

# When Home Hospice Patients Discharge to Nursing Home: A Mixed Method

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## Abstract

**Background:** Hospice care is to provide necessary medical care and support for patients and the families at the end of life (EOL). Hospice care patients typically withdraw from aggressive treatment. Even though home hospice has been shown to improve the quality of care, home hospice patients still revoke the services for various reasons. A little is known about where home hospice patients are being transferred. This study aims to address this gap and explore common reasons for home hospice discharge and placements, where patients being transferred other than home. **Methods:** Data were retrieved from the 2007 National Home and Hospice Care Survey (NHHCS). NHHCS is one in a series of nationally representative sample surveys of U.S. home health and hospice agencies. **Results:** Within identified home hospice patients, approximately 82.1% were deceased at discharge, and 846 (18.2%) were discharged for other reasons, including patients being stabilized or improved (30.2%), aggressive treatment (31.8%), moved (e.g., geographically, 13.5%) and others. Patients lived with a spouse were less likely to utilize external resources, like volunteers, thereby more likely to discharge patients to long-term facilities. **Discussion:** The current study suggest that it is difficult for the family to give all remaining care for their loved ones despite the support and resources for those home hospice patients. The characteristics of those who transferred to nursing facilities from home hospice will be discussed throughout.

## Keywords

Live Discharge, Nursing Facilities, Home Hospice

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## 1. Introduction

Hospice care is to provide necessary medical care and support for patients and the families at the end of life (EOL). Hospice care patients typically withdraw aggressive treatment, including hospitalization [1]. The majority of hospice pa-

tients receive care at home [2] [3] and has been shown to improve quality of care and satisfaction for both patients and caregivers (e.g., family members) [4] [5].

In response to the increasing number of hospice patients and admission, the U.S. Medicare hospice benefit has expanded. Patients can now receive hospice care at long-term care facilities, including skilled nursing facilities and assisted living [6] [7]. Typically, hospice patients receive care in their own residency, and this reflects the common preferences of dying place, home [8] [9].

Despite the individuals' preference for dying at home, the number of live discharges increases [10] [11]. Approximately 6 percent of home hospice patients revoked the care and admitted to the hospital within 30 days of discharge [10] [12] and likely to die within six months without being re-enrolled in hospice care [13]. This is problematic as the transitioning experience may cause stress and burdensome for families and patients due to unwanted aggressive treatment during the end of life and unsatisfactory symptom management [14] [15].

## 2. Home Hospice Patient: What We Know

While majority of home hospice patients discharge at deceased, though those of who discharged other than being deceased, including stabilized condition, to receive aggressive treatment related to primary diagnosis, and eligibilities that are related to the length of stays [16] [17]. Further, low-income families were likely to transfer to nursing facilities due to limited resources, such as financial limitations to hire additional caregivers [18] [19]. Importantly, the inadaptable transitioning of home hospice to nursing facilities tends to increase over time [20]. Although there is limited information on transitioning home hospice to other long-term care facilities, previous studies have suggested transferring to a nursing home may decrease patients' and families' satisfaction [21] [22].

Terminally ill patients to choose hospice setting to receive comfort care during at the end of stage of their lives, ultimately, to achieve quality of death at home [23] [24]. However, increasing number of home hospice patients being discharged to nursing facilities, which in fact decrease both patients and family members' satisfaction. It is important to understand the reasons for patients to being discharged to nursing facility to provide improved care for those home hospice care patients.

The current study attempted to revisit home hospice characteristics live discharge and explore the possible association between individual patients and families to decide live discharge and placements. This observational-exploratory study has two objectives:

Objective 1: Demographics of live discharge patients and what extend impact live discharge decisions and hospice settings other than home.

Objective 2: The reasons for discharge other than deceased.

Meeting these objectives will help researchers and hospice social workers understand the core cause of home hospice enrollees being discharged to long-term care facilities rather than common factors, such as limited financial support and resources.

### **3. Method**

The 2007 National Home and Hospice Care Survey (NHHCS) was used. NHHCS is a nationally representative sample survey of US home health and hospice agencies. The survey was conducted between August 2007 and February 2008 through in-person interviews with the agency and directors and their designated staff, and no patients or families were interviewed. Within the NHHCS, patients and discharge data were retrieved. In this subset, both home health and home hospice agencies and professionals were interviewed. Home hospice caregivers' interviews were used for this study.

