

After Cancer Treatment Ends—The Impact on Caregivers and Families

Report of Focus Groups with Caregivers And Oncology Social Workers

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Executive Summary

Background and Method

The National Cancer Institute's (NCI) Office of Education and Special Initiatives (OESI) and Office of Cancer Survivorship (OCS) are collaborating to produce the "Facing Forward" series, a collection of resources designed to address the needs, concerns, and interests of cancer survivors and their families. Two publications are already available in this series. The third component will focus on the unique information needs of caregivers and other family members. As an important step in the development process, OESI and OCS commissioned a study to gather in-depth qualitative data about the thoughts, feelings, issues, concerns, and challenges that caregivers and their families encounter, once cancer treatment has been completed.

This study examined three subgroups with distinct needs: (1) spouses and partners of adult survivors, (2) other adult family members caring for adult survivors, and (3) children of adult survivors. Because of clearance issues and ethical concerns, however, information about children's needs and concerns was gathered through discussions with oncology social workers and, to a lesser extent, with parents, rather than by interviewing children directly.

For this study, NCI conducted a total of 11 telephone focus groups:

- Two groups with female spouses/partners age 55 and older
- Two groups with male spouses/partners age 55 and older
- One group with female spouses/partners age 21-54
- One group with male spouses/partners age 21-54
- One group with other adult caregivers age 21-45 (mixed gender)
- One group with other adult caregivers age 46 and older (mixed gender)
- One group with caregivers who are part of the NCI Consumer Advocates in Research and Related Activities (CARRA) program (mixed age and gender)
- Two groups with oncology social workers

Caregivers were required to have a surviving family member (other than a child) who had been treated for cancer within the past five years. Potential caregiver participants were recruited and groups configured to reflect diversity of age, race/ethnicity, education, type of cancer and treatment. Oncology social workers were required to have at least three years of professional experience counseling caregivers and children. They were recruited for diversity of race/ethnicity, client population, practice setting, and geographic location. Out of the total 102 participants, slightly over one-third (36 percent) were minority.

Key Findings

- Caregivers found it somewhat difficult to distinguish between their needs and concerns during treatment versus post-treatment. They described the cancer experience as one long continuum, rather than a series of discrete stages. Although the majority of the discussions focused on post-treatment issues, caregivers also identified the treatment phase as a physically demanding and emotionally stressful time.
- The early post-treatment phase is highly stressful for caregivers and their families.
 - Caregivers usually look forward to the end of treatment with great anticipation, only to find they still face many challenges.
 - Many are surprised and saddened to learn there is no quick turnaround after treatment ends.
 - Caregivers commonly suffer from various physical and emotional manifestations of stress in the post-treatment period.
 - The post-treatment period often hits caregivers especially hard because they are not emotionally prepared for it.
- Spousal caregivers may find it especially difficult to negotiate the post-treatment transition.
 - Loneliness and isolation are common problems. Spouses can become so immersed in the caregiving role that they lose track of their own needs.
 - Spouses typically go through a period of grieving as they come to terms with the loss of control over their lives.
 - For both husband and wife caregivers, one of the most difficult challenges is coping with the loss of self-esteem, moodiness and depression that often affects the survivor after treatment ends.
 - In the post-treatment period, caregivers must often overcome physical and emotional challenges in order to rebuild a sexual relationship with their partner.
- Adult children, siblings, and other family members also face challenges in the post-treatment period.
 - Non-spousal caregivers (especially young adult children) often put their careers, schooling, families, and life plans on hold while their family member is in treatment.
 - Post-treatment can be a confusing time as these caregivers try to figure out when and how to get on with their own lives.
 - Adult children may find it emotionally overwhelming to see a parent go through a prolonged period of physical and/or emotional suffering.
- For caregivers and families, probably the most difficult long-term challenge is living with the fear of recurrence. Every physical symptom and every follow-up checkup are cause for anxiety.
- In some cases, cancer has a significant impact on the family income and the caregiver's work and career options long after treatment ends. The caregiver's future job choices may be heavily dependent upon ensuring health insurance coverage.

