

Impact of Pastoral Care Services on Family Decisions and Experience in the Inpatient Hospice Setting

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Abstract

This research examines the role of religion and spirituality in end-of-life treatment at the Stella Maris hospice in Timonium, MD. Throughout the period of four months, twenty family members of hospice patients at the Stella Maris hospice were interviewed. The questions they were asked focused on the role of pastoral care at the Stella Maris inpatient unit and the effect the hospice experience had on their faith, spirituality and/or their views on death. The initial hypothesis was that the availability of pastoral care at Stella Maris hospice was a major influence in family members' decision to choose treatment at Stella Maris. It was also hypothesized that the pastoral care component of hospice care played a crucial role in creating a positive hospice experience for the patients and their families. The results of the research did not strongly support the first part of the hypothesis. The availability of pastoral care was not a large factor in the families' decision to choose hospice care at Stella Maris. However, the results fully confirmed that the pastoral care component was an exceedingly positive force for both patients and their families once they chose hospice treatment at Stella Maris.

Keywords: Religion, Hospice, Pastoral Care

1. Introduction

Hospice care is a relatively new approach to end-of-life care that was developed by Dame Cicely Saunders just over 50 years ago. Saunderson's first profession was nursing, where she witnessed the discomfort that most physicians and many nurses displayed when caring for terminal patients. She noted that many viewed a dying patient as evidence of failure, and would consequently distance themselves emotionally and physically.¹ This experience motivated her to develop a new type of treatment for terminal patients that accepted death as part of life, and focused on maintaining their dignity and comfort. Her approach emphasized pain management as well as the spiritual and emotional care of both patients and their families. At the age of 57 she became a physician and organized the first hospice facility, St. Christopher's Hospice, in London, England in 1967. The first hospice facility in the U.S. was Connecticut Hospice in Branford, CT.¹ Hospice is defined as a form of palliative care, which focuses on making patients more comfortable by reducing their symptoms and pain, rather than curing their underlying illness. Hospice care is palliative care of terminal patients who have less than six months to live.²

Hospice care in the United States is currently receiving renewed interest as a field of medicine. It has been proven that hospice care allows patients to die with dignity, while many people experience needless suffering and loss of dignity with traditional end-of-life care in hospitals.³ Patients who die in hospitals or the ICU show more emotional and physical distress than those who die at home with hospice care; suffering and "dying badly" are common descriptions of the final days of a person's life in a hospital.⁴ Hospice has also been shown to decrease the cost of end-of-life care.⁵ Despite this evidence that hospice is the best form of end-of-life care, it is far from universal. In

2011 the National Hospice and Palliative Care Organization recorded 2,452,000 deaths in the U.S., and only 1,029,000, or 41.9% of those people died in hospice care. Looking into the future, the Centers for Disease Control and Prevention predicts that the number of people over age 65 will increase from 30 million to 71 million between the years 2000 and 2030. Some investigators have begun to ask what makes a patient inclined to choose hospice over traditional end-of life treatment.

Religion and spirituality played a fundamental role in the development of hospice care in the United Kingdom throughout the 1960's. In the early stages of hospice, the Western Christian religious tradition provided the movement with "an ethical foundation and a core set of beliefs".⁶ Over the past forty years, this religious foundation has become less attached to the specific Western Christian tradition and open to each patient's spirituality. The hospice movement defines spirituality as a person's individual "search for meaning".⁶ By acknowledging each patient's spirituality or faith tradition, hospice workers are able to better understand patients as well as increase their quality of life at the end.

There are a few major reasons to explain why people who have a faith tradition experience a better quality of life towards the end. One of these reasons is that organized religion may provide a "reliable social support network throughout the life span, especially in times of increased suffering or crisis, carries positive implications for both physical and psychological functioning".⁷ When a patient is diagnosed they oftentimes undergo a "search for hope and companionship". As he/she begins to experience symptoms, new suffering and change the patient may begin to feel lost or out of control.⁸ This is when a faith tradition may become a source of comfort and strength. It can also reduce their self-blame and increase their acceptance of their illness.⁷ In these ways faith tradition can help patients come to terms with their illness and give them a greater sense of peace.

