



Hospice and Palliative Care: Identifying and Profiling Dying Oregonians - *A Summary*

A research project funded by the Collins Medical Trust in the spring of 2000 allowed OHA to interview the caregivers of 35 hospice patients who had died in 1999. The project was a systematic response to an alarming national trend: hospice referrals and admissions were being made later and later in the disease process. While individuals are eligible for most hospice benefits when they have an estimated life expectancy of six months or less, the median length of stay in Oregon, in 1998, was only 18 days.

The purpose of the project was twofold: (1) to identify factors that impact care, negatively and positively, at the end of life; and (2) to identify elements that are most likely to result in effective end of life care.

Two patient groups were selected via random sampling of hospice death records: (1) individuals who were admitted late (within 14 days of death); (2) individuals who were admitted at an optimal time (within 60 to 90 days of death).

The interviews, and the numbers supported by the interviews, revealed two key barriers to effective end-of-life decision making: (1) ineffectual communication between patients and their families and physicians or other health care professionals; and (2) inadequate knowledge or skills on the part of patients and families to advocate for themselves.

A surprising finding of this study was that many short stay hospice patients had been admitted to the hospital 3 to 5 days prior to their hospice admission. The inpatient admissions were prompted by an “event”—a call to the doctor or 911 because of uncontrolled pain, new symptoms, frightening complications, etc. The inpatient admissions led, then, to either an initial terminal diagnosis, or to the realization that it was time to shift from care to prolong life to palliative care.

We believe that most of these “events” could have been prevented.

The nation’s reluctance to talk about death and dying has created a gap: physicians wait for their patients to ask about hospice and other end of life care; patients wait for their doctors to tell them what they need to know when they need to know it. Most American do not recognize a need to take responsibility for the kind of care they get at the end of life.

The results of this study are based upon interviews with patient caregivers (in most cases, surviving family members) and medical record information. The results represent each caregiver’s sense of their loved one’s medical treatment and hospice experience.

The final sampling included the caregivers of 35 patients: 26 (75% of sampling) in group one (<14 days) and 9 (25%) in group 2 (30-90 days). 21 individuals (60% of total study population)

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had cancer diagnoses.

The study sample is consistent with OHA's 1999 hospice data. 45.7% of hospice patients had a mean or average length of stay (ALOS) of <14 days. 16.3% experienced an ALOS of 30-90 days. (These percentages are for the populations who were enrolled in hospice for <14 days and 30-90 days only. They do not represent those hospice patients who were in hospice from 14-30 days or >90 days.) In 1999, 57.2% of hospice patients had cancer diagnoses.

Hypothesis/Results

1. Persons with non-cancer diagnoses (less predictable disease process), spend less time on hospice care than persons with cancer diagnoses.

True.

The hypothesis was confirmed. In group I (< 14 days on hospice), 13 of 26 patients had cancer diagnoses. The ALOS in group I for both cancer and non-cancer diagnoses was 7 days. In group II (30-90 days on hospice) 8 of 9 patients had cancer diagnoses. The ALOS in group II for cancer patients was 67 days.

2. The age of a terminally ill person is a significant factor in determining when he/she opts for hospice care. (The younger the person, the less time spent in hospice before death.)

In general, we found this to be true. For those patients under the age of 65, the median length of stay (MLOS) was 17 days. For those 65+, the MLOS was 23.0 days. When breaking it down further, those aged 65-79 had an MLOS of 18. The MLOS for those patients 80+ years of age was 30.

3. A patient/family is more likely to be receptive of hospice care - and will be admitted to hospice sooner rather than later - when a *physician* initiates or suggests the idea.

This hypothesis was not confirmed overall. Nurses, having initiated the conversation just under half the number of times compared to physicians, registered an ALOS of 35 days. Physicians, 14 days. When separating the groups, the hypothesis holds true for group I (14 days stay). However, the longest length of stay in group II (30-90 days stay) came when nurses first brought up the idea of hospice.

4. Patients with short lengths of stay are more likely to have had a significant change in health which required a hospital stay shortly before their admission to hospice. (Patients without adequate support are more likely to have a crisis.)

This hypothesis was overwhelmingly confirmed. In group I, 12 of 26 patients (46%) were admitted to the hospital 3 days prior to their admission to hospice. 54% of group I (14 of 26) were admitted to the hospital within 5 days of their hospice admission. In group II, 1 of 9 patients (11%) was admitted to the hospital 3 days before their hospice admission. 29% of all 35 patients experienced an "event" requiring hospitalization shortly before enrolling in hospice. We find these numbers to be astonishing. This may indicate a reluctance on the part of the patient to acknowledge or report any decline to the physician or a lack of understanding of the significance of a symptom. It may also indicate a lack of knowledge/awareness, or monitoring of symptoms by the physician.

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5. The more information an individual has about his/her options of care, the more timely their admission to hospice. (Knowledge is power to make decisions).

While this hypothesis held true for group I, the statistical advantage was not significant. All but one of those with treatment options in group one felt the options were fully explained. Of those in group I with options, three patients had curative options. One of the three patients declined curative treatment. Of the two who received treatment, one undertook treatment over three months prior to being admitted to hospice. The second patient was on a treatment schedule until two weeks prior to hospice admission. In group II, of the five with treatment options, one was curative. This patient participated in treatment over three months prior to admittance to hospice. Three others defined their treatment options as life prolonging or improving quality of life.

6. Patients and patient families are more likely to accept a referral to hospice (and be admitted earlier in the disease process) when they have had a previous and positive hospice experience.

There was no significant statistical evidence to support this hypothesis.

Among other questions asked of participants was the question of prognosis accuracy. Results indicated nearly one-half of patients who were given a prognosis, forty-seven percent (47%) said the prognosis was not accurate. Thirty-one (31%) indicated that they felt the prognosis was only "somewhat accurate."

Conclusion/Recommendations

As a result of this study, Oregon Hospice Association has developed the following recommendations for improving effective end of life care:

1. Support existing, and aid in the creation of additional opportunities for prognostic and communication skills training for physicians.
2. Support existing, and aid in the creation of new educational opportunities for physicians in the monitoring and interdisciplinary assessment of patients with a terminal diagnosis.
3. Engage in public education geared toward younger (<65 year old) individuals about a need to plan for/talk about end of life care with physicians/families, as well as general public education on hospice.
4. Create opportunities for community education targeted toward females of all ages. Females are most likely to be identified as primary care givers. The goal of these educational opportunities will be to empower patients and patient families to take responsibility for care at the end of life.
5. Support physician education on patient communication and end-of-life conversations. Offer specific tools to physicians for times when patients are also friends (i.e., bringing in another physician/PA or nurse to co-manage care). Also, help physicians to identify and utilize pain management experts in the care/management of terminally-ill patients.

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6. Educate and enlist the support and help of discharge planners in hospital settings.
7. Educate the public about their rights as they relate to end of life care. Provide *hands on* support in completing advance directives. Offer tools to help them talk with their physician about end of life issues.

These factors will be integrated into future public education and research grant requests by OHA.

The Oregon Hospice Association's (OHA) mission is to promote and ensure access to high quality hospice and comfort care for all Oregonians. Fifty-seven hospice programs provide palliative health care services for terminally ill Oregonians and their families in 48 Oregon communities and counties. OHA's goals and objectives include programs focusing on community awareness, patient advocacy, professional education, technical assistance, and quality assurance. OHA is recognized by the State of Oregon as an accreditation body for hospice programs and shares responsibility with the State for ensuring compliance with hospice laws. OHA is considered a respected resource for expertise on end of life care.