
PAIN OBSERVED

The Experience of Pain from the Family Caregiver's Perspective

Betty Ferrell, PhD, FAAN

Family caregivers have been defined as more than a sum of individuals and as "a social system in which members have ties to each other, are interdependent, have some common history, and share some common goals".¹⁸ Family has also been defined as whoever is identified as family by the patient. Family caregivers are diverse in many pain populations, such as the elderly who are often cared for by unlicensed non-kin caregivers and in the AIDS population where one's primary caregiver may be a partner, also diagnosed with AIDS. Statistics across several key references in the area of family studies show that caregivers are predominantly female, estimated to comprise 70% to 80%, across most studies. These caregivers are most commonly middle-aged daughters, daughters-in-law, or an elderly spouse. Very importantly, family caregivers often have medical diagnoses of their own. Approximately 60% to 70% of those who care for a patient in pain are actually individuals who have one or more chronic illnesses themselves.

Many family caregivers are employed and are often employed full time. Across a series of family studies, it has been documented that between 40% and 60% of the people who assume this very demanding job of caring for someone they love in pain are performing this care after they have completed 8 hours employment outside the home each day. It is also estimated that 1.6 million people over the age of 65 years require assistance with two or more daily activities and that this number will increase to 2.1 million by the year 2001, along with the reality that there are fewer available family caregivers.^{9, 26, 31}

From the City of Hope National Medical Center, Nursing Research and Education, Duarte, California

Family caregivers often leave the workforce to provide care for patients. Twenty-nine percent of the time they have adjusted work schedules and 18% of the time they take time off without pay. The estimated annual value of kin care in 1990 was \$18 billion, and one can imagine the escalation in the past 10 years. A very important finding is that 32% of family caregivers are categorized as poor.³¹ Although there has been much attention given to statistics like these in recent years and much focus has been on family caregiving, there has been surprisingly little information devoted to family caregiving in pain management.

Beyond discussion of the social context of family is the issue of the family experience of pain. Most people would agree that if there is anything worse than being a patient in pain, it is being a family member in the position of observing a loved one in pain. In recent years, pain researchers have begun to dispel the myth of "Home Sweet Home."^{1,6} This myth dominated from the 1960s to the present as health care providers assumed that everything must be better at home. After all, our patients wanted to be at home, and their family members preferred to have them at home. Yet, important forces in recent years such as the movement out of the hospital created by diagnosis-related groups and the significant force of managed care have created a different reality. Consistently, families and patients are finding themselves at home providing very complex care when that may not necessarily be their preference. The reality is that the living room has become the intensive care unit and the place where family caregivers are exhausted and burdened.² Family caregivers who have very little information about pharmacology, dosing of medications, and assessing or treating pain are asked to become the 24-hour-a-day care providers.^{2,3,7}

Some researchers have begun to help us understand the experience of what it means to be a family member caring for a loved one in pain. The literature has described family caregivers as bearing witness to suffering. Professional caring is quite different from family caregiving. The professional's task of spending a few minutes with a patient in pain and then to be able to go home at the end of the day is very different from living 24 hours a day, seven days a week for years on end with someone in pain. Sherman et al³³ recently described family caregiving through the metaphor of "reciprocal suffering," in which the suffering of the family member is far worse than the suffering of the patient. Boland and Sims² described this experience as a "solitary journey" in stating that regardless of how much support we are able to provide to families, they are very much alone at the end of the day. Lederberg²⁶ described family caregivers as becoming "second order patients." Because of their own chronic illness and the burdens of caregiving, family caregivers in fact often develop many health problems and become our "second" patients.

One example to help us shift our perspective of pain from the view of professionals to that of family caregivers is the area of regulatory issues. Professionals think about the problems faced in pain management because of regulatory barriers, such as what it means to deal with the multiple-copy

prescriptions or to be concerned about laws that restrict the number of pills that can be prescribed. Yet, regulation also creates a tremendous burden on family caregivers as they become the gatekeepers. Family caregivers are concerned about the number of medications they give, and they often have to bargain and manipulate to get the health care system to provide care to the ones they love.^{13, 16} They also become the mediator of regulatory barriers. Dealing with regulatory barriers from a family perspective means that you must travel farther to get prescriptions refilled, you must go to different pharmacies, and you must take your loved one to multiple doctors to get the necessary medications.^{13, 16}

Our research at the City of Hope National Medical Center since 1989 has helped us understand what it is like to be the family caregiver at the bedside of someone who is in pain. Through all of our research and the work of many others, we have found that observing pain in a loved one is an overwhelming experience to a family caregiver.⁵⁻¹⁷ A recent article by Horowitz and Lanes¹⁹ captures well what it means to be witness to illness:

Being witness has a peculiar property of being separate from the action, yet at the same time fully engaged. There is sympathy and empathy, resentment and compassion . . . Often the patient's pain or distress is indirectly felt, transformed, vividly imagined, or distorted by thinking it is much worse than it really is. Witnesses are afraid for the patient and themselves as they, too, face change, while wishing for a return to normalcy.

