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## Timing of Hospice Referral: Assessing Satisfaction While the Patient Receives Hospice Services\*

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### Abstract

Generally, satisfaction with timing of hospice referral was measured in mortality follow back surveys of patients who died in hospice. In contrast in this study, investigators assessed timing of the hospice referral in patients/families enrolled in hospice for a minimum of two weeks. About 1/3 of patients/families identified it would have been easier if they started hospice earlier. Barriers to early hospice access were associated primarily with access to the healthcare system.

### Keywords

Hospice; Hispanics; timing of referral; satisfaction

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Hospice is the most widely used federally-funded program designed to provide end-of-life care for Medicare beneficiaries (Scanlon, 2000). Overall bereaved families of hospice patients reported high levels of satisfaction with hospice services, however, less satisfied families consistently associated dissatisfaction with feelings that the hospice referral was made “too late” (Miceli & Mylod, 2003; Schockett, Teno, Miller, & Sturt, 2005; Teno, Shu, Casarett, Spence, Rhodes, & Connor, 2007). Most studies that investigated perceptions of “too late” hospice referral were retrospective. They were completed using surveys of bereaved family members after the patient’s death. In the present study, patient/family units were interviewed while in hospice to determine perceptions of timeliness of the hospice referral. Selected demographic and health related variables that could be associated with timeliness of the referral were investigated. The more providers understand factors that influence timeliness of hospice referrals, the more successful they will be at getting hospice services to patients/families at the optimal time.

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## Studies of Referral Timing

The decision to start hospice care must be made at the appropriate time – not too early and not too late (Bolmsjö, Nilstun, & Löfmark, 2007). When the decision to start hospice is too late, both patient and family undergo unnecessary suffering. The federal government and hospice care organizations expect hospice care teams to address pain and symptom control, psychosocial distress, and spiritual issues with patients/families, to prepare patients/families for dying and death, to provide information and education about the plan of care, and coordinate care (Hospice and Palliative Nurses Association, 2000; Scanlon, 2000). Experts recommend a 90 day minimum hospice stay to provide multidimensional end-of-life care to patients and their families (Christakis & Iwashyna, 2000; Rickerson, Harrold, Kapo, Carroll, & Casarett, 2005). In contrast to the ideal 90-day hospice stay, the median hospice stay in 2006 was around 20.6 days (National Hospice and Palliative Care Organization [NHPCO], 2007).

Three studies documented that timing of hospice referrals was critical to patient's/family's quality of life and satisfaction with hospice care. In a multi-site study, Miceli & Mylod (2003) measured perceived satisfaction of bereaved families who used hospice services. The Hospice Care Family Survey was mailed to primary caregivers between one and three months after the patient's death. Responses were analyzed from 1,839 family caregivers in 17 different hospice agencies. Ninety-two percent of families perceived their loved ones were referred to hospice "at the right time;" 8% perceived the loved one was referred "too late." Timing of hospice referral and quality of care were measured in a collaborative effort between the NHPCO and Brown Medical School for Gerontology (Teno, et al, 2007). NHPCO member hospices (N = 631) collected data from 106,514 bereaved family members one to three months after the patient's death. From the sample, 11.4% of family members reported that hospice services were initiated "too late." Schockett, Teno, Miller, & Stuart, (2005) investigated bereaved family members perceptions of whether or not their loved ones were referred to hospice "too late" and identified reasons for late referrals. The study was completed in two not-for-profit hospices three to six months after the patient's death. The sample was 237 family members, 32 (13.7%) of which responded that the hospice referral was made "too late." Physicians were identified as the most common (62.5%) barrier to the "too late" hospice referral. Specific physician barriers included inaccuracy of prognosis, disagreement with the hospice philosophy, and oncologist desire to pursue further treatment (clinical trials). Other reported causes of "too late" referrals were related to patient/family knowledge of and beliefs about hospice.

