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NEEDS ASSESSMENT AND HOSPICE PLANNING IN A RURAL SETTING

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A needs assessment is a research and planning activity designed to determine a community's service needs and utilization patterns. One of the most practical ways to plan services is to gather information accurately about a defined population and use that information to revise existing programs or develop new ones. Unfortunately, needs assessment findings often go unused. This article describes how a needs assessment was designed to assess the need for hospice services in a rural Pennsylvania county and how the results of this assessment were useful in determining priorities for program planning and service development. The implications of a model needs assessment such as the one proposed are discussed.

AUTHOR'S NOTE: This article is based on my M.A. thesis in community psychology at Indiana University of Pennsylvania. Requests for reprints should be sent to Colene Byrne, Office of Policy Development, Room 506, Finance Building, Harrisburg, PA 17120.

The hospice philosophy of care in the United States has grown out of the need for improved health and social care for the terminally ill and their families. Currently there are almost 1000 hospice programs in the United States, more than half of which became operational only within the last three years (Aikens and Marx, 1982).

"Hospice" is defined as a concept, not a place, emphasizing palliative and supportive care to meet the special needs of terminally ill patients and their families. A common operational definition of "terminal illness" is "a state of disease characterized by a progressive deterioration with impairment of function and survival limited in time, usually from several days to a few months" (Abdellah et al., 1982). The following nine components of hospice care operationalize the ways in which a hospice program differs from traditional models of care for the terminally ill (Markel and Simon, 1978):

- (1) Coordinated home and inpatient care under a central autonomous hospice administration.
- (2) Skilled symptom control for physical, emotional, and spiritual distress.
- (3) Physician-directed interdisciplinary care.
- (4) On-call services, available 24 hours every day.
- (5) Patient and family regarded as the unit of care.
- (6) Bereavement follow-up.
- (7) Use of volunteers as an integral part of the interdisciplinary team.
- (8) Structured staff support and communication systems.
- (9) Hospice services based on need, not ability to pay.

Despite these commonly accepted standards for hospice care, it has been noted that the intensity of services actually provided varies widely (Alpha Center for Health Planning, 1981). The role of hospice has not yet been determined by the federal government, and the Health Care Financing Administration is currently in the process of studying how the hospice fits into the health care system (Abdellah et al., 1982). Buckingham and Lupu (1982) found in a national survey that two

divergent types of hospices were becoming predominant: (1) independent, heavily volunteer hospices with a variety of professional staff delivering a wide variety of social psychological services with unstable funding, and (2) institutionally based hospices providing both inpatient and home care, greater variety of medical and nursing services and less variety of social psychological services, using fewer types of volunteers and staff, and not experiencing funding problems.

Due to provisions of a congressional tax bill, hospice care is reimbursable for elderly and disabled Americans in the Medicare program. Hospice care, then, is at a critical juncture, and due to the lack of stringent accreditation standards, hospice planners are allowed considerable flexibility in designing services to meet the needs of the client population.

DEVELOPING A HOSPICE PROGRAM

Several members of rural Pennsylvania community perceived the need for hospice services and formed a hospice planning committee. By identifying the specific needs of the terminally ill and their families in the county, the hospice planners felt they would be able to determine hospice priorities better and develop its service programs rationally.

A needs assessment gathers information from or about a defined population and uses that information to revise existing programs or develop new ones. The use of needs assessments has grown from public consciousness of the overwhelming number of personal and social needs in our communities, accompanied by an increasing expectation that human services will be responsive to those needs by developing effective programs. This article discusses the conduct of the needs assessment that was undertaken for the hospice planning committee and how it became an essential part of human service planning.

Although the manner in which this needs assessment was carried out is relevant to all hospice planners, several methodological features are particularly applicable to rural

geographic settings for the following reasons. First, the potential demand for rural hospice services can usually be estimated from a clearly defined geographic area. Metropolitan hospices, on the other hand, usually provide services to clients from a much wider geographic area and generally compete with other health care programs. Second, due to limited health care alternatives in rural areas, hospice planners have a greater responsibility to provide the type of care desired by the terminally ill and their families. Using this marketing approach to service planning, rural hospice planners must also attempt to assess the extent to which the terminally ill in a community will make use of a hospice and what barriers may impede hospice utilization (e.g., distrust of a local hospital). The attitudes of potential referral sources must also be measured. Lack of professional acceptance of the hospice philosophy in a rural community can undermine even the best-planned hospice program.

DESIGN OF THE NEEDS ASSESSMENT

The following commonly accepted needs assessment "standards" (for example, see Siegal et al., 1978; Murrel and Norriss, 1983) were incorporated into the design of the needs assessment:

(a) *Multiple data sources and data collection techniques are employed.* This allows a more comprehensive gathering of information, such that no single information source influences the needs that emerge from the assessment.