- Long-term positive effects of post-treatment include a greater appreciation for life; stronger, closer relationships with family and friends; and commitment to a healthier lifestyle.
- After treatment ends, caregivers find support through a variety of channels, most notably family and friends, religious/spiritual faith, and networking with other cancer survivors and caregivers. Many caregivers also find it highly empowering to become involved in cancer volunteerism and advocacy.
- The post-treatment period may be a particularly reactive time for children and families:
 - Once the crisis of treatment is over, emotions that were put on hold can easily erupt.
 - During treatment, young children may feel pressure to behave perfectly and not cause trouble. After treatment is over, these children may “fall apart.”
 - Older children often take on additional responsibilities while the parent is in treatment. When treatment ends, these children may vent their repressed anger.
 - Teenagers who assume greater independence while a parent is undergoing treatment often display resentment later on when one or both parents step in to reassert authority.
 - Teenagers heading off to college may find it difficult to balance the desire to leave home with their sense of obligation to stay.
- Professionals stress the importance of open, honest communication with children through all stages of the cancer process, including post-treatment. The dialogue that takes place between parent and child once treatment is over should be an extension of the communication and trust that has been established all along.
- Even if they do not ask directly, children are most likely to worry about:
 - “Will my mom/dad/(other family member) die?”
 - “Is it going to happen again? Are they going to get sick again?”
 - “Who will take care of me?”
 - “Is it contagious? Can I get it too? Should I be worried?”
 - “My stomach/head/(other body part) hurts. Does that mean I have cancer, too?”
- Participants indicate there is clearly a need for more information and support on the topic of caregiving. Caregivers would like NCI resources to focus on caregiving across the entire continuum of cancer, including but not limited to post-treatment.
 - Resources for the caregiver should address both how to care for one’s loved one throughout the cancer experience, as well as how to care for oneself.
 - Caregivers are particularly interested in resources that offer personalized support from other caregivers. Telephone and online resources would be ideal. Telephone offers the advantages of anonymity and accessibility. Online resources are anonymous and provide information on demand.
 - Electronic resources, including Internet, television, video, and CD-ROM are considered most effective at reaching older children and teenagers.
 - Some caregivers would prefer to know about post-treatment issues from the very start, when their family member is diagnosed. Others would prefer to wait until midway

through treatment. All believe they should be informed about post-treatment before they reach that stage.

Recommendations

- NCI's caregiving resources should give approximately equal weight to caring for one's loved one and caring for oneself. Under the topic of patient care, caregivers wish to know:
 - How to prepare for medical visits
 - How to research cancer on the Internet
 - How to seek and reconcile different medical opinions
 - What the patient/survivor is likely to experience physically and emotionally throughout the cancer process
 - How the caregiver can best support the patient/survivor at each stage
- The section(s) pertaining to "caregiver care" should include:
 - A description of the various emotions caregivers commonly experience
 - Tips on self-care: keeping up with exercise, friends, and activities
 - The importance of networking with other caregivers
 - The importance of seeking support and assistance from family, friends, and community
 - Warnings about signs of stress and medical risks, including depression
 - General advice about financial and insurance concerns
 - Information about the value of cancer volunteerism and advocacy
- For reaching the adult caregiver audience, NCI may wish to consider establishing one or more of the following:
 - A telephone resource line that caregivers could call to be directed to appropriate resources in their local community
 - A program that puts caregivers in touch with other caregiver mentors who agree to provide one-on-one support via telephone
 - Periodic telephone support groups or "town meetings" for caregivers to share common concerns and strategies
 - A section of the NCI Web site for caregivers. This space could sponsor various resources, including an electronic bulletin board for caregivers to post questions and responses or review past topic threads; small, moderated chat rooms that would allow caregivers to network with one another; guest "speakers" discussing a "topic of the week"; and more.
 - Videotapes showing scenarios that role-model effective communication between spouses/partners or parents and children as they confront common post-treatment concerns.
- Resources should be translated into various languages and should be written and designed in such a way that they relate to the needs and concerns of minority subgroups. Materials directed at some minority audiences need to help break down the taboos surrounding cancer.
- NCI may wish to further explore the need for separate caregiver resources for men and women.

- For reaching older children and teenagers, NCI should consider the following:
 - An online Web site aimed at older children/teenagers whose parents are survivors. Similar to the adult Web site, this space might include a bulletin board, small moderated chat rooms, past threads' and guest speakers.
 - Television, videotapes, and interactive CD-ROMs that help normalize the cancer experience by portraying other children/teenagers facing the same challenges
- Caregiver resources should be designed in a modular fashion, with separate sections on diagnosis, treatment, and post-treatment issues, so that caregivers can easily find the information they are looking for at the time. Information about post-treatment should be made available to caregivers no later than midway through the treatment process. Some caregivers would prefer to have this information earlier (i.e., at the point of diagnosis or start of treatment).

I. Background

The National Cancer Institute's (NCI) Office of Education and Special Initiatives (OESI) and Office of Cancer Survivorship (OCS) are collaborating to produce the "Facing Forward" series, a collection of resources designed to address the needs, concerns, and interests of cancer survivors and their families. Two publications are already available in this series.

