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Family Perspectives of Ovarian Cancer

PURPOSE: This qualitative study explored quality of life (QOL) in family caregivers of ovarian cancer patients to better define their needs for support.

DESCRIPTION OF STUDY: One thousand one hundred pieces of correspondence written by family caregivers of ovarian cancer patients were contributed to the City of Hope investigators by the founder and editor of *Conversations! The International Newsletter for Those Fighting Ovarian Cancer*. The investigators analyzed meaningful comments in the letters using content analysis methods.

RESULTS: Comments by family caregivers reflected little concern for their own physical well-being and, instead, focused on the psychological, social, and spiritual aspects of their experiences. Correspondence on the psychological effects of caregiving demonstrated poor QOL stemming from feelings of lack of control and helplessness. Social data showed that family caregivers lacked support, were given to feelings of isolation, and experienced considerable anxiety regarding the genetic nature of the disease. Spiritual well-being was particularly important to caregivers, as they drew strength from their faith and were able to find positive meaning in their experiences.

CLINICAL IMPLICATIONS: The study findings revealed that caregivers require additional support from the healthcare community, especially to address disease-specific needs in patients with ovarian cancer. The correspondence demonstrates a need in family caregivers to connect with others fighting the same disease. This study also identifies the need for support for at-risk women, as well as a continuing need for palliative-care services.

KEY TERMS: Caregiver; Family caregiving; Ovarian cancer; Quality of life

The American Cancer Society estimated that 23,400 new cases of ovarian cancer were diagnosed in 2001. Approximately 13,900 women died of ovarian cancer last year.¹ Ovarian cancer accounts for 4% of all cancers among women and ranks second among the gynecologic cancers. Treatment is multimodal, including surgery, radiation therapy, and chemotherapy. Seventy-eight percent of patients with ovarian cancer survive 1 year after diagnosis; the 5-year relative survival rate for all stages is 50%. Unfortunately, only about 25% of all cases are detected at the localized stage. The 5-year survival rate for women with regional disease is 79%, but only 28% for those with distant disease.²

The purpose of this article is to contribute to the understanding of family caregivers' perspectives through narratives derived from ovarian cancer experiences. Caregivers often struggle alongside the patients to maintain their own quality of life (QOL) throughout their loved one's cancer experience. The physical, psychological, social, and spiritual QOL domains, as identified by Ferrell³ in a previous study, are affected in family caregivers as they compromise their own concerns to care for loved ones.

Literature Review

In a 1999 study by Houck et al⁴ concerning QOL for patients with advanced ovarian cancer, the most prevalent

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concern expressed by the patients as negatively impacting their QOL was the welfare of family and friends, who often are left physically and emotionally drained by the caregiving experience. This concern is reasonable, because families confronting serious illnesses have been found to experience as much, if not more, distress as the patients.⁵ At a time when the population is aging and healthcare services are reduced due to financial constraints, the number of family caregivers is increasing, as is their burden.⁶ It is already well-documented that more and more patients with cancer are receiving the vast majority of their day-to-day care from family caregivers in the home.⁷ A study by Arno et al⁸ estimated that the national economic value of all family caregiving in 1997 was \$196 billion, and that a large share of this was directed toward individuals with cancer. From the initial phases of illness through the time of death, family caregivers contribute to the patients' QOL and, as a part of this process, are defining their own needs.⁹

Most existing research on family caregiving has involved surveys and interviews with researchers and caregivers. In general, findings highlight the chronic and consuming nature of caregiving and show that caregivers have diminished QOL.^{10,11} Frequently given to feelings of depression, family caregivers typically experience fear of loneliness, a sense of helplessness, lifestyle disruption, and uncertainty.¹²⁻¹⁴ This uncertainty can be exacerbated by ineffectual communication from healthcare providers.¹⁵ Caregivers also struggle with the possibility of their loved ones' deaths, alternately attempting to avoid death and welcoming it as a relief for the patient from extreme pain.¹⁶ Often significantly involved in symptom control and pain management and entirely responsible for household tasks, caregivers believe that their roles have a negative impact on their health, energy, and schedule.¹⁶⁻¹⁸ To remedy these stressors, they frequently engage in a lifestyle pattern that shifts between periods of self-care and periods of caregiving,¹⁹ seeking support through formal and informal networks.²⁰ Family caregivers also use personal strategies that include taking time for themselves, maintaining a sense of humor, and focusing on the present.²¹ Employing the services of hospice organizations has been shown to be particularly effective in reducing caregiver distress in taking care of patients with advanced disease.¹¹