Many research contributions have been made in the area of pain management in recent years. Researchers have studied pain and family caregiving across ages and across various diseases. Researchers have begun to explore barriers to family caregivers' roles in pain management and to assess their knowledge and beliefs about pain. One consistent finding across these studies is that the fears and the inappropriate knowledge and beliefs of family caregivers are often worse than those of the patients themselves. There is great opportunity in the field of pain to synthesize the knowledge across these studies and to advance our research collectively as a discipline and to strengthen clinical interventions for family caregivers.

A brief description is provided of the program of research undertaken by the author and colleagues over the last 16 years related to pain management at home and to the role of family caregivers.

PROGRAM OF RESEARCH

Since 1984, we have conducted a series of studies related to pain at home and to family caregiving. The first of our studies in 1984 explored the question of what is it like for people to manage pain at home and how it is different than the hospital setting.⁷ Our next study evaluated family factors influencing cancer pain management. In this study, we began to show that family members do much to influence the pain relief of the

person in pain.⁶ We then began a series of intervention studies to educate patients and their family caregivers using a three-part approach of pain assessment, drug management, and nondrug pain relief measures.⁸ Subsequent studies disseminated this pain education program in home care,⁵ explored family caregiver quality of life,⁹ and provided cultural adaptation of our pain management program for the Hispanic population.²¹⁻²³

Across these studies, we have described the concept of family caregiver quality of life. This QOL-Family model (Fig. 1) is derived from our work with patients in pain and from work about their quality of life. In this model, family caregiver QOL encompasses physical, psychological, social, and spiritual well-being. Because of their involvement in pain management, family members often have disrupted sleep and are exhausted. They often develop worsened symptoms from their own illness. Family caregivers experience tremendous isolation, role adjustment, and financial burdens. Pain certainly impacts affection and sexual function. Psychologically, we know that relieving pain is a very intense burden for family caregivers, creating much anxiety and depression. Pain is often the concern that creates hopelessness, tremendous fear, and a lack of control in family caregivers. Spiritual well-being is impacted when family caregivers begin