In a single hospice, patients and family members/significant others (hereafter referred to as families) (n = 274) were interviewed on admission to identify if they thought the hospice admission was made "too soon," "at about the right time," or "to late" (Kapo, Harrold, Carroll, Rickerson, & Casarett, 2005). Family members were interviewed one month after the patient's death to elicit the same information. On hospice enrollment (prior to receiving hospice services), 1% of patients and 5% of family members identified hospice enrollment was made "too late." In the interviews one month after the patient's death, 17% of family members said the patient enrolled "too late." Families who believed the enrollment was too late had shorter lengths of stay.

## Critical Analysis of Approaches

The above reviewed studies are referred to as mortality follow-back studies (Miceli & Mylod, 2003; Schockett, et al, 2005; Teno, et al, 2007), or post death surveys (Kapo, et al, 2005; Cassarett, Crowley, & Hirschman, 2003) because data were collected after the patient's death. Collectively, the studies documented that between 8 – 17% of bereaved family members perceived that hospice referrals were made "too late." The perception of a "too late" referral

was associated with lower satisfaction with hospice care, however, in three of the studies no significant association was found between hospice length of stay and family member satisfaction with hospice services (Miceli & Mylod, 2003; Teno, et al, 2007).

The value of using mortality follow-back surveys to evaluate family perceptions of timing of hospice referrals is that family members have a view of the entire hospice episode of care. In addition, family members have temporal and emotional distance from the exhaustion of care giving and distress associated with their loved ones' death; thus, they have a more objective perspective on hospice processes and outcomes. There are also disadvantages to using mortality follow-back studies to evaluate appropriate timing of hospice referrals. One disadvantage is possible loss of contact with family members in the one to six months between the patient's death and the follow-up survey. Thus, data from some bereaved families are lost. Second, increasingly there is no caregiver available for in-home hospice patients. Patients manage their own hospice care at home as long as possible, then some other arrangement is made for their care, e.g. they are admitted to a long term care facility. For these patients, there is no available caregiver to contact for a mortality follow-back study. Third, in the one to six months post death, experiences surrounding caring for the decedent can become idealized (Corless, 2006). Struggles and frustrations of care giving may be lost or minimized. Fourth and perhaps most importantly, the patient – the central figure in hospice care -- is not available to share his/her perspectives on timing of the hospice referral.

An alternative approach to capture information on satisfaction with timing of the hospice referrals is to ask the patient/family member while the patient is receiving hospice services. Concurrent assessment of satisfaction with timing of hospice referral has two major advantages 1) it includes the patient as a respondent, and 2) little or no time gap occurs between hospice referral and assessment of satisfaction with the timing of the hospice referral. Concurrent assessment can provide real time information on differences hospice services make in the day-to-day life of the dying patient and caregiver. Further, by assessing the hospice referral soon after it was made, the patient/family member has more accurate memories of the circumstances surrounding the hospice referral process.

## Purpose of the Study

The present study proposed to investigate patients/family units who were in hospice to 1) identify perceptions of timeliness of the hospice referral, and 2) determine personal and health services variables that were associated with timeliness of the hospice referral.

## Methodology

### Design

The study was a quantitative-qualitative research design. Quantitative data were collected through hospice agency record reviews. Qualitative data were collected through structured interviews.

### Site and Setting

The study site was a moderate size city and county area of approximately 700,000 individuals in west Texas (U.S. Census Bureau, 2000). The majority population was Hispanic (78%), with Whites (17%) and "Other" (5%) ethnicities/races comprising smaller segments of the population. The setting was three Medicare-certified hospice agencies.

## Sample and Sampling

Data were collected in 2004 and 2005. A convenience sample was used. Interviews were completed with 60 Hispanics and 60 Whites. An equal number of males and females were interviewed within ethnicities. All patients were 65 years of age or older and were participating in the Medicare Hospice Benefit. Patients who lived in a nursing home were excluded; however, patients residing in assisted living were included. In hospice the patient/family is considered the unit of service (Davies, 2006). Generally, both patient and family members contributed to the interview.