### **4. Variables**

#### **4.1. Demographic Variables**

Demographic information on the home hospice patients included, age, gender (male or female), race (American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or other Pacific Islander, White or Caucasian, Hispanic, or other), marital status (married, widowed, divorced, separated, never married, living with partner). Patient's socioeconomic status was measured by enrolled in Meals on Wheels.

#### **4.2. Living Arrangement Prior to Home Hospice Discharge**

Patients' living arrangement was captured, including living alone, with family members (spouse/significant other, parent, child), with non-family members, with family and non-family members.

#### **4.3. Level of Assistance Needed**

Patients' level of physical function and need assistance were measured by the total number of activities of daily living by family and by staff (bathing, dressing, toileting, transporting, walking, feeding).

#### **4.4. Reason for Discharge**

A questionnaire asking reasons for discharge (stabilized/improved, more aggressive treatment, moved, and others) and interviewers selected others provided narrative responses.

#### **4.5. Placements after Discharge**

A questionnaire asking where patient go after he/she was discharged from the agency were analyzed including: 1) private home or apartment; 2) residential care place; 3) skilled nursing facility; 4) hospital; 5) another hospice facility. This will alternatively help understand patients' live discharge destination rather than home.

### **5. Data Analysis**

Statistical Package for the Social Science (SPSS) version 25 was used to produce

frequency and percentages. Hierarchical logistic regression was performed to explore a possible association between nursing home discharge and remaining hospice by patients. The intention of Hierarchical logistic regression was to identify any possible moderation effect within predictor variables that commonly influence individuals' decision on hospice live discharge (e.g., gender, age, socioeconomic status). Sub-group analyses were also performed to specify interviewees' responses by discharge reason and by the revocation. To visualize narrative findings, Rstudio Version 1.6.0, *WordCloud package* were used. *WordCloud* allows visualizing most shown words within narrative responses.

The narrative response began by dividing the qualitative responses by longer-term care facility (nursing home, assisted living, residential care facilities), home, hospital, and others. A handful of narrative responses were overlapped with previous answer (Stabilized/Improved; More aggressive treatment, Moved) and questionnaire "Where did patient go after discharged from the agency," the author manually re-coded by nursing facilities or long-term care facility, to have the entire information on patients' placement after discharge. Patients transferred to different hospices were excluded from this analysis. Once re-coded, including narratives, patients' placements after discharge were divided dichotomously (0 = others; 1 = Long-Term Care Facility).

For the subgroup analysis, narratives were narrowed down to discharge reasons other than stabilized, hospitalization, and moved. Identified responses were recorded by 1) eligibility (patients' condition); 2) eligibility (financial); 3) hospital admission; 4) nursing facilities; 5) revoked (by caregiver); 6) revoke (by doctor); 7) revoke (by patients); 8) revoke (by family); 9) revoke (unclear); 10) unrelated emergency.

## 6. Result

**Table 1** shows the demographic of interviewers for the current study. Of 9416, 4733 were identified receiving or have received hospice care at home. Within identified home hospice patients, approximately 82.1% were deceased at discharge. Of the remaining 837, as **Table 1** shows, there were more female ( $n = 510$ , 60.3%) than male patients; majority of home hospice patients were White ( $n = 709$ , 83.8%) and Black or African American ( $n = 116$ , 13.7). Living arrangements were varied. 126 patients lived alone when admitted to home hospice, 247 lived with a spouse or significant others, and 177 lived with their children. Majority of patients were either married ( $n = 289$ , 35.8%) or widowed ( $n = 368$ , 45.6%).

After discharge from home hospice, the majority of patients remained in their own residency (37.5%), about 25 percent of live discharged patients were admitted to the hospital, and about 30% of patients transferred to the nursing facilities ( $n = 248$ ). Prior to the live discharge, the majority of patients required assistance with at least four Activities in Daily Lives by family (29.1%) and by staff (26.5%), and about 70 percent of patients and family had helped with patients ADLs.

