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Program Evaluation of
St. Mary's Hospice
Lyn M. Harper
University of Richmond

Running Head: PROGRAM EVALUATION

Abstract

The purpose of this program evaluation was to identify the needs of families of terminally ill patients and their perceptions of their loved ones needs. Another objective was to determine if these needs were met in St. Mary's Hospice Program and who responded to these needs. Subjects consisted of ten randomly chosen family members, nine females and one male, ages forty to eighty, who had lost loved ones enrolled in the hospice program at least six months prior to the study. The subjects had not received volunteer bereavement care prior to the evaluation. Responses to need questionnaires and interviews indicated that family members were positive about the hospice program and were most concerned about the patients' comfort and support for the family. Also, family members generally felt that these needs were always met in the hospice program, and various members of the hospice interdisciplinary team responded to these needs. It is hoped that examination of the comments and suggestions of the family members will allow for future interventions that will ultimately improve patient and family care in St. Mary's Hospice Program.

Program Evaluation of

St. Mary's Hospice

St. Mary's Hospital is run under the auspices of the Sisters of Bon Secours. The development of a hospice program at St. Mary's grew out of the Sisters' concern for the special needs of dying patients and their families. The hospice program at St. Mary's opened in July of 1983, and it offers specialized services for those patients who have no hope for cure or remission through other medical services. ("Hospice brochure," 1983).

St. Mary's Hospice Program exists to provide wholistic comfort and supportive care for patients and their families. Although the form of comfort care may vary with individual patients, the emphasis is on the whole person. Resuscitation is not appropriate in hospice. Patient care in the hospice program is an active process which relies more on symptom control and human relationships than on acute care techniques. Care is continuous throughout the dying process and the family's bereavement period. St. Mary's Hospice exists to bring dignity and wholeness to dying patients and their families, to relieve their pain and fear, and to bring quality and peace to the last days of life ("Hospice brochure," 1983).

The hospice program at St. Mary's is a department within the hospital. Thus, the program is both hospital and home health service based. This integration assures patients of continuity and quality of care. In the hospice program, emphasis is placed upon patients remaining at home as long as possible. Many patients prefer to die at home, and their illnesses do not necessarily require hospitalization. If hospitalization becomes necessary, the hospice patient stays in a special unit of St. Mary's Hospital which contains three private inpatient rooms, a family lounge, and a kitchen. The inpatient rooms are also designed to accomodate family members. An on-call system is available twenty-four hours a day, seven days a week. Patients and their family members may have questions answered and home visits arranged, if necessary ("Hospice brochure," 1983).

Patient care in St. Mary's Hospice Program is given by an interdisciplinary team composed of medical professionals and trained volunteers. The team includes the program director, a pharmacist, a physician advisor, a physical therapist, a spiritual care coordinator, a social worker, and home and inpatient nurses. Other personnel become involved as they are needed. A

physician of the patient's choice develops a plan of care for the patient. Hospice volunteers are trained, through educational and experiential training, to augment the professional and family care providers. The coordinated team addresses the emotional, spiritual, social, and physical needs of the patient ("Hospice brochure," 1983).

A patient's personal physician may refer a patient to the hospice program when all possibilities for a cure or for prolonging life are exhausted. This service can be prescribed when the patient is distressed or in pain, or when the family needs such physical and spiritual support. A person having a terminal illness and a prognosis of six months or less to live is eligible for the hospice program. The patient and care-giver must also live within a thirty-mile radius of St. Mary's Hospital to insure eligibility for home health care services. Hospice patient admissions are based on informed consent, and the patients, their families, and their physicians mutually agree that the patient will enter the program ("Hospice brochure," 1983).

Given the importance of families in the total hospice patient care process, the purpose of this research is to identify the needs of families of terminally ill patients and their perceptions of their loved ones' needs. It

will also be assessed if these needs were met in the hospice program at St. Mary's Hospital and who met these needs. It is hoped that examination of the suggestions, ideas, and comments of family members will allow for future interventions to: decrease anxiety; increase reassurance; improve cooperation, rapport and mutual understanding; and ultimately improve patient and family care in St. Mary's Hospice Program.