- *Life After Cancer*, which addresses the physical and psychosocial needs of cancer survivors
- *Making A Difference in Cancer*, which focuses on ways to become active in cancer causes and "give back" to the community

The third component in the series will focus on the unique information needs of caregivers and other family members, and will cover issues such as:

- What to expect from the survivor once treatment has ended
- Special needs of caregivers that arise from caring for someone else
- Risk to caregivers and other family members of specific medical and psychosocial conditions
- Effective coping skills for caregivers and other family members

Preliminary planning for the development of this material has already included:

- Conducting an extensive review of the literature
- Performing an environmental scan of existing educational materials, and assessing how they have visually and contextually been presented to the public
- Consulting with experts in family survivorship issues

An additional important step in the development process is to conduct formative research with caregivers themselves about the thoughts, feelings, issues, concerns and challenges they encounter once cancer treatment has been completed. For this purpose, OESI and OCS commissioned a qualitative research study in the form of focus groups, the results of which are reported here.

In a literature review reported under separate cover,¹ OESI and OCS suggest four subgroups with distinct support needs who would benefit from specialized interventions: (1) spouses and partners of adult survivors, (2) other adult family members caring for adult survivors, (3) children of adult survivors, and (4) parents of pediatric cancer survivors. Early discussions with OESI and OCS established that the initial wave of qualitative research would concentrate on the

¹ National Cancer Institute Office of Education and Special Initiatives/Office of Cancer Survivorship - Preliminary Resource Proposal for Educational Material(s)

first three groups only, omitting parents of pediatric cancer survivors who represent a highly specialized audience worthy of separate examination. In addition, due to permission and clearance issues as well as ethical concerns, it was decided that information about children's unique needs and concerns would be gathered mainly through discussions with oncology social workers and, to a lesser extent, with parents rather than by interviewing children directly.

For purposes of this study, the objectives for spouses, partners, and other adult family members were:

- To probe the medical, psychological, social and economic late effects of cancer and its treatment for survivors and their families
- To identify methods for coping with the late effects of cancer and its treatment and to identify predictors of successful coping
- To explore ways of strengthening family adaptation and cohesion
- To identify sources of support from family, friends, health professionals, and community
- To recognize how cancer can positively affect the family experience

For children, the objectives were:

- To explore the difficulties that children and adolescents commonly experience when a parent undergoes cancer treatment and enters the survivor stage;
- To learn about the ways that having cancer in the family can affect a child/adolescent somatically, psychologically, emotionally, academically and socially;
- To identify useful coping strategies for children, as well as predictors of successful coping; and
- To identify sources of support from family, friends, health professionals, and community.

II. Methods

For this study, NCI conducted a total of 11 telephone focus groups, as Table 1 shows.

Table 1. Focus Group Composition

Subgroup	Male	Female
Spouses/Partners (age 55 and older)	2	2
Spouses/Partners (age 21-54)	1	1
Other adult caregivers (age 21-45)	1	
Other adult caregivers (age 46 and older)	1	
CARRA advocates and caregivers	1	
Oncology social workers	2	

The study involved 102 participants, including 73 caregivers, 20 oncology social workers, and 9 family caregivers representing NCI's CARRA² program. Among all participants, 36 percent were minorities. A professional research firm implemented the recruiting by using in-house databases, cancer advocacy organization contacts provided by NCI, and print ads in select minority media outlets. Copies of all screener questionnaires are included in Appendix A.

For this study's purposes, caregiver was loosely defined as an individual who helped care for someone during and after cancer treatment. To qualify for the study, caregivers were required to have a surviving family member (other than a child) who had been treated for cancer within the past five years. Potential participants were recruited and groups configured to reflect diversity with respect to age, race/ethnicity, and education. Special effort was also made to recruit for a variety of cancer types and treatments. Table 2 summarizes caregiver characteristics.³

² The NCI's CARRA program is comprised of consumer advocates who provide viewpoints and ideas directly to NCI staff on an as-needed basis. Cancer survivors and family members apply for membership in the program, which carries a three-year term.

³ CARRA participants were recruited on the basis of their relationship with NCI and were not subject to the same screening criteria. Therefore, they are included only under the gender and race/ethnicity categories.