## Variables

**Independent Variable**—The independent variable, or the variable that divided one group of patients/family members from the other, was the question “Would it have been easier for you if you started to receive hospice services earlier than you did?” Responses were “Yes” or “No.”

**Dependent Variables**—Demographic and selected health services variables known to be associated with access to health services were collected as dependent variables. Demographic variables were age, gender, ethnicity, marital status, religion, residence at start of care, primary caregiver at start of care, and zip code of residence. Healthcare services and selected healthcare access variables were: primary diagnosis, insurance; hospitalization or home health services prior to hospice admission; consistent source of health services; location where received majority of health services; first person to discuss hospice; selection of hospice agency; and seen hospice advertisements prior to hospice admission.

## Instruments

**Patient Demographic Form**—A Patient Demographic Form was developed to collect demographic data from patient record reviews. Using the zip code of the patient and United States census data (U.S. Census Bureau, 2000), the median household income was identified for the area where each patient lived. This median household income by zip code was used as a proxy for patient financial status.

**Patient Interview Form**—A Patient Interview Form was used to collect interview data related to health services not available from patient records. The Patient Interview Form was prepared and pilot tested in English and Spanish. The interview questions were simple, open-ended, and required yes/no or short answers.

## Procedure

The study was approved by a university institutional review board for protection of human subjects. Health Insurance Portability and Accountability Act (HIPAA) guidelines were followed for accessing protected health information of patients in hospice agencies (United States Department of Health and Human Services, 2003). When patients were admitted to the hospice agency, they were notified that a study was taking place on hospice access and use. If patients/family members agreed to participate in the study, they signed a HIPAA agreement form allowing researchers access to their agency records. A registered nurse (RN) experienced in home care reviewed agency records of patients who agreed to participate in the study. The RN contacted patients/families of patients who met study criteria and scheduled home-based interviews. The RN was bilingual – English/Spanish. All patients/families were interviewed after receiving more than two weeks (14 days) of hospice services. The home visits and interviews were held at the convenience of the patient/family. Interviews were conducted in English or Spanish depending on patient/family preferences. Informed consent forms were

available in Spanish or English. The RN read the questions to the patient/family and recorded responses on the Interview Form. The interview took about 30 – 40 minutes to complete.

## Results

Out of the 120 hospice patients/families interviewed, 37 (31.4%) of patients/families responded “Yes” and 81 (68.6%) responded “No” to the question “Would it have been easier for you if you started to receive hospice services earlier than you did?” Two patients/families were unable to decide “Yes” or “No” to the question. Both patients were 81 years of age, Hispanic, lived in their own residence, and the primary caregiver of both was a child. One was a male and the other a female; one was married and one was a widow. The primary diagnosis of one was cancer and of the other renal disease. These two patients were not included in the data analysis.

Patients were divided based on their “Yes” or “No” answer to the starting of hospice services earlier question. Of the 118 patients who responded “Yes” or “No,” a test for equal percentages showed that the difference was significant at the 0.001 level. The two groups were compared on demographic characteristics and on experiences with health services prior to the hospice referral. Data were analyzed using t-tests and chi-square tests. The level of significance was set at  $p = 0.05$ .

A t-test analysis documented no significant difference ( $p = 0.98$ ) in the mean ages of patients based on their response to the starting of hospice services earlier question. When median household income by zip code was calculated, patients who preferred to start hospice earlier (“Yes”,  $M = \$32,997$ ,  $SD = \$12,873$ ) had a significantly ( $p = 0.04$ ) lower income than patients who were satisfied with the referral timing (“No,”  $M = \$38,262$ ,  $SD = \$12,130$ ). Proportionately more Hispanics responded “Yes” ( $n = 24$ , 64.9%) it would have been easier if hospice services were started earlier, than responded “No” ( $n = 34$ , 42%) ( $p = 0.02$ ) (Table1).