Method

Subjects

Subjects consisted of ten randomly chosen family members, nine females and one male, ages forty to eighty, who had lost loved ones enrolled in St. Mary's Hospice Program at least six months prior to the study. All of the subjects lived in suburban areas of a medium-sized southern city. The subjects were voluntary participants, and they had not received volunteer bereavement care prior to the evaluation.

Materials

A self-report need questionnaire based on the work of Abt (1983) was used. The questionnaire listed thirteen needs (support of family members, to have questions answered honestly, to be reassured that the best possible care is being given to the patient and to

be called at home if there were any changes in the patient's condition, to know exactly what is being done for the patient and to have specific facts concerning the patient's progress, to know that the patient is comfortable, to be told about how the patient is going to be treated medically, to feel that the hospice personnel care about the patient, to have explanations given in understandable terms, to know why things are being done for the patient, to feel that there is hope, to know the patient's chances for recovery, to talk about the patient's survival, to have time away from the patient) in three categories: order of importance; who was responsive to the needs; and to what extent the needs were met. The questionnaire also contained a personal data section and the rationale for the study (see Appendix I). A series of interview questions was also used. Interview questions were grouped into six categories: hospice team members, hospice program, patient, care-giver, death, and overall response to the hospice program. The questions concerning hospice personnel referred only to "hospice team members" (see Appendix II).

Procedure

Interviews were scheduled in mornings or evenings at the convenience of the experimenter and the subjects and,

with two exceptions, were conducted in the homes of the participants. One family member was interviewed per session. Approximately two hours were allowed for each session, but the subjects were given as much time as they needed to complete the interview.

The objectives of the evaluation were explained to the participants. Subjects were first asked to complete the need questionnaire using the same response more than once, if necessary. They were given the option of filling out the questionnaire at their convenience and then returning it to the experimenter. Subjects were then asked to respond, in as much detail as they desired, to a series of questions asked by the experimenter. Responses were recorded on paper during the interview.

Results

Personal Data

Responses to the personal information questions indicated that three subjects were retired, four were in business occupations, two worked in the field of education, and one managed a household. Five of the survivors were spouses of their deceased family members, two were children, one was a sibling, and two were neices. One subject held an advanced degree, three were college graduates, two had attended college for one year, two had business degrees, and two graduated from high school.

The hospice patients ranged from sixty to ninety-three years of age. Seven patients were retired and three were homemakers. One patient held a professional degree, two were college graduates, one had a business degree, and five were high school graduates. Nine of the patients were diagnosed as having cancer; one patient had kidney stones and other related problems. Five of the patients died in St. Mary's Hospital, and five patients died at home. Patients were in the hospice program from three days to eight months with an average of two months. Of these patients, four were hospital inpatients at some point in their hospice involvement. The average inpatient stay was two weeks, with a range of one day to two months.

Need Questionnaire

Response percentages were calculated for each of the thirteen needs in each of the three categories.

Ninety percent of the subjects reported that the need for support of family members was most important. Ten percent of the subjects felt that support was important. This need was met by doctors (30%), a combination of care-givers other than doctor and nurse (30%), other relatives (20%), clergy (10%), and social workers (10%). Ninety percent of the subjects said that the need for support of the family members was met throughout their hospice involvement, and ten percent said that this need

was met most of the time.

The need to know what was being done for the patient and to have specific facts about the patient's progress was ranked as most important by eighty percent of the family members, and very important by the rest of the subjects. Doctors (20%), nurses (10%), a combination of doctors and nurses (60%), and other combinations of care-givers (10%) responded to this need. Eighty percent of the subjects felt that the need for factual information was met all of the time, and twenty percent said that this need was met most of the time.

The need to know that the patient was comfortable was ranked as most important by eighty percent of the family members, and very important by twenty percent of the subjects. Nurses were responsive to this need (50%), as were doctors (30%), and other combinations of care-givers (20%). Most family members stated that this need was met all of the time (80%). The remaining twenty percent of the subjects indicated that the need for knowledge of the patient's comfort was met most of the time.

