



Living and Healing During Life-Threatening Illness

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Foreword

Healthcare organizations today commonly develop strategic initiatives aimed at creating healthier communities. Unfortunately, these initiatives are often incomplete because they fail to deal with life-threatening illness, dying, and death. Indeed, such initiatives often help perpetuate our culture's impulse to avoid such topics. The truth is that, in the United States, the care of people with life-threatening illness is grossly inadequate. Organized healthcare bears some responsibility for this fact.

Recognizing this responsibility, six Catholic healthcare organizations--Carondelet Health System, St. Louis; Catholic Health Association of the United States, St. Louis; Catholic Health Initiatives, Denver; Daughters of Charity National Health System, St. Louis; PeaceHealth, Bellevue, WA; and Providence Health System, Seattle--got together in January 1995 to form Supportive Care of the Dying: A Coalition for Compassionate Care.

The coalition is dedicated to promoting cultural change that will encourage society to provide supportive care, compassionate relief of suffering, and pain and symptom management for people with life-threatening illness. A contemporary response by the Catholic healthcare ministry to the special needs of people facing death, the coalition is motivated by the Church's belief that human life is a fundamental value and that both healthcare systems and communities should help people live and die well.

The coalition has three priorities:

- To research the information, service, and support needs of people with life-threatening illness, their families, and their communities
- To develop models of comprehensive, community-based, supportive care for dying people
- To create both a professional mentorship program that teaches holistic supportive care skills and behaviors and a community education program that works for reformed end-of-life care

Each product will be evaluated by the coalition's member healthcare systems before being offered to the world at large for implementation.

Most programs and services for those facing life-threatening illness are based on healthcare providers' assumptions--not the *experience* of the people involved. Because of this, the coalition decided that significant needs assessment research was required before reform could begin. The coalition organized focus groups involving about 400 people in a variety of locations across the nation, including people who had actually faced life-threatening illnesses, family members, professional caregivers, and members of the communities in which they lived.

The coalition is pleased to offer this executive summary of *Living and Healing During Life-Threatening Illness*, based on the research findings from those focus groups. The coalition believes that organizations seeking to provide truly comprehensive healthcare must provide it not just to those sick people who can be expected to recover from their illness, but also to those who will probably not recover, and to their families, friends, and communities as well.

The coalition's members hope that *Living and Healing During Life-Threatening Illness* will contribute to ongoing dialogue about the appropriate partnership between healthcare systems and communities with regard to care for people in the last phase of life.

Lawrence A. Plutko
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The Study

"I don't focus on the dying part all of the time. I might have a month or two where I just kind of really feel drawn to education to learn and kind of really get into it. Then I pull out and live. I work just as hard at living."

--Focus group participant

Until now, little systematic study has been done on the needs and experiences of individuals with life-threatening illness, their families, their caregivers, and their communities. In this study, we at last have a systematic assessment. With it, healthcare organizations can begin to reform the care and services required to meet the real needs of people affected by life-threatening illness.

The Research Purpose

The study was conducted to gather information about living with life-threatening illness as it is experienced by patients, families, community members, and healthcare professionals. From this information, the researchers sought to learn what such people need in terms of information, services, and support.

Research Methods

Focus group methodology is especially conducive to the discussion of complex issues. Because participants discuss the issues freely, exchanging views and concerns with each other, they give researchers a broad understanding of the group's perspective.

Between March and June 1996, the coalition conducted focus groups at member sites across the country. Forty-four Catholic healthcare organizations had volunteered to be sites for the study; from this list the coalition's researchers selected 11. The researchers recruited participants from a variety of populations:

- Both urban and rural
- Both white and nonwhite
- Both employed and unemployed
- Both active and inactive in religious or spiritual matters
- Young, middle-aged, and elderly

The Participants

The researchers appointed local coordinators for the 11 sites, and the coordinators recruited participants for the groups. There were a total of 407 participants, and they described themselves as belonging to one of five categories. At each site, a focus group was organized for each of the categories, which were:

- *Persons with life-threatening illnesses:* People who, either currently or at some earlier point in their lives, had been diagnosed as having a life-threatening illness
- *Personal/family caregivers:* Family members or friends who had provided consistent care for one or more persons with a life-threatening illness
- *Bereaved persons:* People who had experienced the loss of a family member or close friend to illness or trauma
- *Professional caregivers:* A wide variety of healthcare professionals who provide either direct or indirect care or services for people with a life-threatening illness
- *Community:* People chosen from the 11 communities involved in the study

Participants were recruited for the community groups on the assumption that they would have little experience with life-threatening illness, either as patients or as caregivers. As it turned out, more than 90 percent had at least known people with such an illness.

