11.15	1.64-75.69	0.01[*]	0.58	0.24-1.40	0.22

[†]Adjusted for dementia, a spouse capable of caring for the patient, patient/family's intention for death at home, family, sex and age (≥75 years old). [‡]Adjusted hazard ratio, [§]95% confidence interval, [¶]Patient/family's intention for death at home. [*]P-value<0.05.

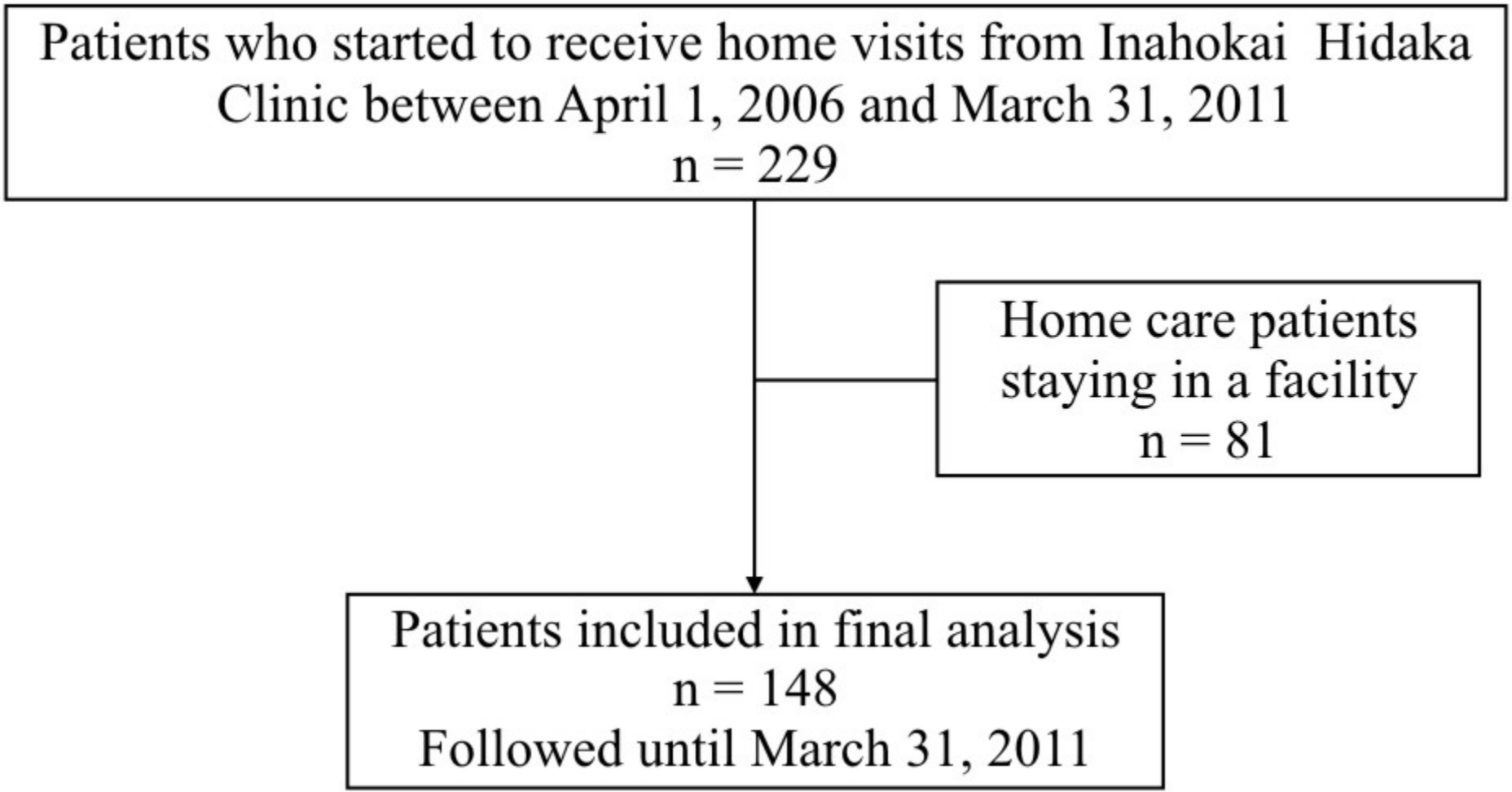
Appendix 1 Independence degree of daily living for the disabled elderly

Rank J	Some disabilities, but daily living is mostly independent; capable of going outdoors unassisted.
	1. Goes outdoors with means of transportation, etc.
	2. Goes out near home.
Rank A	Indoor living predominantly independent, but unable to go out without assistance.
	1. Goes out with assistance, spending most time during the daytime out of bed.
	2. Does not go out frequently, repeating cycles of lying down on and getting up from bed during the daytime.
Rank B	Some assistance needed for indoor living, also lies in bed for much of the daytime, although sitting position is possible.
	1. Uses a wheelchair without assistance, takes meals, and excretes/urinates off the bed.
	2. Uses a wheelchair with assistance.
Rank C	Bedridden all day, requires assistance with excretion/urination, meals, and dressing/undressing.
	1. Capable of changing posture in bed.
	2. Unable to change posture in bed without assistance

Appendix 2 Independence degree of daily living for the demented elderly

Rank I	Has some type of dementia, but almost independent in terms of daily living at home and in society.
Rank II	Some daily life-disturbing symptoms, behaviors and problems in communication seen but can lead daily life independently if kept watched by someone.
IIa	Condition II, mentioned above, seen outside home.
IIb	Condition II, mentioned above, seen at home.
Rank III	Daily life-disturbing symptoms, behaviors, and problems in communication that require assistance.
IIIa	Condition III, mentioned above, seen primarily during the daytime.
IIIb	Condition III, mentioned above, seen primarily at night.
Rank IV	Daily life-disturbing symptoms, behaviors, and problems in communication frequently require assistance.
Rank M	Marked psychiatric symptoms/related symptoms or serious physical disorders require expert management.

Fig. 1


Patients who started to receive home visits from Inahokai Hidaka Clinic between April 1, 2006 and March 31, 2011
n = 229
Home care patients staying in a facility
n = 81
Patients included in final analysis
n = 148
Followed until March 31, 2011