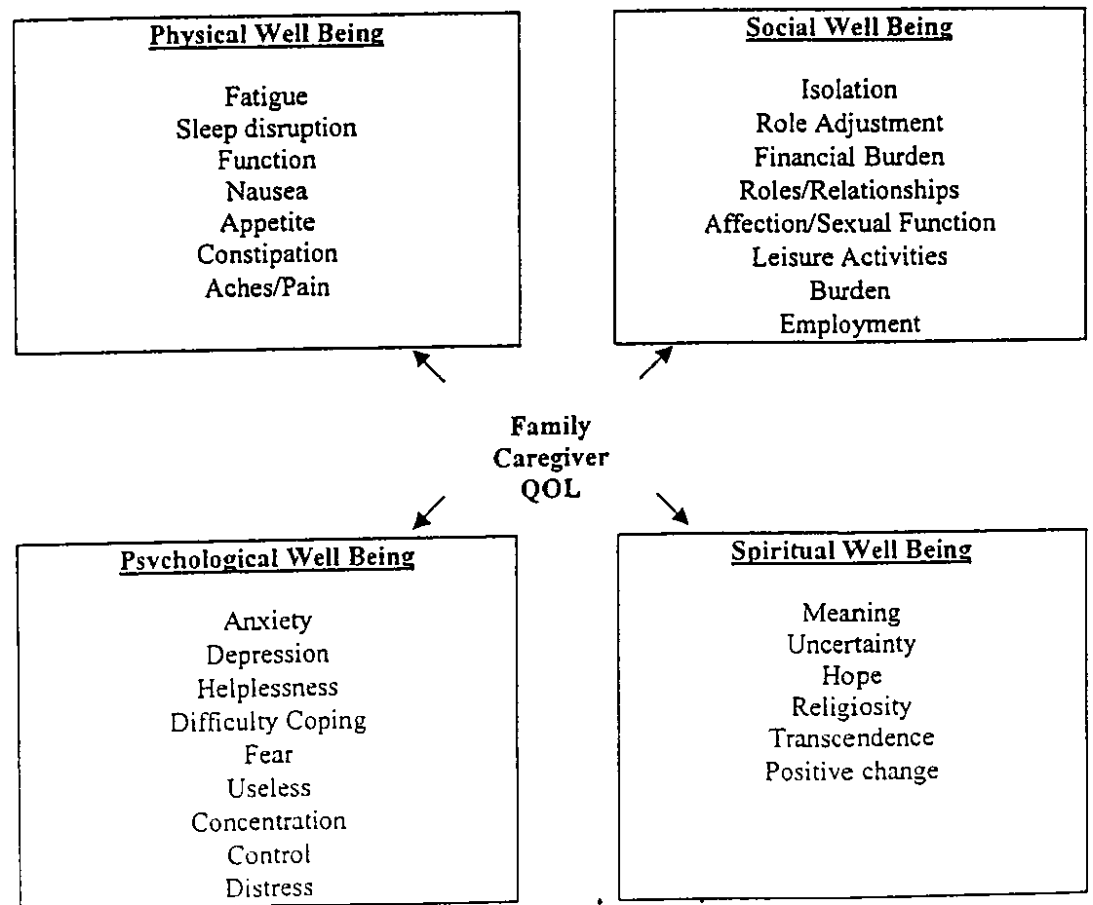


Figure 1. Family caregiver's quality of life.

to question, "Why is it that my loved one not only has to have this disease, but also has to be in pain?" "How can I trust a God that is causing my loved one so much unrelieved pain?" Thus, meaning, hope, uncertainty, religiosity, and all QOL aspects become a part of the pain experience. We also know that with support, family caregiving can be a positive experience as caregivers become competent in feeling that they are providing relief to the patient.^{6, 9, 10}

Figure 2 is from our early work and depicts the family caregiver experience of pain. It begins with the family caregiver's perception of the patient's pain, which is influenced by things such as their own pain experience, their culture, their relationship to the patient, the meaning of pain, and their understanding of it.⁶ Family caregivers experience pain through their own suffering, through the expression of their own emotions, such as anxiety and depression, and through caregiver burden. All of this dynamic is occurring within family members, and all that we see is expression by family caregivers (e.g., as in a phone call in which a spouse is desperately asking us to "do something" else for the patient in pain).

Figure 3 presents findings from a study started in 1991. Interestingly, the same finding has been reaffirmed in every study that we have done in the last nine years. In this first study, we asked patients to rate their own pain on scale of 0 to 100. The patients' mean score was 45. Yet, when we asked family caregivers to rate the patients' pain, the mean score was 70. Family caregivers rated the patients' distress at 75, and their own distress even higher at 78.¹³ Consistently, family caregivers have rated pain to be worse than that of the patient.

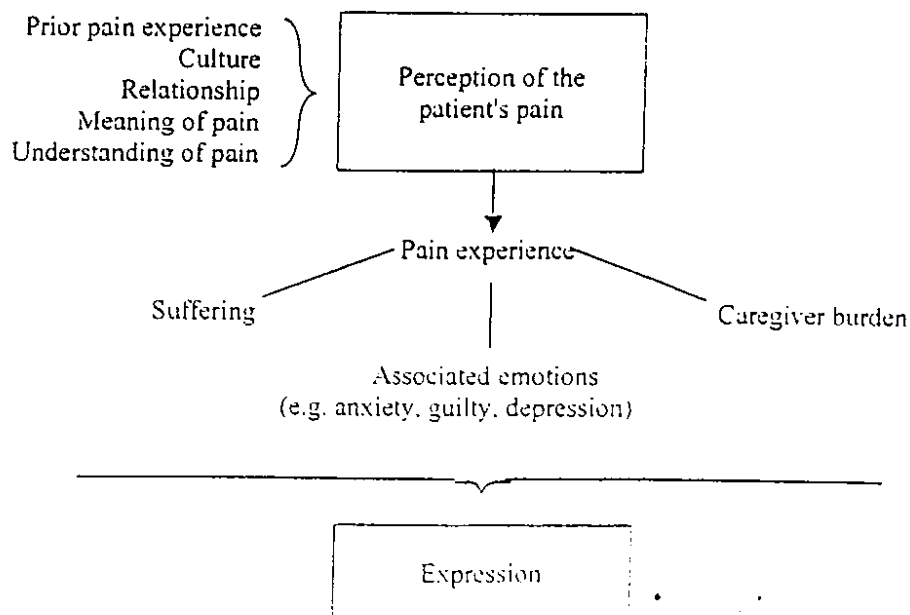


Figure 2. Family caregiver's experience of pain.