Demographics

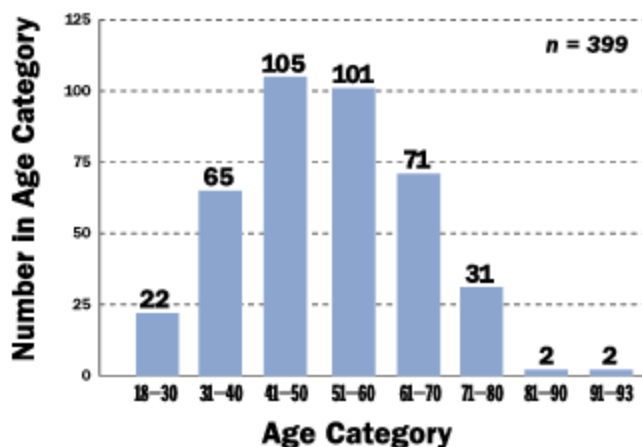
Focus group participants were highly diverse in their occupations and social backgrounds and in the illnesses with which they had dealt. Their ages ranged from 18 to 93 years, although more than half were between 40 and 60. Seventy-two percent were women. Two-thirds said they were frequently involved in religious or spiritual activities, compared with the 25 percent who mentioned only occasional involvement and the 9 percent who said they had no involvement at all.

Finally, although some participants had received treatment at the Catholic healthcare facilities where their focus groups were held, others had not.

The Questions

All participants were asked to respond to the following:

- Tell me about your experience, or the experience of someone you know, from the time the illness appeared to be life threatening or fatal.
- How were you prepared for this? (How did healthcare providers assist you? How did your prior life experiences assist you?)
- What were your concerns or fears?
- What were the problems or barriers you faced? (In meeting the problems and barriers, what was helpful and what was not helpful?)
- Any experience can impact our attitudes and values. How has your experience changed your attitudes or values?
- Is there anything else you would like us to know?



The Analysis

The coalition's researchers employed interpretive data analysis strategies in examining the transcripts of these discussions. Interpretive strategies do not impose a predetermined framework on the data; rather, they allow the primary themes and concepts to emerge from the data. Such strategies are especially appropriate when the researchers seek to understand lived human experience.

The Focus Group Results

What follows are key messages from the five sets of focus group discussions.

Persons with Life-Threatening Illness

Participants with life-threatening illness focused on living rather than dying, regardless of their health. Even when their illness was not cured, they frequently described themselves as "well"--this wellness being related to realms other than the physical.

"Every one of us needs to fight. If they have a life-threatening illness, they need to fight through that illness because that's what we need to do to be well."

Participants often saw in their illnesses opportunities for personal growth and spiritual, emotional, and relational healing. These opportunities allowed them to rise above physical deterioration and diminishment and find wellness even in death.

"I think it's made me a stronger person. I think it's made me appreciate life a lot more, appreciate people a lot more. I try not to take things for granted. I was going to work, coming home, cooking supper, and then doing the wife thing. I just never really took time to enjoy life. I was enjoying life because it was the life that I was in, but I think you need to take time to . . . I love the moon, and I love sunsets, and I love stuff like that. I think if you can even take the time just to appreciate the beauty that there is, the flowers that people plant, just take a little extra time or give somebody an extra hug."

Many participants said they wished physicians would take their symptoms more seriously, even before the diagnosis of a life-threatening illness has been made.

Symptoms evolve over time, and it is the patient--not the physician--who becomes most familiar with this evolution.

"I'm the one who lives with my symptoms."

Persons with life-threatening illness also wanted to learn about the dying process and were distressed when their questions went unanswered.

"I have not experienced a doctor who will talk about that, and I even sat my oncologist down for a one-hour session one time and said, 'What do you do when a person gets to the dying phase? Are they out of your range then? Because you haven't fixed us?' . . . He would just say, 'Don't ever talk about it! As long as you talk about death, then it's going to happen.'"

When they talked about dying, participants said they especially feared losing their capacity to care for themselves and becoming dependent on others.