Table 2. Caregiver Characteristics

Characteristic	Number	Percent of Total
Gender: (n=82)		
Male	34	41
Female	48	59
Race/Ethnicity:⁴ (n=82)		
African American	15	18
Asian	4	5
Caucasian	50	61
Hispanic	13	16
Hawaiian/Pacific Islander	1	1
Highest level of education attained: (n=73)		
High school	13	18
Some college	19	26
College graduate	33	45
Some graduate coursework or graduate degree	8	11
Age: (n=73)		
21-39	15	20
40-55	21	29
56-70	32	44
70+	5	7
Time since family member completed treatment: (n=73)		
<1 year ago	18	25
1-3 years ago	37	50
>3 years ago	18	25
Type of cancer: (n=73)		
Breast	20	27
Prostate	15	21
Colon	10	14
Multiple myeloma	7	10
Leukemia/lymphoma	4	5
Ovarian	3	4
Lung	3	4
Other	11	15

⁴ Number and percentage exceed 100 percent due to a respondent selecting more than one racial/ethnic designation

Oncology social workers were required to have at least three years of professional experience counseling caregivers and children.⁵ They were recruited for diversity of race/ethnicity, client population, practice setting, and geographic location. Table 3 summarizes social worker characteristics.

Table 3. Oncology Social Worker Characteristics

Characteristic	Number	Percent of Total (n=20)
Race/Ethnicity:		
African American	4	20
Caucasian	15	75
Hispanic	1	5
Percentage of patients who are minority:		
Less than 50%	10	50
50% or more	10	50
Practice setting:		
Community hospital/clinic	5	25
University/academic hospital	8	40
Nonprofit agency	7	35

Each group lasted 1½ hours and was moderated by a professional research moderator. Copies of the moderator guides are included in Appendix B. The groups were audiotaped and transcribed for analysis of content. Data analysis began with careful and thorough review of the transcripts. Participant statements were categorized by major topic, and then further divided into subtopics. Within each subtopic, the range of views was reported, with direct quotations used to illustrate key points. Throughout the process, the researcher looked for similarities and differences both within and across focus groups (e.g., comparing the perspectives of social workers and caregivers).

It should be noted that focus groups are most appropriately used as an exploratory research technique to understand and communicate, rather than to measure and predict. Because of the limited number of respondents and other biases inherent in recruiting, this research must be considered within a qualitative framework and should not be considered statistically projectable. At the same time, the open-ended questions and group discussion format allowed participants to respond in a much more expressive way than they could on a closed-ended questionnaire. Thus, the findings offer valuable rich, descriptive information about the ideas, thoughts, and concerns of the target audiences.

Recruiting for this study was successful in that it achieved a significant degree of racial and ethnic diversity.⁶ At the same time, it should be pointed out that the limited number of groups

⁵ It should be noted that the professional groups inadvertently included six oncology social workers who work primarily in pediatric medical institutions. These individuals were asked to direct their comments more to the general needs of caregivers, rather than to the specialized needs of caregivers caring for pediatric patients.

⁶ It has traditionally been difficult to recruit minority participants for focus groups and research studies in general.

did not permit segmentation along racial or ethnic lines, which means that members of a particular racial/ethnic subgroup did not have an opportunity to share concerns within an in-group atmosphere. Therefore this study may not have been optimal for identifying cultural differences as they relate to the topic of cancer and family caregiving.

By the same token, the study recruited men and women across the entire age spectrum (ages 21-85), yet allowed for only crude age segmentation due to the limited number of groups. Within a single group, participants may have varied in age by as much as 20 or 30 years. For this reason, the study design was not ideal for exploring age-related differences. In the future, NCI might wish to consider research designs that would allow for a more detailed examination of the needs of specific racial/ethnic groups and age-specific segments.

III. Detailed Findings

[Note: The indented, italicized paragraphs below represent direct participant quotations. Where necessary, the quotes have been minimally edited to correct grammar and syntax, or to convey context. Following each quote is an attribution indicating caregiver and relationship and age. In a few cases, where the speaker failed to identify him or herself by name, age is listed as “unknown.”]

A. Caregiver⁷ Experience During Treatment

The moderator set the stage for discussing post-treatment issues by asking participants to describe the preceding period when their family member was in treatment.

1. Responsibilities

During the treatment phase, participants⁸ said they took on the following responsibilities:

- Help with household chores, including cooking, cleaning, laundry, shopping, driving, and bill paying
- Support with personal daily activities, including feeding, dressing, and bathing
- Accompanying their loved one to treatments and doctor’s visits
- Participating in decisions regarding treatment options
- Communicating their loved one’s concerns to doctors, nurses, and other medical professionals
- Translating between the patient and medical professionals when there was a language barrier
- Seeking information and, where necessary, second opinions relevant to their loved one’s cancer and treatment
- Serving as a morale booster to help keep their loved one’s spirits up
- Communicating news about their loved one to other family members

⁷ In the first few focus group discussions, the moderator limited use of the term “caregiver” out of concern that this might not be a term of choice among individuals caring for relatively healthy family members. However, it soon became clear that “caregiver” was a comfortable designation, accepted by participants themselves.