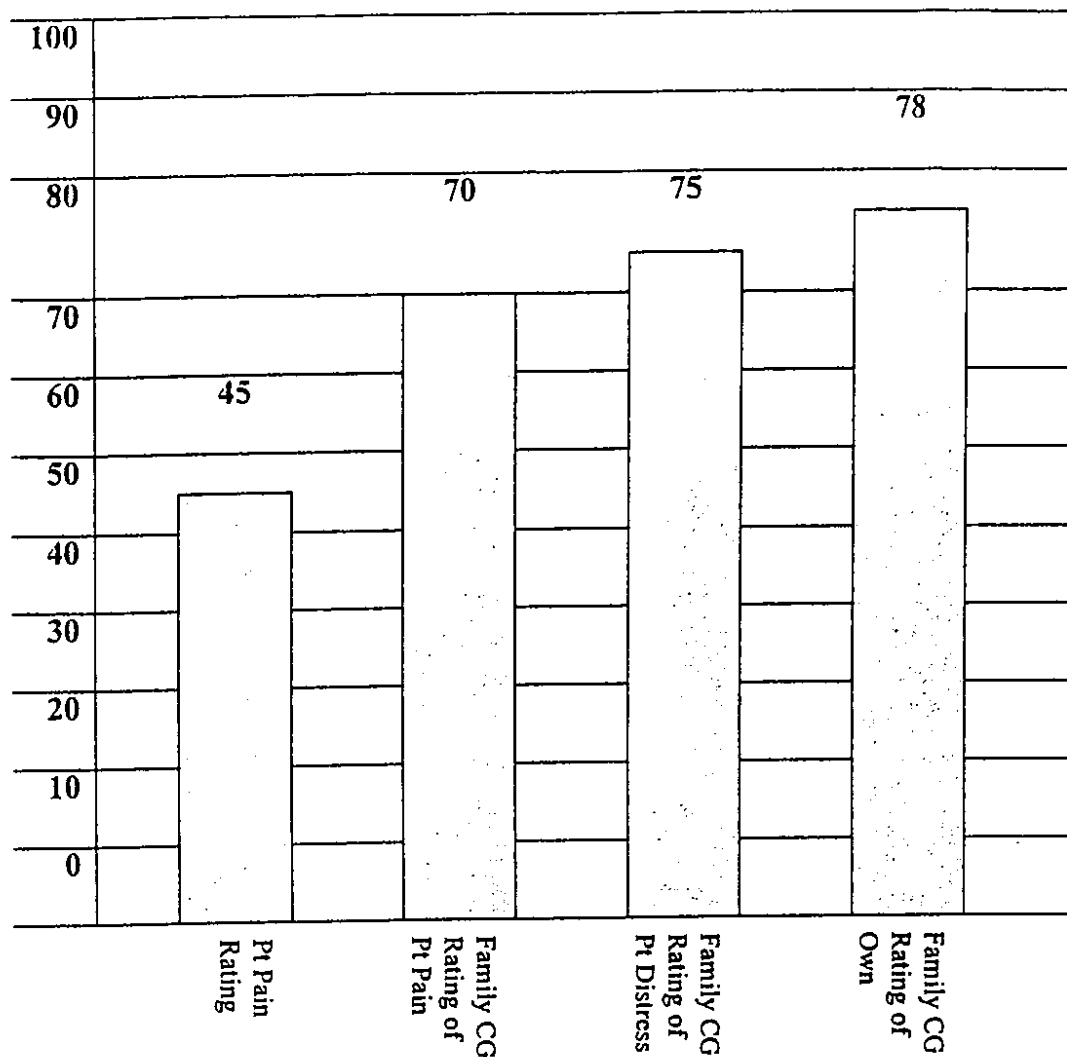


Figure 3. Family caregiver's rating of pain.

One of our other initial steps was to ask family caregivers to describe the patient's pain. Select descriptors used by family caregivers to describe the patient's pain include*:

Aching
 Agonizing
 Bad
 Constant
 Debilitating
 Exasperating
 Excruciating
 Extreme
 Horrendous

*Adapted from Ferrell BR, Rhiner M, Cohen MZ, et al: Pain as a metaphor for illness. Part I: Impact of cancer pain on family caregivers. *Oncol Nurs Forum* 18:1303-1309, 1991; with permission.