"I was never afraid of dying. I was afraid, and I think we all are, of losing our capabilities and the capacity to do things."

Making choices that are in synch with their personal values was a common theme. To do this, participants said they needed information about living with their illnesses, their treatment choices, and the changes likely to happen to them.

Participants also emphasized the importance of their relationships with their physicians and other caregivers. They said it was vital that professional caregivers respect patients' values and wishes concerning care, even if patients happened to choose alternative therapy in addition to standard medical care.

Family was very important to participants. Most said they wanted their professional caregivers to treat them as part of a family unit, with other family members included in discussions about treatment.

Persons with life-threatening illness clearly put a high value on the various kinds of support family members gave them. They also deeply appreciated the support they got from neighbors and other community members, especially when it was given without being asked for.

"[They] just let you know they are there. They would do anything they can--mow your yard, just anything. You just know that they are watching all the time."

Personal/Family Caregivers

Personal caregivers of someone with a life-threatening illness frequently referred to it as "our" illness. They often mentioned their need to be provided with the same information about care that was given to their loved one. In fact, caregivers needed more information than the patient, especially once they assumed the role of primary caregiver. Like the patients themselves, the caregivers said they needed to be treated with respect and to be included in conversations about the illness and its treatment.

In short, personal/family caregivers repeated a point often made by persons with life-threatening illness: They should be treated as if they and the patient formed a unit.

"[We tell her,] 'Hey, it's your health. If you don't take your medicine, you suffer the consequences.' But, knowing her well, we suffer the consequences in whatever. She becomes iller than she is now, and we the family naturally will be the ones having to take care of her."

"We often know the patient's needs better than the healthcare professionals do."

Personal/family caregivers want professionals to listen to and respect their expertise regarding care of a loved one. This sometimes led them to suggest that the patient's medical care be augmented with alternative or complementary therapy, and they wanted professionals to support such suggestions. Participants noted that seeking alternative care for their loved ones gave them something *positive* to do.

"[He] was also into alternative methods, which he also discussed with his doctor. . . . But he found out about Ayurvedic medicine, which is Eastern medicine, herbs and things, from India . . . and he talked to [the doctor] about this way, and said, 'Do you have any problem with this? I don't want to do something behind your back.'"

Personal/family caregivers often talked about the *burden* of caregiving, by which they meant the isolation, lack of help, need to balance multiple roles, time constraints, and simple lack of sleep and exhaustion. Many had to be productive at regular jobs, on top of responding to the demands of caregiving. They spoke of putting their lives "on hold."

"There [were] times I was up with her every hour, you know, [every] 45 minutes to one hour, getting up with her and sitting on the pot. So it's constant--and then to get up and go to work and work a full day. You think, 'Oh, I am so tired!' And then the other thing that's so hard is like when you're not allowed to be sick. You can't be sick!"

"[You can feel cut off from life] when you have [only] an hour or two hours in a week, or a total of maybe four hours in a week that you're not at the house or wherever the person is that you're caring for. If you're there 22 hours for two days, and then 24 hours a day for the rest of the time, you don't really get a chance to shut off for a bit."

Although help for caregivers is often available from family, friends, neighbors, and members of local churches, focus group participants said they did not like to ask for it. (Indeed, having to ask for help seemed to add to the caregiving burden.) Caregivers valued help that was volunteered freely.

Family, friends, and community members should remember that the illness is the caregiver's as well as the patient's. They should routinely express their concern for both.

"[You appreciate it] if somebody comes to you and says, 'Let me vacuum your carpets, let me wash your car'--you know, something specific they can do for you. Because it's so hard for you to say, 'Will you come and vacuum my carpets for me?'"

Despite the burden involved, for some participants caregiving was a way of respecting the last phase of the loved one's life and continuing to integrate him or her into the family. The acts of caregiving involved all generations, even young children,

and seemed to bring satisfaction to the primary caregiver.

"And Mom [wouldn't] have a life in a nursing home. At least in my home she has. . . . My kids come over, of course, all the time, because it's only natural, and my granddaughter is three. My three-year-old granddaughter can tell a nurse anything about my mom, you know. I mean, she helps my mom go to bed. She says, 'I'll do it!' You call my name!' And she raises the bed up and down, and tucks Mom in, and crawls up and gives her a hug and a kiss at night."