Eighty percent of the subjects felt that the need to know the patient's chances for recovery was most important, and twenty percent felt that this need was very important. This need was met by doctors (70%),

nurses (10%), and a combination of doctors and nurses (10%). Ten percent of the subjects said that no one met this need. This need was met all of the time for seventy percent of the family members, some of the time for ten percent of the subjects, and none of the time for twenty percent of the subjects.

For seventy percent of the family members, the need to have questions answered honestly was most important. Others indicated that the need was very important (20%) and important (10%). Seventy percent of the subjects indicated that questions were answered honestly all of the time; thirty percent felt that this need was met most of the time. Doctors were most often responsive to this need (80%), followed by social workers (10%), and other combinations of care-givers (10%).

The need to know how the patient was to be treated medically was ranked as most important by seventy percent of the participants and very important for thirty percent. Ninety percent of the subjects reported that this need was met all of the time and ten percent reported that the need was met most of the time. Doctors were responsive to the need (90%), as were other combinations of care-givers (10%).

Seventy percent of the family members felt that the need for reassurance about the quality of medical care and

knowledge of changes in the patient's condition was most important. Twenty percent ranked the need as very important, and ten percent labelled the need important. Reassurance was provided by doctors (40%), doctor and nurse combinations (30%), nurses (20%), and home health nurses (10%). This need was met all of the time for ninety percent of the subjects and most of the time for ten percent of the subjects.

The need to have explanations given in understandable terms was ranked as most important by seventy percent of the participants, very important by twenty percent of the participants, and important by ten percent of the participants. Ninety percent of the subjects reported that the need for understandable explanations was met all of the time; ten percent felt that the need was met most of the time. Doctors (30%), doctor and nurse combinations (30%), other combinations of care-givers (20%), nurses (10%), and others (10%) responded to the need.

Seventy percent of the subjects said that the need to know why things were being done for the patient was most important. Thirty percent of the subjects felt that this knowledge was important. This need was met by doctors (40%), nurses (20%), a combination of doctors and nurses (20%), and other care-giver combinations (10%). Seventy

percent of the participants reported that the need was always met, and thirty percent said that this need was met most of the time.

The need to feel that there was hope was ranked as most important by seventy percent of the family members, very important by ten percent, important by ten percent, and slightly important by ten percent. Seventy percent of the subjects always had hope, and thirty percent felt that there was hope some of the time. This need was met by doctors (30%), clergy (20%), other combinations of care-givers (30%), friends (10%), and no one (10%).

Sixty percent of the subjects indicated that feeling that the hospice personnel cared about the patient was most important. Twenty percent of the subjects felt that the need was very important, and twenty percent felt that the need was important. Clergy (30%), doctors (20%), other combinations of care-givers (20%), others (20%), and volunteers (10%), responded to this need. All of the participants reported that this need was met throughout their hospice involvement.

The need to talk about the patient's survival was ranked as most important by sixty percent of the family members, very important by twenty percent, important by ten percent, and slightly important by ten percent. This need was met all of the time (70%), most of the time (10%),

some of the time (10%), and none of the time (10%). The need to talk about survival was responded to by doctors (60%), other combinations of care-givers (20%), nurses (10%), and friends (10%).

The need for "time-off" away from the patient was ranked as most important by thirty percent of the participants, very important by ten percent, important by ten percent, slightly important by twenty percent, not important by twenty percent, and least important by ten percent. Friends (30%), volunteers (20%), other care-giver combinations (20%), doctors (10%), social workers (10%), and paid care-givers (10%) responded to the need for time away from the patient. Eighty percent of the subjects felt that this need was met all of the time, and twenty percent said that the need was met some of the time.

Interviews

Team Members

Subjects felt that hospice team members, with the exception of two physicians, were readily available to them. Family members reported that team members were sensitive, able to discuss important concerns, candid, and open, and that they took time to listen to family concerns. With two exceptions (physicians), team members were

thoughtful and considerate communicators and family members felt comfortable talking to them. All participants said that, when it was applicable, team members helped the family make important decisions. Family members depended primarily on doctors for their information, as well as nurses and social workers. All subjects responded favorably about their overall experiences with hospice team members. Subjects used the following words to describe their experiences: 'good,' 'excellent,' 'very effective,' and 'very good.'