Horrible
Hurting
Inconceivable
Intense
Miserable
Overwhelming
Severe
Strong
Tense
Terrible
Unbearable
Uncontrollable

This list was derived from those interviews and describes the emotional perspective of pain. Words such as "agonizing," "excruciating," "horrendous," "inconceivable," "overwhelming," "unbearable" began to describe this experience of family caregiving.¹³

It is notable given the extent of their involvement that there has been little attention given to family caregivers in pain management. In 1992, we conducted a review of the literature by evaluating 7657 publication citations in *Index Medicus* that included the word "pain" as an indexing term. Only 314 citations (4%) also included "family," "home," or "caregivers" or related words as indexing terms.¹⁴ In a later study in 1998 to 1999, we analyzed all end-of-life content in nursing textbooks as a part of our Robert Wood Johnson funded work on end-of-life care. We reviewed 50 textbooks used in schools of nursing encompassing 45,683 pages to analyze nine end of life topics (i.e., pain, symptom management, bereavement, quality of life, legal issues, and ethical issues) and found overall that only 2% of content in textbooks had any relationship to any end of life topic. Interestingly, the area most neglected was the needs and roles of family caregivers. Of the 45,683 pages, only 42 pages (or .1% of content) was related to family. Seventy-one percent of the texts reviewed had no content at all related to family caregivers (Table 1).¹⁵

An additional aspect of our work has been the area of cost, in which we have attempted to demonstrate the direct and indirect costs of family caregiving for patients in pain. Data from a study of 231 family caregivers of cancer patients with pain in which these caregivers estimated the costs

Table 1. TEXTBOOKS

Role/Needs of Family Caregivers in EOL Care	0	+	++
The importance of recognizing family and caregivers needs at EOL	57	37	6
Assessment of family needs	57	26	17
Family dynamics	83	13	4
Recognizing ethnic or cultural influences	91	2	7
Coping strategies and support systems	70	26	4
Average	71	21	8

* 0 = absent; + = present; ++ = commendable; EOL = end of life.

that they had experienced because of their loved one's cancer illness over the past three months include*:

Over the Past 3 Months	
Change in caregiver income	\bar{X} 33%
Total expenses	\bar{X} \$536 (range, 0-\$4000)
Travel expenses	
66% had expenses for travel	
42% had travel expenses related to pain	
mean cost based on \$0.31/mile = \$127	
Over-the-Counter Medications	
56% had out-of-pocket expense	
mean cost = \$77 range	\$1.37-\$600
related to pain	20%
Alternative Pain Relief	
18% incurred out-of-pocket expense	
mean cost = \$283	
Paid for household chores	32%
because of pain	18%
mean cost	\$386
Caregiver lost wages	23% yes
	29% no
	47% N/A
Was pain a factor?	21% yes
Time devoted to caregiving/day	
mean = 747 minutes range, 0-1440 minutes	
Time devoted to pain management	
mean = 194 minutes range, 0-1440 minutes	

This study included predominantly an elderly and low-income population. These statistics reveal the financial burden of caregiving in pain. Thirty-three percent experienced a change in their income. Total expenses over the last three months ranged from 0 to \$4000. Sixty-six percent had expenses for travel; of which 42% had travel expenses related to pain management. Over the past three months, 56% had out-of-pocket expenses for over-the-counter medications, and 20% of those expenses were related to pain. Eighteen percent had incurred out-of-pocket expenses related to alternative pain relief. Thirty-two percent of these family caregivers had paid someone else to do household chores often because of pain, and 23% had lost wages. An important finding was that caregivers estimated that they spent 747 minutes per day in caregiving. When asked to estimate how much time was devoted specifically to pain management, the average time was 194 minutes or more than three hours a day devoted to this task.⁹

An additional topic often viewed only from a professional rather than family caregiver perspective is the area of ethics. We often think of the

*From Ferrell BR, Grant M, Borneman T, et al: Family caregiving in cancer pain management. *J Palliative Med* 2:185-195, 1999; with permission.

dilemmas faced by health care providers in pain management. Yet in our research of family caregivers, we found family caregivers struggled with many ethical decisions. Family caregivers reported tremendous dilemmas in assessing or accepting the patient's report of pain. They made difficult decisions on a daily basis regarding which medicine to give, how much, and when to give analgesics. Family members struggled with titration, when to increase the dose, how to balance relief with side effects, fear of overdosing, and fear of addiction. Family caregivers felt responsible for unrelieved pain. They felt responsible for communicating with health care providers, with balancing goals of comfort versus care, and with causing pain while providing care. They felt responsible for pain relief at home and often reported spiritual and existential conflicts and a tremendous fear of the future.²⁰

Their dilemmas were echoed in questions such as "What will it be like tomorrow when my father's disease is worse?" "What is it like when you the daughter are giving that last dose of morphine to your father?" "What is it like to be at the bedside of someone with sickle cell disease, who has just been sent home from the hospital with totally inadequate pain management?" "What is it like to be the family caregiver seeing someone you love with AIDS in pain and realizing that that same experience may be yours in the near future?" Perhaps our most important research has been our qualitative work in which we have attempted to listen to family caregivers as they describe the experience of pain management. In these words a spouse describes his wife's pain:

She pretends she doesn't have any, but when it really gets bad she says, 'I just can't stand it.' She doesn't want anyone to know it hurts, but since her hospitalization we've made a pact that she'll tell me when she's hurting. She doesn't express her feelings loudly, so when she said it was hurting, you knew it was bad.