Bereaved Persons

The suffering of bereaved survivors is generally protracted and complicated. There is no point at which one is "over it." The experience of losing a loved one shatters the survivor's worldview; his or her emotions fluctuate wildly, from day to day and moment to moment. And even though the intensity of these emotions eases with time, the survivor continues to feel the loss.

Bereaved persons explained the importance of paying attention to the last days of a loved one. These last days are full of opportunities for growth and healing in the spiritual, emotional, and relational realms, for both the person with the illness and those who love him or her. Unfortunately, these opportunities are often missed because professional caregivers, focused on physical signs and symptoms, cannot recognize other signals.

"So here was the person who had given up her.... She didn't drink with people. She hardly ate anything. She didn't laugh a lot. She loved music, but she never listened to music. She never read. She didn't watch the television. And so it was, I think, it was a gradual thinning out like the tail of a comet . . . you know, until it's a million miles down there."

Forewarning families of the last days is different from giving a prognosis. In fact, healthcare professionals' prognoses were both inaccurate and burdensome to family members.

"I had the feeling nurses frequently know more about patients than doctors in working with you directly, and I think [the hospice nurse] worked with us for a month and a half, and I think she saw the change in him--the fast decline. He was gone in two months. And if we had gone by what his physicians told us--this was the oncologist, too, that confirmed that . . . and he said--actually, the first physician said 'less than a year.' The oncologist said 'six to nine months.'"

Bereaved persons' descriptions of their loved ones' last days of life are full of implications for healthcare professionals. Participants said that professionals sometimes made the last days especially difficult by ignoring or misinterpreting patients' living wills and advance directives, by insisting on using burdensome technology to keep the patient alive (often against the patient's and family's wishes), and by keeping family members away from the dying loved one.

"The doctor said he wanted to continue to build him up. I said, 'No, that was not his wishes,' and I wouldn't do it. I said, 'I don't know why you're asking these things; you've got this living will and you can follow that.' I said, 'He told you he wanted no machines and he wanted to die a natural death if he could, with the least amount of pain, and to be made comfortable.'

"The doctor said he had two hours to live. [My husband] made arrangements that he wouldn't have machines.

"So when we [followed him] out in the hall, they said we had to leave because they were going to treat him. They put an oxygen mask on him with 100 percent oxygen to take the fluids out from around his heart. They broke his nose. He had a welt that went from one end of his chin to the other. His ears were blackened from the tight mask.

"To start out with, I didn't think the mask was necessary. He specifically wished that he would have no machines to prolong his life because he was in a lot of pain. A pressure mask that's trying to remove the fluids from around his heart was uncalled for.

"They asked me if they could call [the doctor] in to break his chest bone to go in and take the fluid around his heart. This man had cancer cells everywhere! Why would you do something like that?"

Only when the professionals began to realize that their efforts were fruitless would they shift responsibility back to the family, participants noted. Then they might ask families for permission to remove what was, in fact, death-prolonging technology. Medical routines were so automatic that sometimes, even after the technology was removed, family members had to tell caregivers to stop running laboratory tests on the dying person and taking vital signs or daily weights.

People in their last days of life often indicate that they know the end is coming.

"I was reading. It was at this time [that] he woke and started putting--[he] thought he was putting on his clothes. I got him, and he said, 'I want to go home.' I said, 'You're home. You're not talking about this home, are you?' He said, 'No.' I said, 'You'll be going to your other home.' He said, 'Yes.' He touched my cheek and said, 'But I don't want to leave you.' I told him, 'I don't want you to leave, but you have to go. We'll be okay. We'll miss you, but someday we'll be together. We'll see each other soon. When they come to take you, don't fight it; just go.' I told him I loved him; he said he loved me; and that was about a week before he passed away."

Family members often misunderstood such "messages," dismissing them as the result of confusion or hallucinations on the loved one's part. Later, they did come to understand the messages--and were sad that they had not been able to respond to them while the loved one was still alive.

During the crisis of a loved one's death, friends and family need sensitive care and practical support. It is common for survivors to want to go with the loved one. This desire may be so intense as to cause reckless behavior. Survivors' desire to die can be especially strong after a child has died.

"For a while there after he died, I found myself . . . driving kind of, I don't want to say recklessly, but I really didn't care if an accident happened and something happened to me. It was like I just thought, 'Well, maybe it's okay. If I'm going to die, I'm going to die.'"