**Table 1.** Demographic information for sample ( $N = 846$ )<sup>1</sup>.

		<i>M</i>	Range	<i>n</i>	(%)
	Age	77.82	97		
Gender	Male			336	39.7%
	Female			510	60.3%
Race	White			665	80.3%
	Black or African American			115	13.9%
	Hispanic/Latino/Other			48	5.8
Insurance <sup>2</sup>	Medicare			734	87.1%
	Medicaid			261	31.2%
Living Arrangement	Live Alone			57	37.7%
	Spouse/Significant Others			227	37.5%
	With Child			177	26.9%
Resources	Home Maker			205	24.4%
	Assistance with ADLs			576	68.5%
	Continuing Care			11	1.3%
	Volunteers			280	33.3%
	Wheels on Meals			25	3.0%

<sup>1</sup>Valid percentages are reported. <sup>2</sup>Counted dual-eligible.

As expected, more than 80 percent of home hospice/discharge patients were Medicare beneficiaries, Medicaid (7%) and only 4 percent of patients held private insurance. Only 25 patients were receiving Meals on Wheels (3%). As for access to external resources, 205 patients had homemaker (24.4%), volunteer (33.3%), and only 11 patients received continuing care program (1.3%).

### 6.1. Multiple Regressions on Live Discharge to Long-Term Care Facility

To further specify any factors that may encounter patients and families to decide on live discharge to long-term care facilities, hierarchical logistic regression was performed to identify the effect of level of assistance needed and access to external services with common covariates (e.g., age, gender, income, living arrangement). The order of included variables are the total number of ADLs provided by family (Dress, Bath, Transfer, Walk, Feeding) and staff (Dress, Bath, Transfer, Walking, Feeding), and patients access to external services (Homemaker services, Assistance with ADLs, Volunteers, Continuous home care).

As **Table 2** shows, the *priori* logistic regression revealed, the odds of patients discharged to long-term care facilities were higher when patients lives(d) with spouse or significant others (OR = 4.90, 95% CI, 2.64 to 8.97;  $p < 0.01$ ) and with lives(d) with children (OR = 5.37, 95% CI, 2.72 to 10.61;  $p < 0.01$ ). Patients receives homemaker services were more likely to be transferred to the long-term care after live discharge (OR = 1.97, 95% CI, 1.30 to 3.00;  $p < 0.01$ ), but the odds of

discharged to long-term care facilities were lower if receiving assistance with ADLs (OR = 0.45, 95% CI, 0.31 to 0.67;  $p < 0.01$ ) and receiving volunteer services (OR = 0.63, 95% CI, 0.44 to 0.90;  $p < 0.01$ ). Related to receiving external services for assistance with patients ADLs, patients require more assistance in completing dressing, bathing, transferring, walking, and feeding by a family member had a significantly higher likelihood of discharge to nursing facilities (OR = 1.30, 95% CI, 1.08 to 1.56;  $p < 0.01$ ), though no significant impact on patients discharge to long-term care facilities when staff provides assistance.

The result of Hierarchical Regression is shown here (refers to **Table 3**). The fit indices indicated good fit overall when included all variables ( $\chi^2 = 7.51$ ,  $df = 8$ ,  $p = 0.48$ ,  $R^2 = 0.21$ ). While gender, living arrangement and socioeconomic status were controlled, patients receiving home care, continuing care, volunteer services, and assistance with ADLs became mediated. The odds of being discharged to long-term facilities remained higher for those patients lives(d) with spouse or significant others (OR = 3.69, 95% CI, 2.04 to 6.67;  $p < 0.01$ ) and lives(d) with children (OR = 5.13, 95% CI, 2.66 to 9.87;  $p < 0.01$ ).

**Table 2.** *Priori* Logistic Regression.

	Discharge to Long-Term Facilities
Lives(d) Alone	1.73 (0.94 - 3.16)
Lives(d) Spouse/Significant Others	4.90* (2.67 - 8.97)
Lives(d) Children	1.44 (0.41 - 5.00)
ADLs Needs by Family	1.16 (0.54 - 2.46)
ADLs Needs by Staff	0.76 (0.41 - 1.41)
Homemaker Services	0.31 (0.07 - 1.40)
Assistance with ADLs	1.44* (0.91 - 2.30)
Volunteers	0.90* (0.58 - 1.39)
Continuous Homecare	0.92* (0.36 - 2.35)
Meals on Wheels	0.74 (0.41 - 1.31)

Note: \* $p \leq 0.05$ .