Although caregiving is consistently demonstrated to lessen QOL in caregivers, the positive aspects of the experience also have been documented.^{12,22} A 1997 study by Carson revealed that providing care for a loved one, although stressful, could produce spiritual growth in the caregiver.²³ Similar studies show that considerable meaning is derived from caregiving in that caregivers experience self-transcendence by being with or doing for a loved one.²⁰ Caregivers also have been shown to experience hope as a response to their experiences, and the most common object of this hope has been for a cure.¹⁵ While previous research has been based on structured surveys or interviews, this study sought to augment the existing body of knowledge by exploring the experience of the caregiver in an unprompted fashion, through natural correspondence. This study provides a unique view of the experiences and concerns of the family caregivers of patients with ovarian cancer.

The data reported within this article were derived from family member correspondence sent to a newsletter, *Conversations!: The International Newsletter for those Fighting Ovarian Cancer*. The editor, Cindy Melancon, began the newsletter in 1993 after receiving her own diagnosis of ovarian cancer. Feeling a strong need to connect with other women sharing her own diagnosis, she issued an announcement through a church newsletter requesting correspondence with other ovarian cancer survivors. After receiving 10 contacts, Cindy initiated the newsletter to meet "a driving need to connect with others who are fighting the same cancer." Cindy emphasizes that each issue is written "with a cup of tea at my side and a prayer in my heart for all of us—those diagnosed, our family and friends and caregivers, and our healthcare professionals—who are fighting ovarian cancer." Nine years and 114 issues later, the newsletter written each month "on a wing and a prayer" is distributed to 3600 persons in all 50 states and 30 countries. The actual outreach of the newsletter is likely to be larger in scope, because individuals are encouraged to duplicate the newsletter and to distribute it to all who would find it helpful. The newsletter project has now become a 501-C3, not-for-profit corporation, is eligible for donations, and has a web site at www.ovarian-news.org.

Each issue of the newsletter addresses a broad range of topics. As the editor, Cindy encourages communication from readers on topics for upcoming issues, and thus received a significant volume of correspondence between 1993 and 2000. Cindy's connections with the City of Hope investigators began in 1994, when, after reading their research related to QOL issues in patients with breast cancer, Cindy suggested that similar research be done with ovarian cancer survivors. A survey of the *Conversations!* readership was conducted and was subsequently published in the *Western Journal of Nursing Research*.²⁴

In 2001, Cindy again contacted Dr. Betty Ferrell to suggest that the correspondence from the newsletter be analyzed to more broadly share the experiences of the *Conversations!* readership with others. The total archived correspondence was sent to the City of Hope investigators. A total of 21,806 letters were received, of which approximately 1,100 were found to be communications from family caregivers.

Methods

The data for this analysis consisted of all correspondence sent by family caregivers from the time period 1993 to 2000. The correspondence was sent in a variety of formats, primarily on personal stationery, greeting cards, and, particularly in recent years, by email. The data were considered to be ethnographic in nature as the natural correspondence between members of a newsletter mailing list that functions to a degree as a support group. The study was approved by the City of Hope Institutional Review Board.

The steps of the analysis were as follows: 1) all original data were numbered to provide identification, and the data then were duplicated and the copies were organized in numerical order for further analysis so as to protect the

integrity of the original documents; 2) the data were then read by one of two research assistants to bracket significant responses that could be useful for written analysis, and all identifying factors, including patient, family, and doctor names, and treatment centers, were changed to preserve the confidentiality of the data; 3) the data were analyzed using content analysis techniques²⁵ in which themes from the data were identified in the margins; 4) after all data were bracketed and the initial content codes were assigned, the investigators used a “cut and paste” approach to place the comments into tables that were organized according to the individual items within the four QOL domains of the Quality of Life-Family instrument^{16,26-28}; 5) the research team met on a weekly basis to review the process and analysis, and all aspects of the bracketing, coding, and cutting and pasting were validated by the principal investigator and a master’s degree-prepared research specialist with extensive experience in qualitative data; and 6) several revisions of the final analysis tables were prepared and reviewed by the research team, and the final tables also were reviewed by two experts in the area of family caregiving and cancer.