At such a time, it may be difficult for others to comfort the bereaved person. Although they are meant kindly, words of condolence may strike the survivor as offensive. "I'm sorry" may be the only phrase that truly fits the situation.

Bereaved survivors need friends to simply "be with" them as they ride an emotional roller coaster. This "being with" a person in crisis takes great skill and is genuinely valued.

Support groups are generally helpful to bereaved persons. In such groups, survivors can discuss emotions openly and learn how to cope from the experience of others. Participation in a support group often represents a person's first step toward reintegration and reengagement with life. Some people, however, are uncomfortable in support groups and prefer to cope with bereavement in other ways.

In reengagement with life, the survivor may require some coaching and practical assistance, especially in the performance of tasks previously done by the deceased loved one. Learning these skills will help the survivor feel more confident and independent.

A bereaved survivor often returns to work fairly soon, because he or she wants to be among those who share common goals and interests. Colleagues, however, often do not know how to reach out to the grieving coworker and instead remain distant, aloof, or silent. In fact, bereaved people long to have coworkers acknowledge their loss and pain.

"There for a while, they were sort of stand-offish. They didn't ask me because they're afraid they don't know how you're going to react. If I started talking about it, it was okay, but at first they didn't want to. They don't know what to say. If they see you cry, they think they may be upsetting you and they don't realize that those tears are okay and this is what you need. If other people see you cry, they don't know how to react to this and they don't want to see them cry."

Reintegration takes time and never means the loss is forgotten. In fact, bereaved persons emphasize that the sorrow is a bittersweet possession never to be lost. Remembering the deceased loved one is a precious gift, and a survivor's reintegration is hastened when friends demonstrate they remember the loved one.

Professional Caregivers

Professional caregivers agreed that today's healthcare organizations tend to emphasize the reimbursable aspects of care. Productivity quotas--and the pace needed to maintain them--interfere with caregivers' ability to assess and respond to the actual needs of patients and their families.

"But it is a scarce resource we're dealing with in medicine these days. We are asked to produce based on numbers because, bottom line, that's how we're being paid these days. . . . Even though my boss knows better, she counts productivity based on numbers that I turn in. And to spend the time that would need to be spent to sit down and let these people talk and actively work through processes of loss, with the kind of caseload. . . . That's a problem."

Other data from professional caregivers indicate a serious lack of professional education in the skills, behaviors, and value of comprehensive, supportive care for persons with life-threatening illness. Despite the frequent interactions they have with such patients and their loved ones, professional caregivers often do not take the time to learn from these experiences.

"After a while, you don't even have to try to be emotional and attach with these people. I'm sorry, but it's just hard to get all that involved in them in such short periods of time."

As a result, professional caregivers tend to suffer from a sense of inadequacy when dealing with seriously ill people and their families. Feeling inadequate, they may emotionally withdraw from patients, slip into denial concerning death and dying, or develop "coping" mechanisms that are in fact self-destructive.

"We used to do a thing for medical college that I felt was interesting. Because it's very easy for the person to go through their whole medical training without ever having even talked to a patient about dying--because there are so many people involved and it's easy for the student to leave it up to the resident, and then when a resident, the next year, makes sure the intern has to do it, or the attending, and it's very possible to never, ever, come to grips with it."

"Thank God we don't have time to bond with families anymore."

Many clinicians, admitting they often *act* compassionate in the presence of families, expressed concern about the long-term effects of insensitive care on their own health and well-being.

"Just last night, there was a trauma patient that came in that just died, and there was no--it's scary almost, how we're desensitized to that. I mean, I walk in, the patient is there, we work on him for a while and he dies. Then I walk out, go get a cup of coffee, and I go home. There's not a real grieving process, because there is more work to be done."

Caregivers may ignore patients' advance directives or verbal refusal of treatment in favor of the medical team's preference. Physicians, in particular, wield powerful influence and may prevent staff from advocating for patients' rights.

"I've seen instances where a nurse has tried to get a patient declared incompetent to make a decision because she didn't agree with it. I think that we, as caregivers, have to realize it is a person's right to say, 'I've had enough!' No matter what age they are. And then we should help make the rest of their time as comfortable as possible for them."