⁸ Unless otherwise noted, the term “participants” or “caregivers” refers to both spousal and non-spousal caregivers. Similarly the generic term “spouses” is used when a finding pertains to all spouses regardless of age. Where a finding is specific to a specific caregiver relationship or age, it is so noted.

2. Challenges

Emotional Stress: While there were those whose loved ones received surgery (or other limited forms of treatment) and recovered quickly or with few side effects, for most participants the treatment period was a difficult, tense time, characterized by overwhelming emotion. Caregivers said they worried about their family members dying from cancer or from the side effects of treatment. They felt guilty seeing their loved ones suffer and helpless for not being able to alleviate the suffering. Between treatments, participants said they were in a “constant state of crisis,” worrying about symptoms, monitoring body temperature and blood counts, and running to the hospital at the slightest concern. Caregivers also said they experienced a wide range of emotions during this period, from anxiety, panic, anger and resentment to exhaustion, shock, and disbelief. Many described a sense of despair at realizing their lives would never be the same. A few said they had fantasies about running away as an escape.

Caregivers frequently said they received an outpouring of support from family and friends throughout the treatment period, yet they also described it as a lonely, frightening time that required a high degree of courage and faith. Many said that while they tried to “stay strong” and hide their emotions in front of their loved ones, they frequently broke down in private.

“I put on a very good face. Underneath, I was a wreck.” (wife, aged 64)

“When I first saw what she was going through...I never wanted to break down in front of her...I had to walk out of the room. I just saw what she looked like...I saw her looking at herself in the mirror and what she must have been thinking was enough to just kind of crush me, if you know what I mean.” (husband, aged 66)

Physical Side Effects: Caregivers indicated that the stress they experienced during treatment took a toll on them physically and emotionally. They reported various problems, including: fatigue and physical exhaustion, headaches, insomnia, nightmares, weight gain, weight loss, anxiety, and depression. A few experienced angina, hypertension, panic attacks, hyperventilation, heart palpitations, or arrhythmia. A number of participants described allowing their diabetes to go out of control.

Even as they were experiencing these symptoms, many caregivers said they felt a heavy burden to take care of themselves and stay healthy while their loved ones were in treatment, so that someone would be able to care for the family. As one husband explained it,

“I remember thinking, ‘Well, this is it. I can’t get sick. I can’t falter. I can’t have one unsteady step here. I’ve got to march on.’ I’ve got three children -- two, seven, and nine – and I felt like I was the glue. And I had to keep the whole cancer support machine running.” (husband, aged 38)

Many said they postponed their own medical check-ups, screening tests, and procedures during this time because they could not handle the possibility of getting “additional bad news.” Interestingly, caregivers did not tend to dwell on their own health issues, although one older wife

who was diagnosed with uterine cancer and had a hysterectomy during her husband's treatment said she felt she had to recover more quickly in order to resume caring for her husband.

Multiple Demands: The treatment phase was perhaps most difficult for young spouses caring for children at home, especially if they also held an outside job. On top of the emotional stress of wondering whether or not they would be left to raise their children alone, these parents described the stress of splitting their time between hospital, work, and home. One younger spouse described a constant nagging feeling of "always being in the wrong place." Several families described leaving children behind (either in the care of another family member or, in the case of one 16-year old boy, alone for months to fend for himself) while they accompanied their spouse out of state for treatment.

"As a matter of fact, we had to leave him by himself because we had to be in Gainesville for four months. And being sixteen it was pretty hard... We used to call him like four or five times a day, and he learned a lot of things...he became [like] twenty years old." (husband, aged 56)

Men and women both described the difficulties of meeting work responsibilities while their loved ones were in treatment. Some said they had trouble concentrating on their jobs. Others said they were grateful to have understanding supervisors who allowed them to take extended time off.

"It was terrible, absolutely terrible...I had gone through some hard times in the military, so I felt that I was pretty tough as a person... But for me, in terms of my job, it took a lot away from it. It was very hard to focus. I'm in the financial field, so it was very hard to look at managing other peoples' funds when I was trying to focus on my own issues." (husband, aged 58)

The treatment phase was logistically difficult for non-spouse caregivers, many of whom had traveled long distances (or, in some cases, relocated to a different state) to help care for family members. These individuals also reported on the difficulty of juggling work, school, and family responsibilities long distance while helping a parent, sibling, or other relation get through treatment.

B. Caregiver Challenges in the Early Post-Treatment Period

The challenges commonly faced by caregivers in the early post-treatment period are presented below in two sections. The first section offers the perspective of oncology social workers. The second section summarizes problems described by caregivers themselves.