Having insurance other than Medicare was not associated significantly with patients’ response to the start of hospice services; however, in patients who had insurance other than Medicare ( $n = 92$ ), having Medicaid made a difference. Proportionately more ( $p = 0.01$ ) Medicaid patients respond “Yes” ( $n = 14$ , 51.9%) to the started earlier question than responded “No” ( $n = 16$ , 24.6%) (Table 2). Proportionately fewer ( $p = 0.02$ ) patients who responded “Yes” to the started hospice services earlier question received health services in a physician’s office ( $n = 24$ , 64.9%), when compared to patients who responded “No” ( $n = 67$ , 83.8%). The physician was the first person to discuss hospice with proportionately ( $p = 0.03$ ) fewer patients who respond “Yes” ( $n = 20$ , 54.1%), to the started hospice services earlier question than responded “No” ( $n = 60$ , 74.1%). No other interactions achieved the 0.05 level of significance; however, the significance level of regular source of health services was  $p = 0.08$ . Proportionately fewer patients who responded “Yes” to the started hospice services earlier question, 78.4% ( $n = 29$ ) had a regular location of health services than patients who responded “No” ( $n = 73$ , 90.1%).

## Discussion

At the time of the interviews, study patients/families received hospice services for a minimum of two weeks. In most cases initial hospice staff efforts focused on alleviating or reducing patient symptoms, which contributed to patient’s physical well being and reduced caregiver’s burden. Also, in the beginning weeks of hospice services, staff provided instruction to caregivers on how to care for the patient and answered patient/family questions about the illness. Hospice staff reassured patients/families that hospice staff were available 24/7 should unforeseen events or questions occur. By the end of the second week of hospice services, patients/family members were well able to evaluate the impact of hospice services on their lives. About 1/3 of study patient/families agreed it would have been easier if they started

hospice services earlier. Indirectly, these patients/families acknowledged dissatisfaction with the timing of the hospice referral.

A definite picture emerged of patients/families who reported that they wished they started hospices services earlier—overall, they were more often Hispanics and lived in lower income areas. When they had insurance other than Medicare, the insurer was Medicaid. Proportionately fewer had a regular location of health services or received care in a physician's office. Generally, someone other than a physician was the first person to discuss hospice services with them. Research reports describing Hispanic access and utilization of hospice services including barriers to hospice for Hispanics were reported in other publications and will not be address in this manuscript (Adams, Horn, & Bader, 2005; Adams, Horn, & Bader, 2006; Adams, Horn, & Bader, 2007).

An important characteristic for hospice access is continuity of care defined as regular and ongoing access to a physician or group of physicians (Gordon, 1995). In this study, proportionately more patients who wished they had started hospice earlier had no regular location of health services and/or most received health services in a clinic or emergency department rather than a physician's office. Determining the right time to make hospice referral for an older adult can be challenging in optimal circumstances, e.g., when there is an ongoing physician-patient relationship, because of constraints and requirements of the Medicare Hospice Benefit (Gordon, 1995; Scanlon, 2000). When the patient's primary location of health services is an emergency department or clinic, getting a timely hospice referral may be even more challenging. In both sites, often the patient is not seen by the same physician on successive visits. The physician may have little knowledge of the patient/family and may not know patient/family preferences, wishes, or resources for end-of-life care. Often there is little rapport and trust between the patient and patient/family; thus, even if the physician initiates an end-of-life care discussion, it may not proceed comfortably or fruitfully.

