



# HOSPICE INSIGHTS

**INSIGHTS 91: Barriers to Palliative Care and Advance Directives<sup>1</sup>**

**May, 2005**

This subject is no longer something we whisper about, especially with the national attention the Terry Schiavo case received in Florida. *Supporters of Life-Affirming Care at End of Life (SOLACE)* is a coalition of community members and organizations in northern Virginia committed to better end-of-life care. They have recently completed a survey which polled medical professionals regarding “what are the barriers to palliative care and advance directives”? They polled 236 professionals attending a national palliative care conference in Washington D.C. The survey focused on their personal work environment and the barriers they see in that environment.

The survey respondents were comprised of the following disciplines: 71% nurses; 11% social workers, 6% administrators, 4% physicians, 3% counselors, 3% chaplains, and 2% physical therapists. The majority of the facilities represented were hospices (68%). 75% stated they were directly affiliated with a hospice program; 66.7% stated their facility was associated with a hospice program; and 72% stated they had personal experience with hospice. Of those not affiliated with a hospice, 56% reported using hospice services often and only 4% stated they seldom or never used hospice services. Of the group that hardly ever uses hospice, 58% said their patients go home to die often, while 42% said patients go home to die seldom or never.

The results also showed that 74% of the respondents were given a copy of the patient’s advance directives, while 26% were not. 50% of respondents stated pain was the primary reason patients could not go home. 34% said that patients were not referred to palliative care because the family chose not to be.

Respondents were asked whether they agreed or did not agree with the statement “it is a barrier to provide appropriate end-of-life care to a patient when the patient must be first declared dying or terminal to qualify for specialized hospice care”. 82% “strongly agreed” or “agreed” with the statement.

Of the 13 statements the respondents rated the top three barriers to palliative care and advance directives as follows:

1. Physician reluctance to make referrals.
2. Physician lack of familiarity with availability and suitability of hospice.
3. Association of hospice with death.

<sup>1</sup> Feeg, Veronica D., Elebiary, Hoda. *Exploratory study on end-of-life issues: barriers to palliative care and advance directives*. American Journal of Hospice & Palliative Medicine, Vol. 22, Number 2, March/April 2005, pp. 119-124. (May, 2005 *Insights* is a review of this article)

Other findings in the study are as follows:

- Families are unwilling or even refuse to be referred to a palliative care facility;
- A barrier exists when the patient needs to be declared dying or terminal to consider palliative care;
- The association with hospice care and death is so strong that professionals are even reluctant to discuss it even if they know the patient's pain would be better controlled at home with hospice care;
- Patients who are encouraged to make their wishes about end-of-life care in an advance directive are not encouraged to be educated about palliative care and hospice;
- There are misconceptions about hospice as a place instead of a philosophy of care;
- Referrals to hospice are often too late;
- Hospice connotes death;
- There is an impression that hospice is not under the scrutiny of regulations;
- There is a lack of communication between all of the health care providers;
- Lack of consistent standards in hospice care;
- Inappropriate conversations with patients and families about money for hospice care;
- Some hospices are more inclined to accept cancer patients instead of patients with other diagnoses;
- Lack of consistent data collection and reporting;
- Lack of competency standards;
- Belief that referral to hospice takes away hope from the patient;
- Belief that referral to hospice equates with failure by the healthcare provider;
- Lack of education to healthcare providers on the admission criteria for hospice; and
- Healthcare professionals fear of losing control of the management of the patient's care once they are referred to hospice.

*SOLACE* drew the conclusion from this study that more research is needed to improve and expand hospice and palliative care services despite the system, structural, financial, or perceived obstacles. It is also evident that patient education about advance directives is an essential starting place to the discussion about hospice and palliative care.

This survey report is not news to any of us who provide end-of-life care. We have known about the many barriers for years. But when you have a case like Terry Schiavo, it becomes apparent that we all need to take the time and, at the very least, have the conversation with our loved ones about "how we want to be cared for at the end of life" and "who we want to make our decisions for us should we be unable to make them ourselves". That conversation and the writing of one's advance directive may be the greatest gift you ever give to your family.

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#### **Mission Statement**

Hospice of the Twin cities' Mission is to enhance the quality of the lives of our patients and their families by providing respectful care based on maintaining dignity, alleviating physical, psychosocial, and spiritual suffering, advocating for fundamental rights, and affirming the sacred value of life.