Other descriptors from family caregivers have described what it is like to become involved in caring for a patient in pain:

It is horrible pain. It's burning with a fever inside. It's aching, like turning a hot knife. It's horrible.

It's an unbearable pain. He said he just couldn't take it.

It's completely overwhelming. It radiates throughout her body, causing tremors. Sharp pain.

It's really painful; it never really goes away. It is so painful—she had a swollen tongue with sores down her neck. She says it's worse than childbirth.

We also have many examples where the family suffering associated with observing pain is even worse than their suffering associated with anticipating the patient's death. This is an example from a daughter describing her mother's pain:

She's just a shell of what she used to be . . . yeah, very, very feeble. Really difficult, difficult . . . for me that is by far the toughest part of this whole thing, seeing the effects of the disease, how it ravages, you know, ravages the body.

I feel a great deal of sadness. Being unable to do anything to control what's happening. Being unable to stop this thing that's happening to her... it isn't related to being able to prevent her death. It relates to being able to prevent all the suffering.

To summarize our research over the last 15 years, key findings of pain research involving family caregivers from these studies include:

- Pain is a major concern for family caregivers.
- Low correlation exists between patients and family caregivers regarding pain intensity, distress, concerns, or knowledge.
- Pain perspectives of family caregivers are influenced by the nature of the pain, its duration, and patient prognosis.
- Family caregivers have greater distress regarding pain than patients and perceive pain to be more intense.
- Family caregivers have many concerns and misconceptions regarding pain and its management.
- Pain is a metaphor for worsened illness and death.

Pain is a major concern for family caregivers. We have consistently seen a low correlation between patient and family caregivers regarding pain intensity ratings. The stress, concerns, and knowledge of the family caregiver are distinct from the patient. We believe that the pain perspective of family caregivers is influenced by the nature of the pain, its duration, and the patient's prognosis. Family caregivers have greater distress regarding pain than do patients, and caregivers perceive pain to be more intense. Family caregivers have many concerns and misconceptions regarding pain and its management. One interesting finding from our latest studies is that the family caregivers' fear of addiction and fear of tolerance were worse than the fear experienced by patients themselves.⁹ We also believe that pain is a metaphor for worsened disease and death, and therefore many family members deny that the patient is in pain to avoid the reality of the possibility of death.

RESEARCH METHODS

We have found many important methodologic issues in conducting family research in pain management. One constant challenge is in selecting instruments. Instruments and outcomes measured in family caregiving research include:

- Family APGAR (adaptation, partnership, growth, affection, resolved)
- Family pain questionnaire
- Quality of life—caregiver
- Family communication
- Social support
- Family functioning

- Caregiving demands
- Caregiver burden
- Barriers questionnaire
- Instruments applied from patient outcomes (Coping, Anxiety)
- Family finances survey
- Interview tools

Overall, we believe that there is a need for rigorous work to develop or to adapt instruments specific to the issues of family caregiving and pain.

There are many methodologic challenges in including family caregivers in pain research, including:

- Identification/definition of family
- Assessing individual versus family system outcomes
- Distinguishing family caregiver responses to illness versus pain
- Distinguishing family versus patient outcomes
- Assessing physical versus psychological or emotional burden and suffering
- Use of qualitative methods
- Need for instruments that reflect the current reality of health care and responsibility of family caregivers
- Determining the unit of analysis
- Gaining access to family subjects
- Subject burden
- Assessing cultural meanings of family, religion, traditions, and ethnicity

This begins with identifying who is family and which family members should be included. We also have struggled with assessing individual versus family system outcomes, and we have difficulties distinguishing the family caregiver's response to illness from their response to pain. For example, in research we conducted asking parents to describe their role in managing pain in their children, we first needed to provide the parents an opportunity to discuss what it was like to have a child with cancer before we could focus on what it is like to have a child with pain. This same pattern may well be true in assessing adult children's perspectives of a parent's illness versus their pain. There is also a need to distinguish family versus patient outcomes. We must assess physical versus psychological and emotional burden. Interestingly, in the literature, most work has focused on the emotional burden of family caregiving, and we know very little about the actual work of family caregiving in pain management. In terms of methodologic challenges, there is a tremendous need to combine both quantitative and qualitative methods. Much of our own research has been best illustrated through qualitative studies.