**Table 3.** Hierarchical regression.

	Discharge to Long-Term Facilities
Lives(d) Alone	1.68 (0.91, 3.92)
Lives(d) Spouse/Significant Others	7.14* (3.39 - 15.03)
Lives(d) Children	8.52* (3.88 - 18.73)
Meals on Wheels	1.68 (0.43, 6.55)
ADLs Needs by Family	1.25 (0.96, 1.64)
ADLs Needs by Staff	0.98 (0.80, 1.21)
Homemaker Services	1.12 (0.62, 2.02)
Assistance with ADLs	1.39 (0.61, 3.15)
Volunteers	0.73 (0.41, 1.28)
Continuous Homecare	2.73 (0.33, 22.40)

Note: \* $p \leq 0.05$ .

There were meaningful correlations were shown (refers to **Table 4**), while patients lives(d) with spouse or significant others were negatively correlated with utilizing homemaker services ( $r = -0.07, p < 0.01$ ) and assistance with ADLs ( $r = -0.12, p < 0.01$ ), whereas lives(d) with children were positively correlated with receiving homemaker services ( $r = 0.10, p < 0.01$ ) and assistances with ADLs ( $r = 0.13, p < 0.01$ ).

## 6.2. Subgroup Analysis by Discharge Reasons

Discharge reasons were, including patients being stabilized or improved (30.2%), aggressive treatment (31.8%), moved (e.g., geographically, 13.5%) and others. Within patients who were discharged for other reasons ( $n = 207$ ), 136 reported revoke the care by either patient ( $n = 21, 10.1\%$ ) or family member ( $n = 30, 14.5\%$ ) or unidentified who made decision ( $n = 32, 15.5\%$ ).

As we see on **Figure 1**, nursing home admission was the most common reason for discharge from home hospice ( $n = 31, 15\%$ ). A handful of patients were discharged due to financial reasons ( $n = 15, 7.2\%$ ), and unrelated emergency and hospitalization (e.g., fell, fracture) was also a common factor for home hospice patients to be discharged. Importantly, those patients admitted to the hospital for other reasons than primary diagnosis ended up discharge to and remained at the nursing home ( $n = 2$ ).

**Table 4.** Correlations of living arrangements and use of insurance, external services for home hospice care.

	2	3	4	5	6	7	8	9	10
1) Medicare	-0.17** (0.01)	0.03 (0.43)	-0.06 (0.10)	0.10** (0.01)	0.05 (0.11)	0.15** (0.01)	0.10** (0.01)	0.04 (0.19)	0.06* (0.05)
2) Medicaid	-	0.02 (0.48)	-0.19** (0.01)	0.12** (0.01)	0.06 (0.05)	-0.00 (0.92)	0.07* (0.04)	-0.03 (0.36)	0.06 (0.06)
3) Patient Lives(d) Alone	0.02 (0.48)	-	-0.37* (0.01)	-0.29** (0.01)	-0.01 (0.74)	-0.02 (0.46)	0.00 (0.80)	-0.02 (0.46)	0.05 (0.15)
4) Patient Lives(d) with Spouse/Significant Other	-0.19* (0.01)	-0.37** (0.01)	-	-0.38** (0.01)	-0.07* (0.04)	-0.12** (0.01)	-0.01 (0.75)	-0.02 (0.61)	-0.04 (0.24)
5) Patient Lives(d) with Child	0.12* (0.01)	-0.29** (0.01)	-0.38** (0.01)	-	0.10* (0.01)	0.13** (0.01)	-0.03 (0.44)	0.00 (0.82)	-0.02 (0.56)
6) Used Homemaker Services	0.06 (0.05)	-0.01 (0.74)	-0.07* (0.04)	0.10** (0.01)	-	0.29** (0.01)	0.07* (0.03)	-0.01 (0.63)	0.08* (0.02)
7) Used Assistance with ADLs	-0.00 (0.92)	-0.02 (0.46)	-0.12** (0.01)	0.13** (0.01)	0.29* (0.01)	-	0.11** (0.01)	0.05 (0.10)	-0.03 (0.35)
8) Used Volunteers	0.07 (0.04)	0.00 (0.80)	-0.01 (0.75)	-0.03 (0.44)	0.07* (0.03)	0.11* (0.01)	-	-0.01 (0.67)	0.11** (0.01)
9) Used Continuous Home Care	-0.03 (0.36)	-0.02 (0.46)	-0.02 (0.61)	0.00 (0.82)	-0.01 (0.63)	0.05 (0.10)	-0.01 (0.67)	-	-0.02 (0.56)
10) Used Meals on Wheels	0.06 (0.06)	0.05 (0.15)	-0.04 (0.24)	-0.02 (0.56)	0.08* (0.02)	-0.03 (0.35)	0.11** (0.01)	-0.02 (0.56)	-