Results

Summary of Comments

While the analysis of the data from family members was primarily qualitative in nature, the investigators also attempted to quantify the number of responses across categories to determine the frequency with which various QOL concerns were discussed. Table 1 summarizes the comments according to each specific aspect of QOL. The comments are summarized according to the items of the Quality of Life-Family instrument.³

There were 46 comments in the category of “physical well-being.” However, only four comments by family members were related to their own physical health. These were under the headings of “fatigue” and “overall physical health.” Comments were primarily related to the physical health of the patient. “Psychological well-being” was an extensive category, with 99 comments falling under the 18 individual themes in this domain. The most common comments in this extremely variable domain were overall coping with the illness, distress of cancer treatment, and sense of helplessness. The “social well-being” domain included a total of 76 comments, with the most common themes being need for support and the sense of isolation.

The “spiritual well-being” domain received the highest number of comments, with a total of 170 responses coded in this category. The most common themes included positive changes in life, purpose and mission in life, spiritual life, and end of life. There were several issues communicated from the family caregivers beyond the framework of the QOL domains. Experiences with healthcare providers, including opinions of physicians and attitudes regarding hospice nurses/hospice care, did not fall into any of the domains and were classified as “other.”

Table 1. Summary of Comments by Quality-of-Life Item

<i>QOL Item</i>	<i>No. of Comments</i>
Physical well-being	
Physical well-being of patient*	30
Alternative therapies*	12
Fatigue	2
Overall physical health	2
Aches or pains	0
Sleep changes	0
Physical well-being subtotal	46
Psychological well-being	
Psychological well-being of patient*	29
Coping	26
Distress of cancer treatments	22
Helplessness	21
Distress of initial diagnosis	9
Control	7
Overall psychological well being	7
Quality of life	6
Fear of recurrence/metastasis of cancer	6
Belief in cause of disease*	5
Anxiety	3
Depression	3
Happiness	2
Satisfaction with life	1
Concentration/memory	0
Distress of time since treatment completed	0
Fear of future diagnostic tests	0
Fear of a second cancer	0
Psychological well-being subtotal	99
Social well-being	
Family history of cancer—genetic threat*	35
Support	15
Isolation	10
Family distress	5
Personal relationships	4
Financial burden	4
Activities at home	2
Employment	1
Sexuality	0
Social well-being subtotal	76
Spiritual well-being	
End of life*	90
Positive changes/meaning in illness	22
Purpose/mission for life	21
Spiritual life	18
Hopefulness	17
Spiritual activities	2
Participation in religious activities	0
Uncertainty	0
Spiritual well-being subtotal	170
Other issues—care providers*	
Experience with physician*	44
Home health/hospice*	12
Other issues subtotal*	56
Total	447

*Comments not included in the original QOL framework.

Qualitative Data

The findings of this study provided a unique opportunity to explore QOL in an area that is little known. The naturalistic framework offers a candid look at the caregiving experience for the family members of ovarian cancer patients. Thus, the unprompted correspondence that comprises the data emphasizes the issues that are most pertinent to the caregivers of women with ovarian cancer.

The investigators have summarized some of the most illustrative comments from a review of the data. Table 2 presents examples of comments regarding the physical well-being of the family members. While the frequency of the data revealed that physical problems were not commonly reported by the caregivers for themselves, the fatigue and stress that are indicated illustrate the burden on family members in caring for a loved one with ovarian cancer. The physical stress of caregiving was not as prevalent throughout the data as in previously published studies.²⁹ Perhaps family members are hesitant to express their own health concerns given the serious health concerns of their loved ones. The data agree with a 1999 study by Enyert et al, which found that experiencing fatigue was an expected part of caregiving and was therefore not a concern that caregivers were likely to raise with investigators.¹⁹ Additionally, the general intent of caregivers in writing to the *Conversations!* newsletter was to better support the patient rather than their own physical well-being, as is demonstrated by the large number of comments made concerning the patient's physical health. Families were vigorous in their exploration of alternative and complementary therapies. Often they still hoped to find curative options long after the patient had exhausted all conventional treatment options.