According to the Agency on Health Care Research and Quality (AHRQ) (2004), accessing health services requires 1) getting into the healthcare system, 2) getting the right services once in the healthcare system and 3) establishing a relationship with a physician where there is good communication and trust. For patients who identified too late referral (Schockett, et al, 2005) or preferred to start hospice earlier, barriers to hospice seemed to occur at different access points on the AHRQ model. In the present study, proportionately more patients who would have preferred to start hospice earlier were in a healthcare system prior to hospice referral, albeit, not in an optimal location. They received services in an emergency department or clinic. In contrast, (Schockett, et al, 2005) families who perceived the hospice referral was "too late" identified the physician as the primary barrier to the hospice referral. These patients'/families' descriptions of perceived barriers indicated that physicians were not communicating and/or not listening to their wishes for end-of-life care.

The present study results were compared with those of other researchers who studied timing of hospice referrals (Miceli & Mylod, 2003; Kapo, et al, 2005; Schockett, et al, 2005; Teno, et al, 2007). Collectively, study results suggested that patients/families perceptions of whether or not the hospice referral was made "too late" depended on where they were in the hospice episode of care, e.g., newly enrolled, receiving hospice services, or after death. Patients/families (1%/5% respectively) enrolled in hospice and not yet receiving hospice services had lowest perceptions of "too late" hospice referral (Kapo, et al, 2005). Patients/families that received hospice services two or more weeks had the highest levels; 31% reported it would have been easier if they started hospice earlier. Post death survey family responses fell in the middle; 8% – 17% of family members reported that hospice referrals were made "too late" (Miceli & Mylod, 2003; Kapo, et al, 2005; Schockett, et al, 2005; Teno, et al, 2007).

Reasons for differences in perceptions of timeliness of hospice referral could be related to the patient/family confidence in physician and family resources. For example, just enrolled patients/families could have perceived the hospice referral timing was right because that was when their physician made the referral (Kapo, et al, 2005). Many patients/families know little about hospice. They have confidence their physician knows when a family member is terminal and the physician will make the hospice referral at the right time. After two weeks of hospice services, patients/families were able to compare the quality of their lives before and after the start of hospice services. Many (31%) responded “Yes” it would have been easier if they started hospice services earlier. Place of residence or primary caregiver made no difference in the proportion of patients/families who responded “Yes” versus “No” to the started hospice early question. However, household income was lower in patients/families who responded “Yes.” Perhaps having hospice provide medicines and medical supplies was a factor in the patients’/families’ positive response to the started hospice earlier question. Post death surveys were completed 1 – 6 months after patients’ deaths (Miceli & Mylod, 2003; Kapo, et al, 2005; Schockett, et al, 2005; Teno, et al, 2007). Care giving experiences may have dulled or the hospice episode in the intervening months; thus, smaller percentages of family members evaluated timing of hospice referrals as “too late.”

## Implications

Federal policy supports equity in access to health services for all Americans -- regardless of income or insurance (Smedley, Stith, & Nelson, 2003). Four Medicare-certified hospice agencies were operating in the community at the time the study was completed. All were admitting patients. Yet, about 1/3 of study patients/families identified they did not receive hospice services early enough. No matter their availability, if services are not accessible when needed, then the healthcare system is not functioning as intended. Further, individuals should participate with healthcare providers in all decisions related to their healthcare, which includes hospice treatment (U.S. Department of Health and Human Services, 2002). Physicians in all sites, e.g., clinics, emergency departments, physician’s offices, must increase their awareness to the need for hospice admissions and the right time to make the hospice referral.

Hospice agency clinicians, educators, and marketers were able to use the information that about 1/3 of the patients/families answered “Yes” to the started earlier questions to discuss with physicians the need to make earlier hospice referrals. The Medicare Hospice Benefit anticipates that a hospice patient will live six months or less if the disease runs its normal course. The median length of hospice stay was about 20 days for patients in study community (Adams, et al, 2005). Clearly, there was ample opportunity for hospice patients to be admitted to hospice earlier, e.g., median 20 days versus allowed 180 days (six months) without most patients exceeding Medicare length of stay limits.