Hospice Program

Six subjects used the hospice on-call service. One participant expressed dissatisfaction with the service, but most subjects said that the on-call service was very effective in answering their questions and arranging visits. Subjects also reported that the hospice inpatient component reached its goal of getting the patient and family members physically and emotionally stable enough to go home when applicable. Three subjects stated that the hospice program would have been more helpful to them if they had been involved with the program earlier in the stages of illness. All ten subjects felt that their involvement with the hospice program made their experiences with terminal illness

easier to bear than if they had not participated in the program.

Patient

Four family members reported that severe pain during the final stages of death was a major problem for patients. All subjects said that pain was adequately controlled at home and in the hospital. Pain medication was given to the patients when they were in pain, thus a specified schedule was not always followed. Two patients also had difficulties breathing. Six patients were anorexic, and one patient experienced problems resulting from radiation treatments. Two patients also expressed fears of painful, slow deaths, and one patient was afraid to be left alone. All subjects felt that the hospice team members made every effort within reason to meet the patients' emotional, spiritual, medical, and physical needs. All of the participants said that this care was continuous and consistent and they felt that the hospice personnel genuinely cared about the patients.

Seven patients were alert enough to respond to their care in the hospice program: these patients were satisfied with the program and were glad that they were involved with the program. All subjects felt that actions taken by the hospice team members were in the best

interest of the patient and that team members were effective in offering support to the patients.

Death

In the two situations where it was applicable, hospice team members helped the patient deal with death. Family members reported that team members were supportive of the patient and family when death was expected within a few days. One subject said that although the patient and family members knew that death in a few hours was inevitable, one of the team members would not accept the upcoming death. In the six cases where it was applicable, subjects were satisfied with the assistance in planning for death that they received from team members. The family members also said that they were effectively supported by team members in the aftermath of death. In all cases, at least one representative from the hospice team attended the funeral. Also, all ten subjects kept in contact with either their volunteers or other hospice personnel.

Care-giver

Subjects reported that, as care-givers, they administered medications and oxygen to the patients, positioned the patients in bed, assisted with toileting, bathed the patients, transported the patients inside and

outside the home, fed the patients, and assumed major responsibility for the housework. At home the care-givers were assisted by volunteers, home health nurses, clergy, friends, physicians, extended family, and private duty nurses.. Friends, volunteers, and home health nurses provided the most support to the family members. Most assistant care-givers spent their time sitting with the patients, and their duties also included meal preparation, shopping, and transportation. One care-giver reported having trouble with one of the assistant care-givers, but most subjects felt that the assistants were an integral part of the total hospice effort. Five care-givers stated that they experienced problems during the patients' illnesses. These problems included loss of sleep, exhaustion, and illness.

Evaluation

None of the family members had criticisms (other than the mentioned minor incidents) regarding the hospice program or its personnel. Subjects' suggestions for the future included: developing an extensive bereavement care program, educating doctors and nurses about the concept of hospice, increasing fundraising for the hospice program, and rotating personnel to avoid burnout.

Discussion

Personal Data

Responses to the personal information questions indicate that the typical patient in St. Mary's Hospice Program is a seventy year-old, retired, male high school graduate. He has a diagnosis of cancer and is in the program for two months. Approximately two of these weeks are inpatient hospital days. The patient will most likely die as an inpatient. The typical care-giver is the wife of this patient. She is a college graduate or holds a business degree, and she works outside the home.

Need Questionnaire

The family members most often ranked the following needs as most important: support of family members, the need to know what is being done for the patient, the need to know that the patient is comfortable, and the need to know the patient's chances for recovery. These needs indicate that the goals of the hospice program, i.e. wholistic comfort and supportive care for terminal patients and their families parallel the qualities and services that the family members are seeking in the hospice program. The least important needs were the need for "time-off" away from the patient, the need to talk about the patient's survival,

and the need to feel that the hospice personnel cared about the patient. Thus, family members seem to be aware of the patients' prognoses, and they want to be with their dying loved ones as much as possible.