Table 3 presents example comments related to psychological well-being. The psychological distress of caring for a family member with ovarian cancer is acutely present throughout the correspondence. The spectrum of issues that caregivers relate supports the concept that they experience psychological distress as much as, if not more than, the patients. This distress stems from family members' lack of control and feelings of helplessness, which are exacerbated by fears of recurrence and the stress of the initial

diagnosis related to the silent nature of ovarian cancer symptoms. Family caregivers also frequently expressed distress concerning the cancer treatments that the patients were receiving, because these treatments were often intensive and prolonged with significant side effects. Many caregivers identified closely with the illness experience, frequently referring to ovarian cancer as "our" disease. This included male caregivers who struggled to identify emotionally with a cancer to which they could not relate physically. Concern for the patient's psychological well-being was also a frequent topic.

Table 4 presents examples of comments related to social well-being. The most prominent themes in the social well-being data highlight the isolation that family members experience, while concurrently praising support systems such as the *Conversations!* newsletter for relieving this anxiety. *Conversations!* was a welcome support system as it provided a connection to others who were also caring for a family member with ovarian cancer. The value of this cancer-specific support was noted by a caregiver who stated, "It's funny how someone you don't even know can reach out and give you hope." Caregivers were comforted by others fighting ovarian cancer, because they were able to relate to and support one another through emotional struggles with the genetic association and often late-stage nature of the disease. They also shared helpful experiences and information regarding treatment and symptom-management techniques.

Concern for other family members as well as the effect of ovarian cancer on personal relationships within the family also was discussed by caregivers. As the genetic association of ovarian cancer grew, so too did many women's fears that they would share the fate of their loved one. The additional burden that this threat presented to family caregivers weighed heavily on female relatives, and it was also a source of anxiety for spouses as they feared for their daughters.

Spirituality emerged as the most prominent QOL domain throughout the data (Table 5). The *Conversations!* newsletter frequently includes inspirational poems and scripture, establishing a forum in which topics such as the meaning of illness, transformations in life, and other aspects

Table 2. Physical Well-Being

Items	Comments
Fatigue	"I am very tired, but seem to be somewhere in Oz after this very traumatic roller coaster over the past two weeks, and looking back at five years since my wife's diagnosis."
Overall physical health	"I developed a complex of physiologic problems. The burial was on the 18th, and that night I experienced symptoms which suggested respiratory problems but which I now suspect was a parasympathetic rebound from the weeks of tension."
Alternative and complementary therapies	"My mother wanted more than anything to beat this beast. She tried everything with complete faith. Along with the chemo, we tried Sharks Cartilage, Essiac Tea, Cat's Claw, you name it . . . we did it, or she did it. I took her to special 'energy centers,' I prayed, I lit candles, my Father and I lived on the Internet looking, searching, praying."
Physical well-being of patient	"Pain is still bothersome and goes from mild to bad and we have dealt with and gone through a variety of emotions. We, being her family, just feel so helpless."

Table 3. Psychological Well-Being

<i>Items</i>	<i>Comments</i>
Coping	"My mom seems to be handling this better than myself! I'm really trying to cope, but some days really test my strength."
Overall quality of life	"I am 36 years old and have not had cancer myself. But I've been in the trenches with my mother for 13 long years. They might as well have been putting each needle into my own arm, as I felt each and every one."
Control	"It's hard for me to give up—I'd like her to keep going to the doctor's until she's better, but that's not my decision, and even if it were, it's probably not very realistic."
Helplessness	"I would like to close by saying that being a caregiver (and I was not alone) to my mom was emotionally and physically exhausting. It is heart wrenching to see the person, who took care of you all of your life, suffering and scared. There were so many times that I did not know what to do. I did not know how to help her. My mom was always the person that I went to for guidance and now she needed me to be the strong one."
Distress of initial diagnosis	"It was a complete shock to all of us when we found out. It angered all of us to find out that there is no test that could have detected this horrible cancer. The survival rates alone should make someone think that this is serious enough that research needs to be done. It's disturbing to know that with technology today that there is no machine that can detect this. If someone can invent a machine that x-rays the brain or lungs, then there should be one that x-rays the ovaries instead of inventing TV's in cars, car phones, or computers that fit in your pocket."
Distress of cancer treatments	"With stage 3 diagnosed March '98 and all the chemo, and radical stuff she has been through since, we figured if cancer didn't kill her, all the treatments would."
Anxiety	"I just don't understand why the chemotherapy did not work this time. I can only tell you that, I am, yes I am anxious and will dig way down deep to make certain that she is kept happy and that I show no anxiety that will suggest otherwise to her." "I would go to school and teach for four hours and worry the entire time I was gone that something might happen to her, and I wouldn't be there to help her."
Fear of recurrence	"I am so scared that it will come back and pray to God everyday that I can have her with me for many, many years."
Overall psychological well-being	"I am just disturbed, confused, anxious, emotionally drained and feel trepidation about the future."

