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# Evaluating Hospice Care: The Family's Perspective

by Linda Clark, Susan Jones, Doris Thayer, and Beverly Cook

**C**aring is the basic ingredient of hospice services. It was this feeling of caring for others that motivated individuals to develop and implement a home-based hospice program in Bowling Green, Kentucky, in 1981. The program was composed entirely of volunteers who were interested in the care of terminally ill patients and their families. To ensure the quality of care for the hospice program, each volunteer, both nurse and lay, completed an intensive 40-hour hospice training program. However, the varied backgrounds of the volunteers, both in education and experience, indicated the need for specific criteria and standards, frequent evaluation of care, and proper documentation of services. With these goals in mind, the executive board directed the development of a Criteria and Standards Committee.

The committee's mission was to develop and oversee a quality assurance program for hospice care. This included the development of care standards, policies, and procedures; job descriptions; evaluation of patient care and the documentation of that care; and development and implementation of quality assurance audits. Thus, the committee's overall goal was to maintain and improve patient/family care through a comprehensive evaluation program.

Audits were developed and implemented for the hospice medical records, nurse and lay volunteers, the interdisciplinary team, and the executive director. These proved valuable in identifying strengths and weaknesses in the care provided for hospice patients and families. However, several questions continued to surface in our regular meetings. Did we meet our standards as perceived by the family? How did the family feel about the care

provided? Did the nurse and the lay volunteers improve the quality of life for the patient as perceived by the family? The committee felt a strong need to obtain information from the family's perspective in order to effectively evaluate the hospice program. Since the family and patient are viewed as the hospice "unit of care" it was felt that the family

*After the death of the hospice patient, the family can provide valuable information for the evaluation of hospice care and services. A family evaluation form facilitates this evaluation.*

could, after the death of the identified patient, provide valuable evaluation of hospice care and services.

Review of the literature gave little insight on family evaluation of home-based hospice care. There are a limited number of documented studies in which the relatives completed an evaluation form, but most of the literature points out the need for the family's involvement in the evaluation of services given to the patient. Therefore, the limited information in the literature served as an incentive to the development and implementation of a family evaluation form.

An evaluation form was developed for both the nurse and lay volunteer. Criteria used

were positive statements of the roles and functions of the volunteers. A five-point scale with options to be circled was the chosen format, with space provided for general comments. (See Figure I and II.) After several revisions, the executive committee approved and suggested the form be field tested for 10 families.

The evaluation forms were mailed by the executive director to the primary care giver of 10 randomly selected families in Spring 1985. A self-addressed, stamped envelope was included to increase the return rate. Six nurse volunteer forms and four lay volunteer forms were returned. General comments made by the family were positive for both the nurse and lay volunteer.

One hundred percent of the respondents reported that they strongly agreed or agreed that the nurse volunteer clearly explained the hospice program, assisted in obtaining needed supplies, listened, explained the physical changes to expect, took time to talk, and provided information regarding other needed support agencies. Eighty-three percent of the families strongly agreed or agreed that the nurse volunteer assisted with symptom control, whereas 17% checked non-applicable. Sixty-seven percent of the relatives reported that the nurse informed them of her plan of care whereas 33% were undecided or checked non-applicable for this criterion. Only five relatives responded to three criteria with 100% agreeing or strongly agreeing that the nurse continued to contact them after the death of their loved one and 100% reporting that the nurse communicated with other individuals on their behalf. Sixty percent of the respondents were undecided if the nurse invited them to attend team meetings, whereas 40% checked non-applicable for this criterion.



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One hundred percent of the families strongly agreed or agreed that the lay volunteer listened to their opinions and suggestions, was available to talk, and provided information regarding other support agencies. Seventy-five percent of the respondents agreed that the lay volunteers communicated with other individuals and agencies on their behalf with 25% reporting that this task was non-applicable. Fifty percent of the families strongly agreed that the lay volunteers assisted with household functions whereas 50% of the families were undecided or reported that the task was non-applicable. Fifty percent of the families reported that the lay volunteer continued to contact them after the death of their loved one whereas 50% disagreed with this criterion. Fifty percent of the respondents strongly agreed that the lay volunteer assisted them in obtaining needed supplies whereas 25% were undecided and 25% disagreed with this criterion. Only three families responded to the criterion that referred to the lay volunteer discussing steps to take at the time of death with 33% disagreeing and 67% undecided or checking non-applicable.