1. Social Worker Perspective

According to social workers, the early post-treatment period is a highly stressful period in which they see a lot of depression in survivors and caregivers, regardless of the type of treatment

received. They explained that the treatment period is often a “honeymoon phase” when patient and family receive a high level of support from medical personnel. The patient and family are united in their goal of completing treatment. As one social worker put it, “While in treatment, it’s like being on a treadmill. You don’t have time to think. You’re in fight mode.” When treatment is finished or nearly finished, “the bottom drops out.” Or, as another social worker described it: “The impact of their ordeal hits them.” The survivor and family must go through a period of accepting the trauma of their experience. In fact, many professionals describe the early post-treatment period as a post-traumatic stress experience.

Often exhausted physically, mentally, and emotionally, the survivor has gone through a life-altering experience and is struggling to make sense of it. He is not necessarily sure how he wants to be treated and not necessarily able to communicate his needs. The survivor may look the same to others, but doesn’t feel the same inside.

According to social workers, survivors often feel pressure from family and friends to get back on their feet, but find it difficult to do so. Former family dynamics may feel irritating or uncomfortable. Work may not have the same importance as before. Social workers say that survivors often go through a period of introspective soul-searching before they reach a “new normal” in the post-treatment period.

Meanwhile, the caregiver and family may not have much insight into how the survivor is feeling. According to social workers, family members who have put their own needs on hold while their loved one is in treatment are sometimes impatient to put the cancer experience behind them and get on with their lives. Alternatively, family members may experience post-traumatic stress and delayed grief as a result of living on heightened alert. One social worker described the family’s experience as “an emotional roller coaster ride.” She added, “It’s a different ride for the caregiver, but equally difficult.”

As social workers described it, the survivor and family are often out of sync in the initial post-treatment period. In some cases, the family tries to keep their loved one in a dependent role, out of the belief that they need to protect him or her. In other cases, the survivor may emerge from illness with new goals and priorities, only to find that the family is unwilling to support these changes.

Social workers report that the initial post-treatment period can be a difficult time for couples and marriages. Partners who are individually under stress may find they are unable to relate to one another and unable to bridge the gap. Survivor and caregiver may find it difficult to renegotiate their roles as they try to regain co-equal status. The well spouse may feel it is time to look after his or her own needs, while the survivor may feel that his needs should still come first. Often, too, there are parenting challenges at this stage, with children challenging the authority of the parent who was, for a time, effectively absent. Social workers noted they see a significant percentage of separation and divorce in the post-treatment stage, as well as “an even higher incidence of emotional desertion.” Particularly at risk for problems are:

- Families with young children
- Families with poor parenting skills

- Families under financial stress
- Families with prior marital stress

2. Caregiver Perspective⁹

a. *Common Reactions*

Elation and Sadness: Caregivers have their own perspective. In general, they described greeting the end of treatment with relief and elation. Many said they treated the last day of treatment as a milestone. One adult child caregiver said he felt as if he had passed “the big exam.” Many said they celebrated the end of treatment by planning a special trip with their loved one and other family members. However, participants typically said their high spirits quickly dissipated as they came to realize that their loved ones were in a highly weakened state, physically and emotionally. One wife described her husband’s homecoming as follows:

“He was exhausted. He had lost so much weight. He had lost his hair. He was drained. He was weak. So when I took him home, he felt like, ‘Oh God, I’m so glad this is over...let me just die and get this over with.’ And I remember feeling a great sense of loss and sadness because he was like a shell of a man.” (wife, aged 43)

Anxiety About Ending Treatment: Despite their eagerness to get through treatment, some caregivers experienced anxiety because they were no longer actively fighting the disease. Caregivers said they found themselves worrying every time their loved one displayed a physical symptom, no matter how slight. As this caregiver explained:

“There’s a lot of anxiety when you stop treatment because you’re not actively doing anything... You’re kind of in a state of limbo. Not actively doing anything and knowing there still could be something there.” (husband, age unknown)

Disorientation and Helplessness: In the initial weeks and months following the end of treatment, some caregivers described feeling confused or detached. Some caregivers found the immediate post-treatment period to be upsetting because they no longer knew what to do or how to help their loved ones. During treatment, everyone had had a role to perform. Afterwards, there was a void. Caregivers were left wondering, “Now what?” Spouses wondered if they should continue to stay home or return to work. Non-spouses wondered if they should return home to their own families. Once treatment ended, caregivers were no longer certain of their role and responsibilities.

⁹ Although participants were specifically asked to distinguish between treatment and post-treatment, this was often difficult for them to do. In the course of the discussions, participants said they tended to think of their cancer experience as one long continuum, rather than a series of discrete stages.