Table 4. Social Well-Being

<i>Items</i>	<i>Comments</i>
Support	"As a 'caring partner,' I constantly struggle to balance my emotions and needs with what support Susan needs. My fears, concerns, questions and needs come second to those of Susan. I agree that 'the system' assumes the 'caring partner' will be alright and therefore concentrates its efforts on the person who is sick. I truly believe that if one is to survive cancer, the 'whole person'—emotionally, physically, and environmentally—must be taken care of. This cannot be achieved if the people charged with helping are not taken care of as well."
Personal relationships	"This whole experience has brought me so much closer to my mom and dad. We talk about things I don't think would ever have come up without this."
Employment	"I have retired from my business and am spending my time as her full-time husband and caregiver."
Activities at home	"My father and I have spent the last few months taking care of my mom, bringing her ice chips, making her icy grapefruit drinks (her favorite), holding her hand, praying with her, helping her to the bathroom, watching <i>Oprah</i> and <i>Touched By an Angel</i> with her, washing her sheets, flushing out her PEG tube, doing anything in our power to help care for her, and now she's gone."
Isolation	"This disease that randomly strikes out and grips women worldwide in its relentless vice, also pulls at the men who share their lives. We are bound together in this fight, and there is never a need for us to feel alone or defeated."
Financial burden	"We ran out of health insurance coverage after \$1,000,000 major medical cap was exceeded. Today I face a daily battle to raise a son and battle doctor bills and other professional agencies who want more. What more is there to give? My life, my son, my house or my car."
Family history—genetic threat	"My other problem is I diagnose myself with cancer every other day and I fear for my daughters." "Her mother died at 51 of pancreatic cancer. Seems we can't break the pattern. Her two sisters have had prophylactic hysterectomies as a result of her diagnosis."

Table 5. Spiritual Well-Being

<i>Items</i>	<i>Comments</i>
Spiritual activities	"Beautiful morning and just thanked God for the bliss of this new wondrous day. Do that each day as a matter of fact. Just my way and opinion. Makes me feel better. I feel much better though when my wife has a good day and yesterday was another. So I thank God each day for one more day of quality life."
Spiritual life	"God has played a big (understatement) part in the last 6 years—and He sends us people like you to provide info, support and HOPE."
Positive changes in life/meaning in illness	"Being intensely involved in helping her die was the most profound experience of my life. Opening our souls to the flow of grace made the journey not only bearable, but wondrous."
Purpose, mission for life	"A few days before she died, she kept saying 'Why, Why,' I wish I had an answer for her. I have not seen anyone suffering more than she has in the last 3 years since her initial diagnosis. I am planning to devote my life to ensure that no other woman has to go through this again."
Hopefulness	"Indeed, as long as we take one breath, there is always hope. We learned that." "We are a family living with Hope . . . Watching a woman, So brave and so strong, While the rest of us struggle and wonder How long? Please, work your magic, I know it exists. My faith has been tested, I can feel myself resist."
Death	"Her death was beautiful—spiritually, and that far outweighs the ugliness of disease, emaciated flesh and the messiness of physical death. Mom had hoped in her very deepest wishes that she die peacefully with no struggle and surrounded by love. She stopped the 'work' of dying about a half hour before her actual death, so her passing was no more difficult than slipping thru a doorway. In fact we almost didn't notice it because we were very busy being a family—sharing growing up memories and falling in love with our pasts—the good things."

of spirituality are discussed. Thus, family members likely thought that it was a welcome place for expressing spiritual beliefs. Faith bestowed many caregivers with the strength to draw positive meaning and to assign purpose to their experience with ovarian cancer; many family members wrote about the positive changes in their lives. Once the patient had died, family members found solace in their spiritual beliefs. Because of the limited public knowledge regarding ovarian cancer and its symptoms, many family caregivers looked to advocacy and education as a mechanism through which to channel this newfound purpose. The ability to maintain hope while facing a cancer with a typically poor prognosis also was discussed frequently by the caregivers. Most of the data concerning hospice care and death reflected a positive experience for the caregiver. However, although many cited the dying process as being positive, accepting that their loved one was gone and that

their role as a caregiver had ended often was reported as being difficult.