Ironically, the need to feel that hospice personnel cared about the patient was met throughout the hospice involvement for all subjects, thus the hospice team's concern for the patients and families is evident in their care. The other twelve needs (support of family members, to have questions answered honestly, to be reassured that the best care possible is given to the patient and to be alerted about changes in the patient's condition, to know what is being done for the patient and to have specific facts concerning the patient's progress, to know that the patient is comfortable, to be told how the patient is going to be treated medically, to have explanations given in understandable terms, to know why things are being done for the patient, to feel that there is hope, to know the patient's chances for recovery, to talk about the patient's survival, and to have "time-off" away from the patient) were met all of the time for a majority of the subjects. Thus, the hospice program addresses a wide variety of patient and family needs, and its goal of

meeting these needs is often reached. Patient and family needs were most often met by doctors and by doctor and nurse combinations. Needs were also met by clergy, social workers, other relatives, a combination of care-givers other than doctors and nurses, volunteers, home health nurses, friends, and others. The hospice program, then, reaches its goal of providing care through an interdisciplinary, coordinated team of medical professionals and trained volunteers. Friends and relatives of the patient also augment the team effort.

Interviews

Subjects reported that, for the most part, hospice team members were sensitive, thoughtful communicators who were willing to take time to listen and discuss important concerns with the family members. All participants responded favorably about their overall experiences with team members. Thus, the team members showed their concern about the patients and family members and performed their jobs effectively. Generally, family members were satisfied and pleased with the hospice program. All subjects reported that their involvement with the program lessened their burdens during the difficult period. Thrity percent of the subjects felt that the program would have been more

helpful to them if they had been involved with the program earlier in the illness.

Family members stated that pain was adequately controlled both at home and in the hospital. Patients also faced other problems, such as breathing difficulties and fears. All participants felt that team members did their best to meet the patients' emotional, spiritual, physical, and medical needs, and that care was consistent and continuous throughout their hospice involvement. All of the patients who were alert enough to respond were glad that the hospice program had been a part of their last days of life. Thus, the program is also reaching its goal of bringing quality to the last days of patients' lives.

When it was applicable, team members helped patients and family members deal with and plan for death. Family members also felt that team members effectively supported them after the death event.

As care-givers, the subjects performed a variety of duties for the patients. Care-givers were most often assisted by friends, volunteers, and home health nurses. Assistants usually sat with the patients, but they also performed other tasks. Most subjects said that the assistant care-givers were an important component of the

total hospice effort. Again, the hospice effort is interdisciplinary and offers support to family members, as well as to patients.

Family members cited no major criticisms of the hospice program or its personnel. Most subjects offered only praise for the hospice program, and many felt that they would not have survived the ordeal of death without the concern and support of the entire hospice team. Subjects' suggestions for the future included: developing an extensive bereavement care program, educating doctors and nurses about the concept of hospice, increasing fundraising for the hospice program, and rotating personnel to avoid burnout. A specific program of bereavement care has been developed for the hospice family members. Also, a separate study is currently being conducted to identify areas of need for the education of hospital personnel. In this way, it is hoped that misconceptions about the hospice concept will be eliminated and more physicians will consider the hospice program for their patients. More education for community members is also planned with the hope that the hospice program will reach out to help more people.

The views expressed by the interviewed families

strongly suggest that the hospice program at St. Mary's Hospital is effective in offering wholistic comfort and supportive care for patient and their families, and in bringing dignity and wholeness to dying patients and the dying process. Also, patients' pain and fears are alleviated. The patients and family members' emotional, spiritual, and personal needs are met by the program. For the most part, quality and peace are brought to the last days of life through care provided by a coordinated interdisciplinary team of medical personnel and volunteers and the patients' friends and loved ones. The hospice personnel should continue to manage and operate the hospice program as they do now. Individuals on the hospice team should also strive to improve their communication with and understanding of hospice patients and their families to allow for maximum cooperation and support between families and team members and continued high-quality hospice care.

References

Abt, M. E. (1983). An identification of the needs of family members of terminally ill patients in a hospital setting. Military Medicine, 148, 712-716.

Hospice brochure. (1983). (Available from St. Mary's Hospice, 5801 Bremono Road, Richmond, Virginia 23226).

Bibliography

About Dying. (1976). South Deerfield, MA : Channing L. Bete Co., Inc.