As a result of this study data, the hospital-affiliated hospice agency staff completed a brochure for emergency department personnel on hospice services and referrals. They provided in-service education seminars for ED staff on these topics. Emergency department staff was encouraged to call the hospice staff and/or make a referral even when they were not completely sure about the need for the referral. Emergency department staff was assured by the hospice department personnel that it was more important to receive a wrong referral than to miss a hospice referral that was needed.

## Limitations and Future Studies

The present study was an initial investigation of patient/family satisfaction with hospice referral while the patient is in hospice. The study answered some questions about patient’s/families’ perceptions; however, it had limitations primarily related to methodology. The study was completed on 120 hospice patients in one location. The study needs to be repeated and results

verified in multiple sites, with multiple ethnicities and with larger samples. Personal and health service factors that limited hospice referral need additional investigation. More detailed questions should be asked about factors that resulted in patient/family satisfaction after start of hospice services. Disparity in hospice access associated with insurance, ethnicity and household certainly needs verification. Specific hospice interventions that made the patient's and caregiver's life easier should be identified.

Present study data integrated with that of other researchers suggested patient/family perception of hospice referral timing was associated with where the patient/family member was in the hospice care episode. A future study could be to follow a cadre of patients/family members through an episode of hospice care and measure their perception of timeliness of the hospice referral at various points in the episode, e.g., at admission, several weeks after admission, and in post death surveys. In addition to group data, researchers could compare specific patient/family responses over the hospice episode to identify the effect of hospice services on perceptions of timing of service and effect of hospice services on their lives.

## Conclusions

Overall about 1/3 of patients/families who were interviewed while in hospice identified that it would have been easier if they started hospice services earlier. When compared to patients who were satisfied with the hospice referral timing, these patients were more often Hispanic, lived in lower income neighborhoods, and were enrolled in Medicaid. The most common barriers to hospice were health service barriers.

## References

- Adams CE, Horn K, Bader J. A comparison of utilization of hospice services between Hispanics and Whites. *Journal of Hospice and Palliative Nursing* 2005;7:328–336.
- Adams CE, Horn K, Bader J. Hispanic access to hospice services in a predominantly Hispanic community. *American Journal of Hospice & Palliative Medicine* 2006;23:9–16. [PubMed: 16450658]
- Adams CE, Horn K, Bader J. Hispanics' experiences in the health system prior to hospice admission. *Journal of Cultural Diversity* 2007;14:155–163. [PubMed: 19172980]
- Agency for Healthcare Research and Quality. National healthcare disparities report. Rockville, MD: U.S. Department of Health and Human Services; 2004. (AHRQ publication no. 05-0014)
- Bolmsjö IÅ, Nilstun T, Löfmark R. From cure to palliation: Agreement, timing, and decision making within staff. *American Journal of Hospice & Palliative Medicine* 2007;24:366–370. [PubMed: 17601832]
- Casarett DJ, Crowley R, Hirschman KB. Surveys to assess satisfaction with end-of-life care: Does timing matter? *Journal of Pain and Symptom Management* 2003;25:128–132. [PubMed: 12590028]
- Christakis NA, Iwashyna TJ. Impact of individual and market factors on the timing of initiation of hospice terminal care. *Medical Care* 2000;38:528–541. [PubMed: 10800979]
- Corless, IB. Bereavement. In: Ferrell, BR.; Coyle, N., editors. *Textbook of palliative nursing*. New York: Oxford University Press; 2006. p. 531-544.
- Davies, B. Supporting families in palliative care. In: Ferrell, BR.; Coyle, N., editors. *Textbook of palliative nursing*. New York: Oxford University Press, Inc; 2006. p. 545-560.
- Gordon AK. Deterrents to access and service for Blacks and Hispanics: The Medicare Hospice Benefit, healthcare utilization, and cultural barriers. *The Hospice Journal* 1995;10(2):65–83. [PubMed: 7557934]
- Hospice and Palliative Nurses Association. Statement on the scope and standards of hospice and palliative nursing practice. Dubuque, IA: Kendall/Hunt; 2000.
- Kapo J, Harrold J, Carroll JT, Rickerson E, Casarett D. Are we referring patients to hospice too late? Patients' and families' opinions. *Journal of Palliative Medicine* 2005;8:521–527. [PubMed: 15992193]