Many professionals *do* learn the values and skills necessary for comprehensive supportive care when loved ones face life-threatening illness. In those instances, the caregiver quickly learns that the usual hierarchy of needs is reversed: Spiritual, emotional, and relational growth and healing take priority when the physical body cannot be made well.

"I think we all are unique and different in how we walk our walk, but I think none of us goes unaffected by the experiences that we have of people from different phases of life, different cultures, different ethnic backgrounds, and I think in a way you bring them back and you try to think about them. Then it challenges sometimes what you think, but then you discover something new about yourself in the process."

Personal loss often changes the professional's outlook permanently. After suffering the loss of a loved one, the caregiver is likely to see a sharp conflict between professional expectations and his or her own recent experience. As the caregiver tries to integrate this experience with professional practice, he or she may be criticized by colleagues and superiors. The professional may find that a desire to provide dying patients and their families with truly supportive care, on one hand, and the traditional

demands for productivity, on the other, are nearly irreconcilable.

Community

Community focus groups contained a few persons who had little experience with loss of a loved one but many who had lost several. Experience with death made them recognize their own, and their loved ones', vulnerability. With each new experience, they learned how to reach out to suffering friends, neighbors, and coworkers. In doing so, participants noted, they moved away from the death-denying attitude of popular culture and developed new understandings of life and death as inseparable.

"He didn't want a funeral, so we celebrated his life. A few weeks later, we went up into the mountain to his fishing hole and scattered his ashes. . . . It was all family, and [we] scattered his ashes in the river, and then we stood there. And then we had helium balloons and we let them go. And we stood there just kind of thoughtfully, just thinking and crying and stuff. And I looked down at the river in the same place where his son had let the ashes go, and here were the next three generations gathered together, throwing rocks in the river together, and the three generations following him. And I thought, 'Boy, this makes so much sense.'"

In most cases, the community was not organized to support one another or share what they had learned. Their ability to respond to each other in healing ways seemed to be learned one person at a time.

"In your living you don't be so wrapped up in yourself that you aren't able to reach out and help somebody along the way. If you go down the road and the road is a good road, don't go down that road by yourself. Grab somebody. Somebody else was meant to be there and show them what it's about. . . . Plus, when they get to the bottom, I say, 'Well, get up and come back to the top again.' And when you get back up, try to help somebody so they don't have to go down the same path as you did."

Occasionally, churches or volunteer groups facilitated contact with others. With very few exceptions, healthcare systems and providers did not meet the community's needs, particularly guidance in living with life-threatening illness, anticipating death, grieving, and recognizing and benefiting from the loved one's last days. Instead, community members found and gave support to their own friends, coworkers, and loved ones. Indeed, community members expressed a preference to receive support from each other rather than from "strangers."

A Call to Action

In our society, many healthcare professionals and community members believe that healthcare systems alone are able to care for persons in life's final phase. In fact, this study revealed that healthcare providers are poorly prepared to support holistic healing and growth.

Healthcare organizations must prepare to be transformed by the lessons from this study. The study's findings argue for reform, not just improvement, of the care provided to people with life-threatening illness, to their families, and to the communities in which they live.

Life-threatening illness is not a purely medical event. Good medical care is certainly imperative, but individuals and their families in community are the ones who must manage a life-threatening illness. Truly reformed care must be built on a partnership between the healthcare system and the community.

To this end, healthcare systems should:

- Challenge the idea that care for persons with life-threatening illness occurs primarily within healthcare systems
- Fund programs that promote community-based spiritual, emotional, and relational healing for the dying and their families
- Adopt productivity standards that reward individuals and programs focused on healing and integration of people, families, and communities
- Challenge the current managed care concept of "managed lives," which fails to recognize that individuals and families cope with life-threatening illness as members of a community

- Challenge any program for "healthier communities" that does not take the natural process of illness, dying, and death into account
- Improve hospice programs through provider training
- Replace traditional medical hierarchies with collaborative teams
- Abandon provider-centric protocols in favor of flexible, patient-centered care
- Create experiential learning programs that teach holistic supportive care skills and behaviors to professional caregivers
- Recognize that strategic goals and policies created in system offices affect the quality of care persons receive
- Work with communities to share knowledge and create effective support networks for both persons with life-threatening illness and their families, in both traditional settings (e.g., hospitals and hospices) and nontraditional ones (e.g., schools, factories, homeless shelters, and spiritual centers)

Catholic healthcare systems have a unique opportunity to strengthen our ministry by leading the reform effort in care for the dying. Some we can cure; many, we cannot; but for all human beings we will provide care, comfort, and compassion all the days of the journey.