Clinical pastoral care is a form of spiritual and religious support in which Pastoral Care Practitioners (PCP's) offer an unconditional presence to patients and their families as they navigate through difficult medical decisions. According to the Journal of Asia-Pacific Psychiatry, PCP's help patients and families in the face of grief and unwelcome life challenges. PCP's strive to help families "retain meaning and hope" in these painful situations.⁹ The care that PCP's offer is distinctly *pastoral* because it focuses on "soul-care" in the context of the Christian history. The Journal of Pastoral Psychology states that "soul-care" is the act of fostering "healing, sustenance, guidance, and reconciliation, for not merely individuals but for communities of people".¹⁰ In the clinical setting the community in question consists mainly of the patient's family, but also may include their religious community. In pastoral care, PCP's expand the scope of what "health" means. Instead of viewing patients as lists of symptoms to be addressed and treated, "Individual patients are conceived of not only as physical, mental, and emotional beings, but spiritual ones as well".¹¹ In this way patients are respected and treated as whole beings.

Besides spiritual or faithful fulfillment, there are several other factors that can contribute to a person living and ultimately "dying well". According to Myles N. Sheehan, S.J., M.D.'s article "On Dying Well" there are a few crucial parts of having a peaceful and fulfilling death. The primary part is "living well with God". According to Sheehan "living well with God" means making a daily effort to grow closer to the Lord. The second most crucial factor is making sure a patient's preferences and priorities regarding end-of-life medical cares are discussed and documented through an advance directive. However, the national average of people with advance directives recorded in 2011 was only forty five percent.² The lack of advance directives places additional stress on the family members during the decline of the patient. The task of putting the patient's illness into perspective has traditionally fallen into the hands of the physicians. However in a 2005 AARP survey of Massachusetts's seniors, "less than 20% stated that they had discussed their end of life wishes with their physicians".¹²

Previous studies have focused on demographic characteristics of hospice patients, such as education, race, religion, socioeconomic level, and whether or not their doctors receive education about hospice. In my study I wanted to look at the decision to die in hospice as a choice made by individuals based on personal factors, and not determined by demographic factors. Nothing is more personal than spirituality, and it seemed like a good first place to look. My hypothesis was that the availability of spiritual counseling from pastoral care was a major factor in the decision of patients and their families to choose hospice care, particularly care at Stella Maris. I also predicted that the pastoral care component of hospice care played a crucial role in creating a positive hospice experience for the patients and their families.

2. Methods

It is important for me to note that my initial plan of interviewing patients at the Stella Maris hospice was altered once I proposed my project to the pastoral care staff at Stella Maris. In my conversations with them, it soon became clear that it would not be possible for me to interview patients because the vast majority of them are sedated or otherwise in no condition to carry on a lengthy interview. Instead of interviewing patients, we decided that it would be best for me to interview the patients' families members.

Interview questions were reviewed and approved by the Institutional Review Board of Loyola University Maryland and the staff of Stella Maris. These questions explore the role of religion or spirituality in the treatment of the patients with a focus on the impact of pastoral care. The answers to the interview questions can be found in the results section below. For the five months prior to the project, I volunteered weekly on the hospice floor. The chaplains and volunteer coordinator introduced me to patients' family members who were willing to be interviewed for the project. For each interview I introduced the research objectives, explained the consent form, and then proceeded with the questions. Ultimately 20 family members of hospice patients were interviewed. Once the interviews were complete, the data was then analyzed using qualitative analysis methods.

3. Results

Question 1. How important was the availability of pastoral care in your decision to place your family member in hospice care?

Sixty five percent of the family interviewees stated that the availability of pastoral care at Stella Maris hospice played large role in the family's decision to place their relative at Stella Maris. One trend that did occur was that families who were Catholic or Christian found it comforting to learn that pastoral care was available to both them and their loved one once they were placed in hospice treatment. For thirteen family members, learning that there was a chapel on the first floor of the facility and they had the option to attend mass every weekend played an important role in why they chose Stella Maris. The seven remaining interviewees stated that the fact that Stella Maris was a faith based hospice played no role in their decision to place them in Stella Maris.

Question 2. What role has the pastoral care program played in your family's experience at Stella Maris? Can you describe how a typical meeting with them goes? How do you feel after the meetings?

One hundred percent of the family members found the pastoral care representatives including the priest, chaplains and secretaries comforting and understanding. One family member stated, "They are incredibly supportive. They know when you need your space and when you need your hug. They know how to respond quickly and effectively to the needs of the family."