(b) *The information is immediately useful to service planners.* A common complaint of human service planners is that needs assessment results often go unused (Murrel and Norris, 1983). To overcome this barrier, three steps were taken to determine what information would be of use to hospice planners: (1) a review of the hospice literature, (2) interviewing persons familiar with the individual experience of terminal illness for county residents (e.g., the type, location, and costs of treatment alternatives), and (3) discovering the specific information needs of the hospice planning committee.

(c) *Reduce response bias by not informing needs assessment participants of current service planning efforts.* When possible, interviewed persons were informed only that they were contributing to a research project studying the problems related to terminal illness in the county.

(d) *Include a wide variety of participants in the design.* Past needs assessors have often relied on a narrow group of individuals as sources, using only hospital staff or agency personnel already interested in starting hospice services. A wide range of community services that might serve a terminally ill individual or his or her family was represented in this assessment.

(e) *Directly gather information about the need for and acceptability of a specific service from existing records and from persons already familiar with the problem under study.* Some needs assessors have estimated such data by using an epidemiologic survey of citizens at large (Community Needs Assessment, 1980). However, this is not an efficient manner by which to gather the needed data when assessing the need for hospice services. Little relevant information would be collected from citizens who have no experience with terminal illness within the family.

(f) *Pretest measuring instruments with professionals involved with the population under study.* Because of the highly emotional nature of the topic, this is particularly important when interviewing terminally ill persons and their family members. A poorly worded questionnaire can elicit responses that the interviewer may feel poorly equipped to handle. In addition, highly personal questions may bias responses, such that the emotional and psychological aspects of terminal illness may overshadow the other types of problems experienced. On the other hand, professionals warned of the unintended consequences that might result from highly impersonal questions. By avoiding emotionally laden questions, a researcher may convey a lack of concern for or understanding of the family's plight.

(g) *Rely on many open-ended interviews to facilitate the gathering of rich and in-depth qualitative information.* Past

researchers have used primarily closed-item questionnaires for ease in analyzing data from a large number of participants when assessing the need for a hospice. However, several unanticipated but important problems related to terminal illness were discovered from the open-ended interviews used in this assessment.

(h) Determine the relative importance of identified service needs for use in program planning. Murrel and Norris (1983) point out that needs assessments that merely identify needs without attempting to prioritize them are a major factor in the underutilization of needs assessment results. The criteria used in prioritizing needs in this study were the prevalence of reported problems and needs and the extent to which existing services were designed to meet these needs.

In formulating the hypotheses to be tested by the needs assessment, the specific information needs of the hospice planning committee were taken into consideration. During the committee meetings, members expressed a need for answers to such basic types of questions as these: What geographic area should be covered by a potential hospice? What types of terminal illness might a hospice be appropriate for? How many people die from terminal illness in the county each year?

An outline of a needs assessment methodology was then presented to committee members, and input was requested for additional information needs. Five types of information needs were subsequently identified and incorporated into the design of the needs assessment: (1) extent of terminal illness in the county, (2) needs and problems faced by the terminally ill and their families, (3) acceptability of the hospice philosophy, (4) potential demand for a hospice program, and (5) extent to which existing services are meeting identified needs.

METHODOLOGY

Seven different techniques or strategies were employed to gather information.

(1) Social and health indicator data from existing records were used, including the 1980 census, the Health Systems Agency, and the State Health Data Center.

(2) A survey of existing resources in the community determined how many of the terminally ill and their family members used certain services, how frequently these services were used, what type of service fees were required, and what special training the staff had in handling the special problems related to terminal illness.

(3) Interviews were conducted with family members who had cared for a terminally ill relative. Three agencies provided these referrals by giving the names of family members who had been considerably involved in the care of a terminally ill relative and who were felt to be willing to be interviewed. The average length of time since the death of the relative was seven months. The interviews, conducted at the homes of families from all areas of the county, lasted an average of 45 minutes.

(4) Interviews were conducted with physicians who treat terminal patients from the county, most of whom were chosen randomly from a list of practitioners in the county. None of these physicians was involved with hospice planning efforts in the county. Because a large proportion of the county residents receive care from physicians outside the county, several physicians known to have many county terminal patients were also interviewed.

(5) Key informants, representing all of the services available for the terminally ill in the county, were interviewed. These informants included nurses, social workers, visiting nurses and homemakers, citizen volunteers, and members of the clergy. These interviews generally lasted 30 minutes.

(6) A questionnaire was distributed to the therapists of the local mental health center and the nursing staff of the Visiting Nurses Association. Both of these questionnaires requested respondents to identify major problems with their terminally ill clients and their families.

(7) Questionnaires were sent to hospices from surrounding counties to collect information on policies and client caseload.

Although it was not possible to negotiate the administrative agreements that would have been necessary to interview terminal patients, future needs assessors should consider including this group as participants, to assure that their needs are assessed accurately.