“When you’re taking care of somebody, you’re so busy. A lot of people view that sort of busyness as a chore. But for some people, me included, it’s therapeutic. You stay very busy; you’re very active; it’s very fulfilling. You’re taking care of somebody. But then, when it’s over, there can be this vacuum.” (husband, age unknown)

Physical and Emotional Impact: In the post-treatment period, caregivers said they themselves experienced physical and emotional signs of stress, just as they had during treatment. Some caregivers said they finally attended to health problems they had put off from before. Others said that new, stress-related problems (e.g., insomnia, teeth grinding, headaches) manifested themselves. Numerous participants said they began taking antidepressant or anti-anxiety medication to help them cope.

Realization and Acceptance: Caregivers across the board suggested that the initial post-treatment period hit them especially hard because they were relatively unprepared for it. They reached the end of treatment thinking that the worst was over. No one had told them that it would take a long time for their loved one to regain physical and emotional health—and that the process would be draining, both for the patient and family.

Many said their loved one’s recovery was a long, slow process, characterized by one step forward, one step backward. For most people, the good days gradually began to outnumber the bad. Yet there were many participants who, even one or two years out of treatment, said that their families were still struggling to return to normal.

“There’s a period of time when you’re sort of just floating. And I think it takes quite a number of months...and even to this point in time, we’re not through it. Two years after, he still has a great risk of recurrence. And so, although life is back to normal, it’s never the same.” (wife, aged 43)

“We found that the period right after treatment was one of the most difficult times. I don’t think we were prepared for it. We sort of naively thought that, even after surgery, chemo and radiation, he would come home, miraculously bounce back and feel much better, and slowly be able to do things again. And it was quite awhile before he even started to improve. The treatment had been so harsh and severe and had practically killed him. And he had no resources left. And of course, by then, I was exhausted having taken care of him. And then he got depressed and we had to deal with that issue. I tried to get all the information I could ahead of time, but I’m urging people now to find out all they can about not only what happens during treatment, but what to expect right afterwards so that you don’t get depressed when it doesn’t magically all go away.” (wife, aged 70)

While the issues noted above were common to all caregivers, other issues seemed to be particularly salient depending upon the caregiver’s relationship to the survivor.

b. *Issues for Spouses*

Loneliness and Isolation: Spouses, in particular, spoke about the loneliness and isolation they felt in the first weeks and months following treatment. Many said they and their loved ones received less attention from family and friends than they had while they were in treatment. A number of participants described their disappointment at seeing long-time friends disappear, as well as their gratitude to new friends who spontaneously came forward to offer support.

“The thing that I felt was most strange was the disappearance of friends that you thought were your best friends. [Meanwhile other] people came out of the woodwork [and] became your better friends. It’s very weird that some people just deny it and then shut you out of their lives. I guess it questions their own mortality. My wife’s best friend just kind of disappeared for several years.”
(husband, aged 40)

Some participants admitted that they chose, as a couple, to isolate themselves during the post-treatment period, either because they lacked the energy to socialize or because they had been through such a traumatic experience, they could now only relate to one another. Younger caregivers, in particular, related how the cancer experience seemed to isolate them from their peer group. One woman, for example, explained that she and her husband could no longer relate to their 20-something friends who had such different priorities:

“I think we feel separated from our peer group in a lot of ways. And so it’s made us close because we’re the only ones that can understand each other. Our friends were, meanwhile rightly so, worrying about things that are more appropriate for your mid-twenties—like where to go out and party.”(wife, aged 28)

At the very extreme, two female participants described feeling isolated, almost to the point of being trapped, by husbands who were too depressed to leave the house. In the early post-treatment period, some caregivers may be afraid to leave their loved ones at home, for fear of an emergency in their absence.

Sublimation of Self: Some caregivers described becoming almost entirely immersed in a caregiving role in the weeks and months following the end of treatment. For some, this self-denial was easy to accept, as was the case for one husband who explained: “I believe that I totally subordinated everything that I was doing to be supportive of my wife, but not to the extent of being a doormat. It felt very good, honestly.”

However, for others, it was more difficult. Some caregivers said they almost felt they lost their own identity:

“I slid under. My personality and everything I wanted and needed kind of disappeared. And everything went toward working with my spouse and with my children and trying to make things livable and tolerable.” (husband, aged 40)

Other caregivers, most notably some of the wives, said they were exhausted from trying to keep up with their spouses' demands in the post-treatment period. Many said they would have appreciated practical help and emotional support from others, but found it difficult to ask for it.