There is also a need for instruments that will reflect the current reality of health care and the responsibilities of family caregivers. We have experienced challenges in determining the unit of analysis; a statistical consideration when applying for funding and estimating sample size. Gaining

access to family subjects is also a challenge. For example, we generally interview family caregivers outside of the room or away from the patient so that their responses aren't biased by the patient. Similar to studying patients in pain, there is tremendous subject burden with family caregivers who are often older and sicker than the patients themselves. There are also many cultural factors, religious traditions, and ethnicity.

CLINICAL IMPLICATIONS

Beyond the research implications, there are important clinical implications, including:

Family caregiver involvement in pain management is significantly influenced by relationship, family developmental stage, and communication

The "community of suffering" offers support

There is a need to identify high-risk families

Determine family pain history

Use of family conferences

Empowerment through involvement in drug and nondrug interventions

Family care requires interdisciplinary care

Support requires attention to knowledge and experience

From our research, we have learned how to better support family caregivers at home and that family caregiver involvement in pain management is significantly influenced by the relationship. It is one thing to care for your spouse, but yet another to care for a parent in pain. Family developmental stage and communication become important. We have also learned that the community of suffering is important because family caregivers can gain much by support through other family caregivers who are also doing the work of pain management. We need to identify high-risk families for whom we should target our interventions in pain management, and we should also determine family pain histories as an influence on the experience. Just like other aspects of health care, we know that the use of family conferences in planning pain management would probably lead to greater success. Empowerment of families through involvement in both drug and nondrug intervention is valuable. Our task is to move family caregivers from a sense of helplessness to a sense of helpfulness. Family caregivers require an interdisciplinary approach. The work of psychologists, social workers, chaplains, and others is necessary to tend to these multiple needs. Support will require attention not only to their knowledge (i.e., teaching them about pain), but also to supporting their experience.

Table 2 summarizes the overall program of research as described above. Being witness to illness as a family caregiver can best be understood with the words of an African-American daughter from a very low-income family who described what it was like to deal with her mother's pain. The

Table 2. PROGRAM OF RESEARCH RELATED TO PAIN MANAGEMENT AT HOME/FAMILY CAREGIVERS PAIN AND FAMILY CAREGIVERS STUDIES 1984-1999

Study	Key Findings
Pain Management at Home ^{7,8}	Initial studies described the experience of pain at home and documented that pain is often not well controlled.
Family Factors Influencing Cancer Pain Management ^{9, 20}	This study described pain from the family perspective rather than the patient perspective. This research also documented the tremendous caregiver burdens of pain management and the family meaning of pain.
Pain Education for Patients and Family Caregivers ¹⁰	This intervention study developed and evaluated a structured pain education program that included both patients and family caregivers.
Dissemination of Pain Education in Home Care ^{5, 10, 21}	After developing and testing of the pain education program by the research team, this study extended the pain education to be provided by home care nurses.
Family Caregiver Quality of Life ⁹	Extended the QOL model including dimensions of physical, psychological, social, and spiritual well-being to family CG.
Cultural Adaptation of Pain Education ^{22, 23}	This research has extended the pain education program to Hispanic patients and also recognized the significant influence of culture on pain.
Ethical Issues in Pain Management ²⁰	This study compared the decisions and conflicts of patients, family caregivers, and home care nurses in pain management showing the immense dilemmas and conflicts in pain management.

words that she used caught our attention because she described herself as the family caregiver as being "disabled". She said:

When she does get that pain that I can't control that's when I feel disabled. And you should be able to, to stop that pain. And when that happens, I, I feel, what's a good word? I just feel disabled. I feel like I can't help her. I can't do what I'm supposed to do... That's when I can't fix her pain, I feel very, very disabled.

References

1. Berry PE, Ward SE: Barriers to pain management in hospice: A study of family caregivers. *Hospice J* 10(part 4):19, 1995
2. Boland D, Sims S: Family caregiving at home as a solitary journey. *Image J Nurs Sch* 28(part 1):55, 1996
3. Borneman T, Ferrell BR: Ethical issues in pain management. *Clin Geriatr Med* 12(part 3): 615, 1996