Note: \* $p \leq 0.05$ ; \*\* $p \leq 0.01$ ; Note:  $p$  value is reported in parentheses.





home hospice agencies included in the current study all have routine care at home, including nurses, home health aides, and social services designees. Perhaps, these services may not sufficiently reduce the burden on family caregivers [18] [30].

Other possibilities would be family caregivers may not utilize available resources enough. Previously suggested, mid-to older-aged spouses tend to act as primary caregivers as an obligation and less likely to utilize extra help than their children [29] [31]. The current study showed spousal caregivers were less likely to use those resources, compared to child caregivers. There was a smaller number of homecare and volunteer services were used when the spouse or significant others were the primary caregivers for the patients. Spousal caregivers may feel obligated to provide care for the patients themselves, thereby not accepting extra resources. This is a problematic as patients requiring more assistance increases a live discharge, spousal caregivers are less likely to utilize help in order to maintain well-being for both patients and the family member. Also, spousal caregivers are more common than child caregiver.

Within narrative responses, the most common reasons for discharge from home hospice were to be transferred to nursing facilities. Observable differences were identified in between living arrangements. Hospice patients who lived with the family were likely to end up discharging to the nursing home (50%). Assumedly, this pattern suggests that despite the support and resources for those home hospice patients, it is still difficult for families to provide all necessary care for their loved ones until one's death and likely to seek external support, nursing facilities.

Previous research has indicated that patients to be remained under home hospice care heavily rely on family caregivers [14]. A burden of family caregivers is a well-known concern in a home hospice setting [27], and despite the support from agencies and volunteers, certain family caregivers are not accessing those available resources is the problem. Characteristics and reasons for the family not accessing extra help from agencies or volunteers need to be explored further.

## **8. Limitations**

The current study was first to specify reasons for live discharge from home hospice and examine the possible relationship between individuals' financial assets and related physical conditions and insurance policies. However, this study concerns several limitations.

First, this study is a non-experimental, observational study that is not possibly associated with hypothetically impact families' decisions on live discharge and transfer to long-term care facilities. Further within narrative responses, there were no significant associations or correlations were found between patients' needing ADLs by staff, insurance policy (e.g., Medicare vs. Medicaid vs. private), and living arrangements (e.g., living with family or alone) by discharged to be enrolled in the nursing facilities. However, these non-significant findings could

be meaningful. Previously, income and insurance policy played an important factor for patients and families to the nursing home due to limited resources (e.g., lack of resources). This current study suggests that volunteer and social services personnel were available as part of home hospice services, but spousal caregivers did not utilize these resources. Further, although performing ADLs does not indicate that the family has less to provide for the patients, it is noteworthy to look at the number of ADLs that individual patients and families did not significantly influence in deciding to revoke the care and transfer to nursing facilities.

The second limitation is that the data used in this current study is outdated. The interview was collected between the year 2007-2008. However, home hospice benefit has not been modified significantly since early 2000 [1] [10] and similar studies explored home hospice patients' live discharge using data collected between 2000 to 2013 [32]. This current study was the first to specify the reasons to be discharged (*i.e.*, narrative responses) and understand the pattern of accessing extra assistance by spousal and child. Yet, newer home hospice data needs to be studied to examine the most up-to-date patterns with updated benefits that are available to patients and families.

## 9. Conclusion

Home hospice can benefit both families and patients at the end of the stage. Home hospice care will allow patients to receive care at home, where they feel most comfortable and can die at the most preferred location, home. Simultaneously, the trend suggests many individuals are now accepting hospice care and palliative care at home than in the past. However, spousal caregivers are often obligated to become primary caregivers, thereby less likely to utilize services available for them, thereby overwhelmed and transferred to nursing facilities. Reducing family caregivers' obligations is essential.

## Conflicts of Interest

The author declares no conflicts of interest regarding the publication of this paper.

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