- Miceli PJ, Mylod DE. Satisfaction of families using end-of-life care: Current successes and challenges in the hospice industry. *American Journal of Hospice and Palliative Care* 2003;20:360–370. [PubMed: 14529039]
- National Hospice and Palliative Care Organization. NHPCO facts and figures: Hospice care in America. 2007 Nov. Retrieved from <http://www.nhpc.org/research>
- Rickerson E, Harrold J, Kapo J, Carroll JT, Casarett D. Timing of hospice referral and families' perceptions of services: Are earlier hospice referrals better? *Journal of the American Geriatric Society* 2005;53:819–823.
- Scanlon, WJ. Medicare: More beneficiaries use hospice; many factors contribute to shorter periods of use. Washington, DC: United States General Accounting Office; 2000 Sep 18. (GAO/T-HEHS-00-201) [Testimony]
- Schockett ER, Teno JM, Miller SC, Stuart B. Late referral to hospice and bereaved family member perception of quality of end-of-life care. *Journal of Pain and Symptom Management* 2005;30:400–407. [PubMed: 16310614]
- Smedley, BD.; Stith, AY.; Nelson, AR., editors. Unequal treatment: Confronting racial and ethnic disparities in health care. Washington, DC: National Academies Press; 2003.
- Teno JM, Shu JE, Casarett D, Spence C, Rhodes R, Connor S. Timing of referral to hospice and quality of care: Length of stay and bereaved family member's perceptions of the timing of hospice referral. *Journal of Pain and Symptom Management* 2007;34:120–125. [PubMed: 17583469]
- U.S. Census Bureau. Census 2000 Summary. 2000 [Retrieved December 23, 2005]. (Files 1 & 3) from <http://factfinder.census.gov/servlet/BasicFactsServlet>
- United States Department of Health and Human Services. A profile of older Americans. 2002 [Retrieved April 26, 2005]. from <http://www.aoa.gov/prof/statistics/profile/profiles2002.asp>
- United States Department of Health and Human Services. Summary of the HIPAA privacy rule. 2003 [Retrieved May 3, 2005]. from <http://www.hhs.gov/ocr/privacysummary.pdf>

**Table 1**

Interaction between responses to started hospice services earlier question and patient demographic characteristics.

| Easier if you started to receive hospice services earlier than you did? | Responded "Yes" frequency (percent) | Responded "No" frequency (percent) | P - value |
|---|-------------------------------------|------------------------------------|-----------|
| Hospice Patient Demographics  |                                     |                                    |           |
| Gender (n=118)  |                                     |                                    | 0.32      |
| Female  | 16 (43.2%)                          | 43 (53.1%)                         |           |
| Male  | 21 (56.8%)                          | 38 (46.9%)                         |           |
| Ethnicity (n=118)   |                                     |                                    | 0.02      |
| Hispanic  | 24 (64.9%)                          | 34 (42.0%)                         |           |
| White   | 13 (35.1%)                          | 47 (58.0%)                         |           |
| Marital Status (n=115)  |                                     |                                    | 0.83      |
| Married   | 19 (52.8%)                          | 40 (50.6%)                         |           |
| Unmarried   | 17 (47.2%)                          | 39 (49.4%)                         |           |
| Religion (n=115)  |                                     |                                    | 0.21      |
| Catholic  | 22 (61.1%)                          | 39 (49.4%)                         |           |
| Protestant  | 5 (13.9%)                           | 7 (8.9%)                           |           |
| None/Other  | 9 (25.0%)                           | 33 (41.8%)                         |           |
| Residence at Start of Care (n=118)                                      |                                     |                                    | 0.12      |
| Own home  | 27 (73.0%)                          | 45 (55.6%)                         |           |
| Children/Extended Family  | 8 (21.6%)                           | 22 (27.2%)                         |           |
| Assisted living   | 2 (5.4%)                            | 14 (17.2%)                         |           |
| Primary caregiver at Start of Care (n=117)                              |                                     |                                    | 0.21      |
| Spouse  | 13 (35.1%)                          | 25 (31.3%)                         |           |
| Children/Extended Family  | 21 (56.8%)                          | 38 (47.5%)                         |           |
| Paid Caregiver  | 3 (8.1%)                            | 17 (21.2%)                         |           |