4. Dar R, Beach CM, Barden PL, et al: Cancer pain in the marital system: A study of patients and their spouses. *J Pain Symptom Manage* 7(part 2):87, 1992
5. Ferrell BR, Borneman T, Juarez G: Integration of pain education in home care. *J Palliat Care* 14(part 3):62, 1998
6. Ferrell BR, Cohen MZ, Rhiner M, et al: Pain as a metaphor for illness. Part II: Family caregivers' management of pain. *Oncol Nurs Forum* 18(part 8):1315, 1991
7. Ferrell BA, Ferrell BR: Pain management at home. *Clin Geriatr Med* 7(part 4):765, 1991
8. Ferrell BR, Ferrell BA, Ahn C, et al: Pain management for elderly patients with cancer at home. *Cancer* 74:2139, 1994
9. Ferrell BR, Grant M, Borneman T, et al: Family caregiving in cancer pain management. *J Palliat Med* 2(part 2):185, 1999
10. Ferrell BR, Grant M, Chan J, et al: The impact of cancer pain education on family caregivers of elderly patients. *Oncol Nurs Forum* 22(part 8):1211, 1995
11. Ferrell BR, Griffith H: Cost issues related to pain management: Report from the cancer pain panel of the agency for health care policy and research. *J Pain Symptom Manage* 9(part 4):221, 1994
12. Ferrell BR, Johnston-Taylor E, Sattler GR, et al: Searching for the meaning of pain. *Cancer Pract* 1(part 3):185, 1993
13. Ferrell BR, Rhiner M, Cohen MZ, et al: Pain as a metaphor for illness. Part I: Impact of cancer pain on family caregivers. *Oncol Nurs Forum* 18(part 8):1303, 1991
14. Ferrell BR, Rhiner M, Ferrell BA: Development and implementation of a pain education program. *Cancer* 72:3426, 1993
15. Ferrell BR, Virani R, Grant M: Analysis of end of life content in nursing textbooks. *Oncol Nurs Forum* 26(part 5):869, 1999
16. Ferrell BR, Rhiner M, Shapiro B, et al: The experience of pediatric cancer pain. Part I: Impact of pain on the family. *J Pediatr Nurs* 9(part 6):368, 1994
17. Ferrell BR, Rivera LM: Cancer pain education for patients. *Semin Oncol Nurs* 13(part 1):42, 1997
18. Germino B, Fife B, Funk S: Cancer and the partner relationship: What is its meaning? *Semin Oncol Nurs* 11(part 1):43, 1995
19. Horowitz KE, Lanes DM: *Witness to Illness: Strategies for Caregiving and Coping*. Reading, MA, Addison-Wesley, 1992
20. Johnston-Taylor E, Ferrell BR, Grant M, et al: Managing cancer pain at home: The decisions and ethical conflicts of patients, family caregivers, and homecare nurses. *Oncol Nurs Forum* 20(part 6):919, 1993
21. Juarez G, Ferrell BR: Family and caregiver involvement in pain management. *Clin Geriatr Med* 12(part 3):531, 1996
22. Juarez G, Ferrell BR, Borneman T: Influence of culture on cancer pain management in Hispanic patients (Part I). *Cancer Pract* 6(part 5):262, 1998
23. Juarez G, Ferrell BR, Borneman T: Perceptions of quality of life in Hispanic patients with cancer (Part II). *Cancer Pract* 6(part 6):318, 1998
24. Kristjanson LJ: Indicators of quality of palliative care from a family perspective. *J Palliat Care* 1(part 2):8, 1986
25. Kurtz ME, Kurtz JC, Given CC, et al: Concordance of cancer patient and caregiver symptom reports. *Cancer Pract* 4(part 4):185, 1996
26. Lederberg M: The family of the cancer patient. In Holland J (ed): *Psycho-Oncology*. New York, Oxford University Press, 1998, 981
27. Lobchuk MM, Kristjanson L, Degner L, et al: Perceptions of symptom distress in lung cancer patients: I. Congruence between patients and primary family caregivers. *J Pain Symptom Manage* 14(part 3):136, 1997
28. Longman AJ, Atwood JR, Sherman JB, et al: Care needs of home-based cancer patients and their caregivers. *Cancer Nurs* 15(part 3):182, 1992
29. Miaskowski C, Kragness L, Dibble S, et al: Differences in mood states, health status, and related pain. *J Pain Symptom Manage* 13(part 3):138, 1997
30. Rhiner M, Ferrell BR, Shapiro B, et al: The experience of pediatric cancer pain. Part II: Management of pain. *J Pediatr Nurs* 9(part 6):380, 1994
31. Robinson KM: Family caregiving: Who provides the care, and at what cost? *Nurs Econom* 15(part 5):243, 1997

32. Rowat KM, Knafel KA: Living with chronic pain: The spouse's perspective. *Pain* 23 (part 3):259, 1985
33. Sherman SE, Reuben D: Measures of functional status in community-dwelling elders. *J Gen Intern Med* 13(part 12):817, 1998
34. Ward SE, Berry PE, Misiewicz H: Concerns about analgesics among patients and family caregivers in a hospice setting. *Res Nurs Health* 19(part 3):205, 1996

Address reprint requests to

Betty Ferrell, PhD, FAAN
City of Hope National Medical Center
Nursing Research and Education
1500 East Duarte Road
Duarte, CA 91010