About facing death as a Christian. (1976). South Deerfield, MA : Channing L. Bete Co., Inc.

Gold, M. (1983). Life support: Families speak about hospital, hospice and home care for the fatally ill. Mount Vernon, NY : Consumers Union Foundation, Inc.

Hamilton, M., & Reid, H. (Eds.). (1980). A hospice handbook. Grand Rapids: William B. Eerdmans Publishing Co.

Kubler-Ross, E. (1978). To live until we say good-bye. Englewood Cliffs, NJ : Prentice-Hall, Inc.

Markel, W.M., & Sinon, V.B. (1978). The hospice concept. New York: American Cancer Society

National Funeral Directors Association, Inc. (1981).

Hospice: A manual of concern, cooperation, care.

Milwaukee, WI: Author.

National Hospice Organization. (1980). Hospice in America: Author.

O'Brien Abt, M. E. (1983). An identification of the needs of family members of terminally ill patients in a hospital setting. Military Medicine, 148,

712-716

Rossmann, P. (1979). Hospice. New York: Fawcett
Columbine.

Stoddard, S. (1978). The hospice movement. New York;
Vintage Books.

Walsh, E. K. & Cavanaugh, J. C. (1984, November).

Does hospice meet clients' and families' needs?

Paper presented at the annual meeting of the
Gerontological Society, San Antonio.

Appendix I

HOSPICE PROGRAM EVALUATION

A QUESTIONNAIRE

St. Mary's Hospital
Hospice Program

University of Richmond
Department of Psychology

Rationale

Given the importance of families in the total hospice patient care process, the purpose of this research is to identify the needs of families of terminally ill patients and their perceptions of their loved one's needs. It will also be assessed if these needs were met in the hospice program and who met these needs. It is hoped that examination of the suggestions, ideas, and comments of family members will allow for future interventions to: decrease anxiety, increase reassurance, improve cooperation, rapport, and mutual understanding, and ultimately improve patient care in the hospice program. This study is a research project co-sponsored by St. Mary's Hospice and the Department of Psychology of the University of Richmond. All identities and individual responses will remain confidential. Group data will be reported and interviews and surveys will be assigned numbers, and names will be excluded.

If you are willing to participate in this evaluative study, please fill out the following questionnaire. In addition to the questionnaire, a personal interview will be conducted, if you wish to participate.

Personal Data (Survivor)

Age

Sex

Relationship to patient

Occupation

Patient's age

Patient's sex

Patient's occupation

Date of patient's last previous admissions to hospital

Diagnosis

Length of last hospice inpatient stay if applicable

Educational level

Patient's educational level

Place of death

PART A: FAMILY NEEDS

Please rank the following needs in order of their importance according to your opinion/experience. More than one need may be "most important."

<u>Category</u>	<u>Rank-Scale</u>
Most important	1
Very important	2
Important	3
Slightly important	4
Not important.	5
Least important	6

- | <u>Rank</u> | |
|-------------|---|
| _____ | 1. Support of family members |
| _____ | 2. To have questions answered honestly |
| _____ | 3. To be reassured that the best care possible is being given to the patient; (and) to be called at home if there were any changes in the patient's condition |
| _____ | 4. To know exactly what is being done for the patient; (and) to have specific facts concerning the patient's progress |
| _____ | 5. To know that the patient is comfortable |
| _____ | 6. To be told about how the patient is going to be treated medically |
| _____ | 7. To feel that the hospice personnel care about the patient |
| _____ | 8. To have explanations given in understandable terms |
| _____ | 9. To know why things are being done for the patient |
| _____ | 10. To feel that there is hope |
| _____ | 11. To know the patient's chances for recovering |
| _____ | 12. To talk about the patient's survival |
| _____ | 13. To have "time-off" away from the patient |
| _____ | 14. Other (what are they?) |

PART B: RESPONSES TO NEEDS

For the following needs, please indicate who, if anyone, was responsive to the need.