The second family evaluation audit was conducted in April 1986. The identical evaluation form used in the first audit with the addition of a statement regarding the nurse and lay volunteer maintaining confidentiality was sent by the executive director to the primary care giver of 12 families. One hundred percent of the respondents thought that the nurse and lay volunteer listened to their opinions and suggestions and maintained confidentiality. The primary care givers felt that they were informed about the plan of care, that the volunteers were available when needed and had time to talk, and that they obtained needed supplies. One problem, which was also noted on the original audit, related to the nurse's invitation to the family members to attend team meetings. Thirty-seven percent were undecided or disagreed that they had received the invitation. Seventy-five percent of the respondents felt that the nurse explained the physical changes to expect and continued to contact the family after death of the hospice patient. Forty to sixty percent of the respondents felt that the lay volunteers' role of providing information, contacting other agencies, and discussing the steps to take at the time of death was non-applicable. General comments received on the survey were positive and supportive of the hospice home-based program.

The family evaluation audit has provided valuable information to our home-based hos-

## Family Evaluation Form—Nurse Volunteer

Figure I

April, 1986	SA	A	U	D	N/A	TOTAL
<b>Nurse Volunteer</b>						
1. The Hospice Program was clearly explained to me on the nurse's first visit.						
2. The nurse assisted me in obtaining the supplies I needed.						
3. The nurse invited me to attend team meetings.						
4. The nurse informed me of her plan of care.						
5. The nurse listened to my opinions and suggestions.						
6. The nurse assisted with symptom control, i.e., pain, comfort, nausea.						
7. The nurse taught me techniques for caring for my loved one, i.e., turning, skin care, giving medication, using special equipment, nutritional counseling.						
8. The nurse explained the physical changes that occur with a terminal illness.						
9. The nurse had time to talk and was available when needed.						
10. The nurse provided information regarding other agencies that I could use.						
11. As needed, the nurse communicated with other individuals and agencies on my behalf.						
12. The nurse discussed with me the steps to take at the time of death and assisted with funeral plans.						
13. The nurse continued to contact me after the death of my loved one.						
14. The Hospice Nurse maintained confidentiality.						
Comments:						

## Family Evaluation Form—Lay Volunteer

Figure II

	SA	A	U	D	N/A	TOTAL
<b>Lay Volunteer</b>						
1. The lay volunteer assisted me in obtaining the supplies I needed.						
2. The lay volunteer listened to my opinions and suggestions.						
3. The lay volunteer provided information regarding other agencies available.						
4. As needed the lay volunteer communicated with other individuals and agencies on my behalf.						
5. The lay volunteer was there when I needed him/her and had time to talk.						
6. The lay volunteer assisted with household functions, i.e., babysitting, transportation, grocery shopping.						
7. The lay volunteer discussed with me steps to take at the time of death and assisted with funeral plans.						
8. The lay volunteer continued to contact me after the death of my loved one.						
9. The lay volunteer maintained our confidentiality.						
Comments:						



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pice program. Analysis of data provided direction to initiate changes in several areas: revision of evaluation tool, clarification of the functions of the nurse and lay volunteers, and the implementations of specific interventions with the hospice patients and their families.

The family evaluation is being continuously revised. After the committee's second audit, the option "undecided" was deleted from the tool, leading the family to provide more specific information. In the future, families will be asked to evaluate the functions of the volunteers based on four options: strongly agree, agree, disagree, and non-applicable.

Based on the information obtained from the most recent audit, the committee has recommended that two functions be deleted from the job description of the lay volunteer. It is more appropriate for the hospice nurse to inform families of community resources and to discuss with the families steps to take at the time of death. Thus, the family evaluation tool has helped clarify the roles of the volunteers.

A specific intervention that resulted from the family evaluation is that families are now strongly encouraged to attend the interdisciplinary team meetings. The committee's

first audit revealed that families did not perceive an invitation to attend these meetings. Since the basis of hospice care is "care" planned by an interdisciplinary team, the process is actually incomplete without the family's input. The families are the primary care givers and have valuable contributions to the interdisciplinary team as the plan of care that they are expected to implement is formulated at these meetings. During the past few months there has been an increase in attendance of family members at the interdisciplinary team meetings.

The feedback obtained from the family evaluation tool has stimulated many ideas regarding future changes that would improve the quality assurance of our hospice program. We anticipate revisions of the form to encourage more comments by the families. The committee desires both positive and negative comments. To solicit negative comments a statement will be added asking the families what they would desire hospice to change.

One committee goal is to study the role of the physician in the hospice program as perceived by the family. One study reported that about 40% of the families had difficulty getting information from physicians. Barzelai,

L.P. "Evaluation of a Home Based Hospice." *Journal of Family Practice*, 122 (no. 2, 1981): 241-45). As the evaluation tool reveals problems areas, focused audits will be conducted as appropriate.

In summary, the family evaluation tool has provided valuable information to our hospice program. This information could only be obtained from families, the primary care givers of hospice patients. The information they have so generously shared has provided rationale and direction for change. As the committee continues to perfect the evaluation tool and implement these changes, we feel we have had a small part in improving the care of our hospice patients and their families. Caring is the basis of a hospice program; through a quality assurance program involving family input we can continue to improve that care. □

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