Appendix

Focus Group Method

Many useful books and articles have been published on how to conduct focus groups. This appendix provides specific information only on the method employed in this particular study.

Rationale

Since current information from the literature, professionals, and patients failed to provide a complete picture of the needs of persons with life-threatening illness, we decided to conduct focus groups to learn about these needs at first hand. A focus group methodology encourages group members to discuss complex issues fully, thereby providing researchers with a broad understanding of the group's perspective. Group members hear each other's concerns and reply with stories and opinions of their own, which increase the richness of the information gathered. These data can then be analyzed in terms of both content and meaning.

Focus Group Participants

At each focus group site, a local coordinator recruited 3 to 10 participants for each group. The group categories were:

- *Persons with life-threatening illness*: People who have, or once had, a diagnosis of a life-threatening illness
- *Personal/family caregivers*: Family members or friends who were providing consistent supportive care for one or more persons with a life-threatening illness
- *Bereaved persons*: People who have lost a loved one to illness or other trauma
- *Professional caregivers*: A wide variety of healthcare professionals who provide direct or indirect care or services to persons with life-threatening illness
- *Community*: People selected from the community at large

The local coordinator contacted participants by telephone and then sent each participant a follow-up letter that explained the purpose of the focus groups and reminded them of the date, time, and place of the meeting. To confirm attendance, the coordinator called each participant again.

Conducting the Group

To ensure consistency in approach, the project coordinator facilitated all the groups using a structured introductory script and open-ended questions. Participants signed consent forms and gave verbal permission for the sessions to be audiotaped. They received a \$10 token gift and refreshments. The focus groups lasted about 90 minutes. Audio-tapes were transcribed so they could be analyzed later.

Key Questions

Topics and questions addressed in the focus groups were:

- Tell me about your experience, or the experiences of someone you know, from the time the illness appeared to be life

threatening or fatal.

- How were you prepared for this? (Cues: How did healthcare providers assist you? How did your prior life experiences assist you?)
- What were your concerns or fears?
- What were the problems or barriers you faced? (Cue: In meeting the problems and barriers, what was helpful and what was not helpful?)
- Any experience can impact our attitude and values. How has your experience changed your attitudes or values?
- Is there anything else you would like us to know?

The project coordinator asked additional questions to probe the meaning of the participants' stories.

Analyzing the Data

The interviewer reviewed the transcriptions for accuracy. Then a team used interpretive data analysis strategies to identify the primary themes. The team asked the following questions:

- What is this informant trying to tell us about his or her experience?
- What is the meaning he or she ascribes to the experience?
- What is healthcare's role in the experience?
- Which themes are repeated by the participants in this focus group category?
- How are the themes related?

To uncover these themes, the research team used the following process:

- Together, the team members coded one transcript from each of the five groups to establish consistency in the coding process and discuss emerging themes.
- Each team member coded 2 of the remaining 10 transcripts.
- The team met to review the themes and suggest preliminary groupings, or concepts.
- Team members entered coded transcripts into Ethnograph 4 and sorted them by themes and possible concepts.
- Team members then reviewed the sorted data to ensure that each story and its theme fit into the emerging concept.
- Each team member wrote commentaries on several concepts. The team began to identify similarities and differences across the categories.
- Each team member then analyzed and wrote a commentary on a category of focus group.
- The team selected a paradigm case containing most of the themes and concepts and illustrating their interrelationships.

The analysis team took care to accurately represent each participant's story in terms of what happened, the impact of the events on the participant and others involved, the participant's emotional response to the events, and the meaning the participant made of them.

Goals of the Coalition

- Assess the current level of care to identify, develop, and share delivery models pertaining to all dimensions of care for the suffering and dying
- Develop and implement a paradigm of compassionate care which integrates ethical, clinical, and spiritual dimensions
- Develop educational programs for professional caregivers, families, and the broader community
- Establish criteria and measurement guidelines to assess processes, outcomes of education, compassionate care services, and methods of assigning accountability for these guidelines and processes
- Foster networking among caregivers and identify resources within the broader community supportive of compassionate care of persons with life-threatening illness

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