<u>Rank</u>	<u>Category</u>	<u>Rank- Scale</u>
	Doctor	1
	Doctor & nurse	2
	Nurse	3
	Chaplain (clergy)	4
	Volunteer	5
	Friend	6
	Other relative	7
	Home health	8
	Primary caregiver	9
	Social worker	10
	Other	11
	Other combination of caregivers	12
	No one	13
	Paid caregiver	14

_____	1. Support of family members
_____	2. To have questions answered honestly
_____	3. To be reassured that the best care possible is being given to the patient; (and) to be called at home if there were any changes in the patient's condition
_____	4. To know exactly what is being done for the patient; (and) to have specific facts concerning the patient's progress
_____	5. To know that the patient is comfortable
_____	6. To be told about how the patient is going to be treated medically
_____	7. To feel that the hospice personnel care about the patient
_____	8. To have explanations given in understandable terms
_____	9. To know why things are being done for the patient
_____	10. To feel that there is hope
_____	11. To know the patient's chances for recovering
_____	12. To talk about the patient's survival
_____	13. To have "time-off" away from the patient
_____	14. Other (what are they?)

PART C: MEETING NEEDS

Please indicate to what extent the needs cited below were actually met.

<u>Category</u>	<u>Rank-Scale</u>
All of the time	1
Most of the time	2
Some of the time	3
A little of the time	4
None of the time	5

Rank

- _____ 1. Support of family members
- _____ 2. To have questions answered honestly
- _____ 3. To be reassured that the best care possible is being given to the patient;
(and) to be called at home if there were any changes in the patient's
condition
- _____ 4. To know exactly what is being done for the patient; (and) to have
specific facts concerning the patient's progress
- _____ 5. To know that the patient is comfortable
- _____ 6. To be told about how the patient is going to be treated medically
- _____ 7. To feel that the hospice personnel care about the patient
- _____ 8. To have explanations given in understandable terms
- _____ 9. To know why things are being done for the patient
- _____ 10. To feel that there is hope
- _____ 11. To know the patient's chances for recovery
- _____ 12. To talk about the patient's survival
- _____ 13. To have "time-off" away from the patient
- _____ 14. Other (what are they?)

Thank you for your cooperation on this project.

Jane Towner
Director of Hospice
St. Mary's Hospital

Lyn Harper
Department of Psychology
University of Richmond

Appendix II

Interview Questions

Team Members

Were team members readily available to you?
Were they candid in their answers?
Did they take time to listen?
Were they sensitive?
Did they contact the family readily and return phone calls?
Were they willing and able to discuss important concerns?
Were they open?
Did they communicate in a thoughtful or considerate way?
Did they volunteer information?
Did they help the family make important decisions?
Which team members were you dependent on for your information?
How would you describe your overall experiences with the hospice team members?

Hospice Program

Was the on-call service effective in answering your questions and/or arranging visits?
How close did the hospice inpatient component come to reaching its goal of getting the patient and family physically and emotionally stable enough for the patient to go home?
Would hospice have been more effective or helpful to you if it had entered the picture earlier?

Patient

Was severe pain a major problem for the patient during the final stages?
Was pain adequately controlled at home? In the hospital?
Was control of pain consistent?
Was pain medication given when the patient experienced pain or was it given on a specified schedule?
Did patients respond favorably to their hospice care?
Did the patient express any fears?
What other physical problems made it difficult to care for the patient at home?
Do you feel satisfied that every effort was made to alleviate the patient's physical pain? to meet the patient's emotional needs? to meet the patient's spiritual needs? to meet the patient's personal needs?
Do you feel that the actions taken by the hospice team members were in the best interest of the patient?
Was the hospice team effective in offering support for the patient?
Did the hospice team members seem to care about the patient?

Death

- Did team members help the patient deal with death?
- How did team members act toward you and the patient when death was expected soon?
- Did team members help you adequately with planning and preparation for death?
- How were you treated by team members in the aftermath of the death event?
- Do you still have contact with any team members?

Care-giver

- What kinds of things did you do for the patient at home and in the hospital?
- Who assisted you at home?
- what did the assistants do?
- Which form of assistance was most helpful to you?
- Did you experience any problems with your helpers?
- What kinds of problems did you (as the care-giver) experience?

Evaluation

- Do you have any criticisms and/or praises of hospice?
- Do you have any suggestions for the future?
- Is there anything about the program you would like to change?