RESULTS

A summary of the results will be reviewed around each of the five areas of information needs.

EXTENT OF TERMINAL ILLNESS IN THE COUNTY

The hospice planning committee was provided with information on terminal cancer in the county, including (a) the number of annual cancer deaths, (b) the most prevalent types of terminal cancer, (c) a comparison of cancer death rates with those of the state and nation, (d) the age of persons dying of cancer, and (e) an estimate of where people die. Other diseases considered to be "terminal" by local physicians and other hospice programs include renal failure, some degenerative neurological and muscular diseases, amyotrophic lateral sclerosis, chronic heart failure, severe heart disease, and chronic lung failure. The committee was also provided with results of a national survey by Buckingham and Lupu, indicating that the average percentage of hospice patients suffering from cancer is around 94%.

PROBLEMS AND NEEDS OF THE TERMINALLY ILL AND THEIR FAMILIES

When asked what major problems are faced by persons dying of terminal illness, the assessment respondents provided a total of 35 different problems. Table 1 presents the most frequently listed problems and shows to what extent the problems were felt to be the most important problem or one of the major problems.

TABLE 1
Problems Faced by the Terminally Ill

Problem	Percent of Respondents Stating this is the Most Important Problem	Percent of Respondents Stating this is a Major Problem
1. Accepting relative's illness	21.0	34.2
2. Accepting relative's death	13.1	23.6
3. Providing care for relative	13.1	50.0
4. Guilt	7.9	18.4
5. Poor communication within family	7.9	23.6
6. Financial problems	0.0	21.0

Problem Category	Percent of Total Responses
1. Emotional/Psychological Aspects of Relative's Illness	48.0
2. Providing Care	24.5
3. Interpersonal/Communication Problems	10.7

NOTE: N = 38.

The problems of the terminally ill were also grouped into problem areas (see Table 1). Almost half of the problems listed were believed by respondents to be a result of the terminal patient's reactions to the illness and death; one-fourth of all responses were a result of physical complications of the illness.

Interview respondents also listed problems thought to be faced by the families of the terminally ill, and the family members were asked to identify the major problems they faced during the illness of their relative. Table 2 lists these major problems, again comparing those problems considered the most important ones with all listed problems. The table also groups problems into the major problem categories.

TABLE 2
Problems Faced by Families of the Terminally Ill

Problem	Percent of Respondents Stating this is the Most Important Problem	Percent of Respondents Stating this is a Major Problem
1. Accepting illness	16.2	27.0
2. Accepting death	13.5	24.3
3. Pain	13.5	46.0
4. Feeling alone	10.8	8.1
5. Fear	8.1	13.5
6. Poor communication with family	2.7	24.3
7. Loss of control or independence	2.7	18.9

Problem Category	Percent of Total Responses
1. Emotional/Psychological Aspects of Illness	48.1
2. Physical Pain/Discomfort and Poor Nutrition	24.5
3. Receiving Good Care	11.8
4. Interpersonal/Communication Problems	10.9

NOTE: N = 38.

Few of the key informants and physicians were able to remain in contact with the families after the death of their relative. Of those who did, the most common problems experienced by these families were loneliness, lack of emotional support, grief, adjustment, and financial problems.

Specific Problems Addressed

Presence of caregiver in the home. Because most hospices require that a primary caregiver be available to care for the

terminally ill individual, the key informants and physicians were asked to estimate the percentage of the terminally ill they have known with someone physically capable of caring for them.

Finances. Although there was considerable difficulty in obtaining direct information on the financial burden terminal illness places on the family, several sources of information did give an indication of the extent to which this was a problem. For example, estimates from a local company's insurance coverage and from the American Cancer Society on the total cost of terminal cancer care (medical and medicine coverage) was \$25,000. Most of the interviewed family members had unpaid expenses for the illness.

Transportation. Because 72% of the county residents live in rural areas, traveling to physicians' offices or hospitals was a problem for family caregivers.

Additional Problems and Needs

Some insight into the problems faced by the families of the terminally ill was gained from the personal interviews. Most of the families had some difficulty in deciding what type of treatment their family member should receive, and lack of physician coordination aggravated this situation. Family members also seemed to feel that caring for their ill relative was their burden, not to be pushed onto others, and were very reluctant to accept help from others. The interviewed family members expressed considerable grief over the death of their relative and had lingering questions about the quality of care their relative had received.

When asked what problems the terminally ill in the county were facing with inadequate resources, key informants and physicians identified these major unmet needs: emotional support, quality home care, openness about illness and death, and adequate pain relief. The families of the terminally ill were found to be most in need of emotional support, respite, follow-

up bereavement care, home care assistance, and financial assistance by respondents.