**Table 2**

Interaction between response to started hospice services earlier question and patient health service factors prior to hospice referral.

| Easier if you started to receive hospice services earlier than you did? | Responded "Yes" frequency (percent) | Responded "No" frequency (percent) | P - value |
|---|-------------------------------------|------------------------------------|-----------|
| Health Services Factors   |                                     |                                    |           |
| Primary Diagnosis (n=118)   |                                     |                                    | 0.25      |
| Cancer  | 11 (29.7%)                          | 33 (40.7%)                         |           |
| Non-cancer  | 26 (70.3%)                          | 48 (59.3%)                         |           |
| Insurance other than Medicare (n=118)                                   |                                     |                                    | 0.38      |
| Yes   | 27 (73.0%)                          | 65 (80.2%)                         |           |
| No  | 10 (27.0%)                          | 16 (19.8%)                         |           |
| Type of Insurance other than Medicare (n=92)                            |                                     |                                    | 0.01      |
| Medicaid  | 14 (51.9%)                          | 16 (24.6%)                         |           |
| Private insurance   | 13 (48.1%)                          | 49 (75.4%)                         |           |
| Hospital inpatient care prior to hospice (n=118)                        |                                     |                                    | 0.72      |
| Yes   | 25 (67.6%)                          | 52 (64.2%)                         |           |
| No  | 12 (32.4%)                          | 29 (35.8%)                         |           |
| Home health services prior to hospice (n=118)                           |                                     |                                    | 0.66      |
| Yes   | 12 (32.4%)                          | 23 (28.4%)                         |           |
| No  | 25 (67.6%)                          | 58 (71.6%)                         |           |
| Regular place or source of health services (n=118)                      |                                     |                                    | 0.08      |
| Yes   | 29 (78.4%)                          | 73 (90.1%)                         |           |
| No  | 8 (21.6%)                           | 8 (9.9%)                           |           |
| Type of place where received most of health services (n=117)            |                                     |                                    | 0.02      |
| Physician's office  | 24 (64.9%)                          | 67 (83.8%)                         |           |
| Clinic or Emergency Department  | 13 (35.1%)                          | 13 (16.2%)                         |           |
| Was the physician the first person to discuss hospice with you? (n=118) |                                     |                                    | 0.03      |
| Yes   | 20 (54.1%)                          | 60 (74.1%)                         |           |
| No  | 17 (45.9%)                          | 21 (25.9%)                         |           |
| Did the physician select or recommend a hospice agency? (n=108)         |                                     |                                    | 0.19      |
| Yes   | 14 (42.4%)                          | 42 (56.0%)                         |           |

| Easier if you started to receive hospice services earlier than you did?               | Responded "Yes" frequency (percent) | Responded "No" frequency (percent) | P - value |
|---|-------------------------------------|------------------------------------|-----------|
| No  | 19 (57.6%)                          | 33 (44.0%)                         |           |
| Prior to hospice referral, did you see advertisements about hospice services? (n=118) |                                     |                                    | 0.11      |
| Yes   | 19 (51.4%)                          | 54 (66.7%)                         |           |
| No  | 18 (48.6%)                          | 27 (33.3%)                         |           |