Most family members said that a chaplain visited their loved one and the rest of the family regularly. The meetings with the chaplains varied every day. If the family was interested in socializing with the chaplain, the visit could last up to an hour and a half. During longer visits the topic could vary from funeral arrangements for the patient to how the family was coping with the patients treatment. If the family was tired or busy spending time with their loved one, the chaplain would quickly stop in to greet everyone and ask if there was anything they could bring the family or make them more comfortable.

4. Discussion

The results of my research did not support my hypothesis that the spiritual component of hospice care was an important factor in a patient's family's decision to place their loved one into the hospice program. Only thirteen out of the twenty interviewees stated that the availability of pastoral care influenced their decision to choose Stella Maris. Strong evidence of this hypothesis would have shown eighty percent, or sixteen out of the twenty, interviewees stating that pastoral care support was a deciding factor in their decision to choose Stella Maris. The results did support my hypothesis that spiritual counseling plays a major role in the positive experience reported by patients and their families once they are receiving care. Once a patient was placed in hospice care at Stella Maris, pastoral care played a significant role in providing support and comfort to patients and families, both in expected and unexpected ways.

Despite frequently not knowing about the availability of pastoral care until arrival, eighty five percent of the family members stated that the department had a strongly positive impact on their experience with hospice. Family members looked forward to meeting with a chaplain on a daily basis. These visits could last for a couple minutes to over an hour. Their conversations with the family members could range from cooking tips, to their children's activities, to their issues with the Catholic Church. They were willing to talk about anything or just sit and be with the families if that was what they preferred. Religion was not the topic of discussion unless the family brought it up. Almost all of the interview respondents stated that they looked forward to the pastoral care visits and found the chaplains to be welcoming and comforting. Many mentioned their appreciation of the fact that the pastoral care program did not require them to be Roman Catholic or encourage conversion to Catholicism.

Through my interviews, I found that the chaplains from pastoral care do help console and comfort patients and families, as expected. I also learned that they capably act as a valuable liaison between patients, families, and the medical care team. Many interviewees stated that the chaplains helped explain their loved one's previously mysterious diagnosis in laymen's terms. In another unexpected part of their role, chaplains were also able to help families make funeral and other final logistical arrangements for the patient. In this way they were able to give concrete guidance to the family and relieve them of some of the stress of making these arrangements.

The interview results support my hypothesis that pastoral care plays a crucial role in making hospice care so successful at helping terminal patients to "die well", but suggest that even among those who enter hospice, there is less than widespread awareness of the existence of pastoral care. The combination of these results then beg the question, would more families and patients be comfortable choosing hospice care if they knew? In fact, several interviewees even stated that if they had had the opportunity to meet the pastoral care representatives in advance, it would have had a positive influence on their decision, especially if they had received reassurance about the lack of evangelical emphasis.

It is interesting to consider what difference it would make if patients and families were first introduced to the benefits of hospice care by a pastoral care representative. A conversation with a spiritual director or chaplain about hospice eligibility would be more informative for the family and more reassuring. Many respondents said they knew that they had made the right choice after just the first meeting with a pastoral care representative on arrival at the hospice. What if this meeting happened before they made the decision?

It is important for me to mention the limitations of this research. Although I adhered to quantitative methods of results analysis, this was far from an objective study. I conducted and transcribed all the interviews myself. I was only able to interview those family members who were capable and willing to speak with me. Others were too emotionally distressed or overwhelmed, and refused. I had originally wanted to interview patients, but most were incapable of being interviewed, due to strong sedatives, pain medication, or the effects of their terminal illness. On the other hand, the family members I spoke to had all been the primary decision makers who chose hospice care, and all had spent nearly as much time there as their loved ones. The fact that I performed this project at a Catholic denominated hospice impacted not only the selection of interviewees available, but also the way in which family members responded. The majority of them were Christian or Roman Catholic, with at least some involvement in their faith. Also, since I was working at a hospice, I did not get to interview anyone who chose to decline hospice care and hear why they chose not to undergo hospice treatment. This is a subject that I would be interested in exploring in more depth. After performing this study, the question I would like to pursue further would be what factors made patients and/or their families decide to decline hospice care?

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