ACCEPTABILITY OF THE HOSPICE PHILOSOPHY

Most of the physicians and key informants (94%) believed that a hospice would be a useful addition to health care. Hospice acceptability was also determined from measures of (a) support for services volunteers could provide, (b) need for physician referral and involvement in hospice care, (c) number of family members who indicated they might have used a hospice during interviews, (d) perception of physicians and key informants as to potential use of a hospice, and (e) acceptance of home care by families and terminally ill. Although hospital care was rated between good and excellent by all groups of respondents, there was total agreement that the terminally ill prefer to be, and receive the best care, at home. A different outlook emerged when informants were asked where the families would prefer care be given. Only 28% of the respondents felt that families wanted to provide home care, whereas another 28% felt that families prefer institutional care. The remainder (about half) thought that families varied so greatly in how they felt about this that they could not be characterized.

POTENTIAL DEMAND FOR HOSPICE

The Alpha Center for Health Planning (1981) estimated that 30%-35% of the annual number of cancer deaths in an area is fairly accurate in representing the number of hospice clients for that area. Information collected from other hospices supported this estimate. The hospice committee was able to form some type of estimate of the number of potential clients around which services could be planned.

Information regarding the perception of "hospice" by those interviewed indicated that the manner in which a future hospice planning program is marketed may influence the number of clients entering a program. For instance, physicians were most likely to see hospice services as being provided in a special

facility or in a hospital ward, whereas key informants had a tendency to see hospice as dealing with the “death and dying” aspects of terminal illness through a variety of professionals. Family members, on the other hand, described hospice in terms of more compassion and concern from medical professionals and a homelike environment for the dying relative. It seems reasonable to assume that the nature of the future hospice may greatly influence the number of clients who desire hospice care in the county.

ABILITY OF EXISTING SERVICES TO MEET IDENTIFIED NEEDS AND PROBLEMS

A variety of service providers were studied to determine in what capacity they currently serve the terminally ill population and their families. It was determined that many of the basic hospice-type services were being provided, but that there were still major limitations in these basic services. Service providers agreed that with greater continuity of inpatient and home care and early coordination of services, many more of the terminally ill in the county and their families would benefit from the variety of services currently available.

DISCUSSION

UTILIZATION OF THE NEEDS ASSESSMENT

Hospice committee members were presented with research results, and members noted that the extent of need for hospice services was less than originally expected. As a result, hospice services are currently being developed on a smaller scale than previously anticipated. Another way in which results of this needs assessment were able to be incorporated into service planning was that some data indicated that many of the terminally ill were being referred to other hospices and the county Visiting Nurses Association within weeks or days of death, and that earlier coordination of services would be needed for the terminally ill to benefit from hospice services.

Committee members acknowledged the need to attract the large number of terminal patients now migrating outside the county for health care. The needs assessment results also affirmed for members that the greatest problems faced by the terminally ill and their families were of an emotional or psychological nature, rather than of a physical or material nature. Hospice care providers were advised to place priority in emotional types of care rather than the physical types. The need for follow-up bereavement care was also stressed to committee members. Finally, based on the different participants' perceptions of hospice, as well as results from a recent survey of hospice knowledge in a rural area, committee members were given marketing issues to consider. For instance, citizens were more aware of the spiritual aspects of hospice care but least knowledgeable about the assistance hospice provides with home care.

The needs assessment results were submitted to the policy-making board of the county home care organization under which hospice care was to be provided, and later to administrators of the local nursing home and hospital. Board members and administrators had many questions that were addressed by the assessment, such as how many persons might use a hospice, whether physicians would refer to it, and whether people would use it.

Input on the needs assessment report from hospice committee members indicated that new knowledge was provided to most members in the areas of cancer prevalence in the county, age of terminal patients, major types of terminal cancer, and estimated number of clients who might use hospice services. Descriptions of the special needs and problems of the terminally ill and their families in the county will most likely influence future training. The volunteer trainer emphasized the importance that would be placed in training volunteers to provide bereavement support. The information provided on barriers to the use of hospice services was seen as important for planning community education activities. In addition, it was felt that some of the information would influence the philosophical approach that would ultimately be taken in caring for the terminally ill.

IMPLICATIONS

An implication of the conduct of a model needs assessment such as the one described is that it not only determines the extent of need for a hospice program in a geographic area, but that it can also provide several types of relevant information and be used in prioritizing service needs. This needs assessment has already affected hospice planning efforts; most likely it will continue to influence planning decisions.

Several factors have been found to facilitate the utilization of needs assessments (Robins, 1982), and many of these factors were present when this project was undertaken: (1) commitment of agency officials, (2) ability to modify programs substantially, (3) a needs assessment design with clear and direct ties to the organization's planning process, and (4) an assessment engineered by members of the agency. Future needs assessors may benefit by incorporating these factors into their assessment design.

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