The unstructured, naturalistic source of the data provided a wealth of information beyond the QOL domains (Table 6). The opinion of doctors was a particularly prevalent topic among caregivers. Negative comments reflected a desire for more information from healthcare professionals, and occasionally blame was laid for late-stage diagnosis. However, many positive comments also were made in thanks to physicians who gave time and information above expectations.

The rare, candid source of data reported in this article enabled a poignant investigation of the experience of caring for a family member with ovarian cancer. This study was limited to narrative data of a socially proactive group of ovarian cancer caregivers. Further research is needed to assess caregiver QOL in this population, using both quan-

Table 6. Other Issues

<i>Items</i>	<i>Comments</i>
Opinion of physician	"At first I wanted to blame my mom's oncologist for her quick death—but he really did offer her the most up-to-date treatment available and she liked and trusted him—which is very important in such an intimate relationship." "My wife complained to her doctor for 2 years about symptoms that are typical of ovarian cancer. I am convinced that if the doctor had listened and ordered the proper tests, the cancer would have been detected at stage 1 or 2, rather than at stage 3C. The really sad part is, I doubt that this doctor will not do anything different with the next patient who has the same complaints."
Hospice care	"My dad and I were with her the last two nights at hospice. She was not in pain and the staff treated her with the most gentle love and care I have ever seen . . . After spending 4 months and 2 days at hospice, these people had become our new family. They hugged us and prayed with us and told us that we wanted to know about death."

Table 7. Ovarian Cancer/Family Caregiving Resources

www.Oncology.com

Sponsored by the American Society of Clinical Oncology (ASCO). A website for people living with cancer. Offers extensive caregiving resources with a section specific to ovarian cancer

Conversations! The Newsletter for Those Fighting Ovarian Cancer

PO box 7948

Amarillo, TX 79114-7948

www.ovarian-news.com

Family Caregiver Alliance

A good resource for general caregiving support

http://www.caregiving.com

National Ovarian Cancer Coalition (NOCC)

500 NE Spanish River Boulevard, Suite 14

Boca Raton, FL 33431

1-888-Ovarian

www.ovarian.org

Ovarian Cancer National Alliance

910 17th Street, NW, Suite 413

Washington, D.C. 20006

www.ovariancancer.org

Gilda's Club Worldwide

322 Eighth Avenue, Suite 1402

New York, NY 10001

(917) 305-1200

www.gildasclub.org

titative and qualitative methods in conjunction with access to demographic and treatment data. These *Conversations!* with ovarian cancer family caregivers provided a unique insight into the need for future research and quality care.

Clinical Implications

Correspondence from the family caregivers of women facing ovarian cancer reveals critical areas of needed support. Family members emphasized psychosocial and spiritual needs. The importance of complementary therapies primarily aimed at a cure of the disease was significant, as was the need to share experiences with the medical providers. Thus, family caregivers need to be regarded as active participants in healthcare. This consideration would potentially help to quell their sense of helplessness and lack of control.

The correspondence highlights the valuable support offered through the newsletter and reinforces previous research documenting the value of peer support and the sharing of common experiences. This national network of support offers a means by which to discuss the unique aspects of ovarian cancer that were echoed throughout the data as being vitally important.

Most of the literature has acknowledged the importance of in-person support such as focus groups or individual counseling.³⁰ Support groups also function to disseminate awareness and education to caregiving families. Table 7 includes sources for support for patients with ovar-

ian cancer and their family members. Continuing to educate the families about the risk factors for and early symptoms of ovarian cancer, as well as about genetic testing and counseling, will help to alleviate the feeling of personal threat that many family members experience. These data also recognize the continuing need for hospice support during advanced illness and for bereavement support.

Family caregiving in cancer is an enormous challenge with both shared and unique concerns across diagnoses. The means of support include personal counseling and participation in group support but also are provided through more distant means such as web sites, newsletters, and email correspondence via listservers. The newsletter *Conversations!* provided a source of support and communication for family caregivers. The voices spoken through this newsletter and analyzed in this research have provided important messages for healthcare providers.

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