"I actually felt isolated in the sense that I felt like I couldn't talk about how I was feeling to a lot of people because I felt like more of the focus was on my husband. I felt almost guilty talking about myself." (wife, aged 28)

"I felt tired. I felt drained. He had energy to do nothing. It's like he felt that because he was sick, I had to wait on him hand and foot. He was always: 'I want this. I want that.' It's like he had no consideration for me and I found myself overwhelmed, tired and stressed." (wife, aged 43)

Responding to Spouse's Loss of Self-Esteem: Many spouse caregivers said that one of the hardest challenges was responding to a spouse's moodiness, depression, and loss of self-esteem. Many wives noted that cancer deeply affected their husbands' egos and left them feeling like "less of a man." For some men, this feeling was tied to loss of sexual function (see next section for more detail). However, for others it was more a problem of becoming dependent and no longer feeling like the strong caretaker. One particularly graphic illustration was offered by a 43-year old wife who explained that her husband, a policeman, had to go on desk duty after treatment: "Now he feels not only is he not functioning as a husband and as a man, but in his job as well... He feels he's no longer an asset to society."

Many wives said that they looked for ways to help "build up their husbands," while at the same time struggling not to treat them like invalids. This was particularly tricky when the husband still needed a lot of assistance. Although they knew it was important for their husbands' emotional well being, some wives had trouble letting go of the caregiver role they had played for many months. As one woman noted: "I'm trying to figure out how I go back to being a wife and not his mother because that's what I have felt like for the last ten months."

"The greatest challenge for me was to find a balance between being strong and giving care and being there for him all the time, but not taking away everything from him, even though he was very, very sick. And making him feel that he could still make some decisions. Basically he couldn't do anything. But I tried not do things that would emasculate him." (wife, aged 70)

"My husband had a colostomy...and during the treatment it seemed like he felt like less of a man. And I think that even now sometimes he feels that way. He feels like I'm the one that is in control. And sometimes I feel bad because I had to take over. But now I don't really know how to deal with those feelings of his." (wife, aged 32)

Husbands also said they struggled to understand how best to respond to their wives' emotional needs after treatment. Several said it was difficult to know how to give the right kind of support. One 71-year-old husband said it took a lot of energy "trying to be careful all the time not to say the wrong thing or look the wrong way."

Changes in the Sexual Relationship: Both husbands and wives talked about the challenges associated with resuming physical intimacy after treatment, although wives were more likely to talk about dysfunctionality (possibly due to a higher level of comfort talking with a female moderator). Many wives cited a decline in their sex lives for weeks, months, or years following their husbands' treatment. In some cases, this was attributed to physical impairment brought about by prostate cancer; in other cases, it was a primary effect of clinical depression in their husbands or a side effect of antidepressant medication. Some wives reported that the disruption was short-term and said they were gradually able to improve sexual relations through better communication, or by seeking professional help in the form of counseling, Viagra, or injections.

"I would say physically it took about four months for him to get back to normal. He was on Viagra for a while and he said that it was not working and I thought it was working and I realized that he was still struggling emotionally and mentally with what had happened to his body..." (wife, aged 68)

"It's been up and down...and a challenge. We had the Viagra situation and that is something we're still working with now. But it takes the spontaneity away, which is difficult. But the main thing is that we're doing this together. We're a team and we try to keep that in mind. And we laugh. We have to laugh and have a sense of humor...and that helps." (wife, aged 63)

Other women said they have come to accept less sex in their marriage and are comfortable with that. Some noted they were simply grateful for their husbands to be alive:

"We [have] just kind of got to where we laugh about it. And this too shall pass. Things are different...they're not the way they were. But we're working back to where we were, I guess you might say." (wife, aged 53)

"There are physical limitations now since he's been sick. We acknowledge it and we move on. That's not the total aspect of our relationship." (wife, aged 56)

Finally, a few women (of diverse ages) reported with tremendous regret and sadness that they no longer enjoy any sexual relations with their husbands:

"At the risk of sounding selfish, all I can say is that our sex life has gone to hell. We enjoyed a very healthy one before, but now with all this, he's not in the mood and neither am I." (wife, aged 43)

"I just wanted to say that fifteen years later, we have still not been able to solve the problem. Not only did he lose his ability to have an erection, but he lost his libido, which means he lost total desire. ...He has not been able to work out that he is not a man. It's very painful and we have talked about it and we have had therapy. We have done so many things, but he just doesn't seem to be able to accept that this is ok and it has to be. ...To me, it's just sadness because there's something missing—that extra closeness that I really still would love to have." (wife, aged 63)

In talking about sexual relations, men spoke mainly about the difficulty their wives had feeling attractive or sexy after treatment, particularly for those who experienced hair loss and/or breast cancer surgery. Husbands talked about various ways they helped reassure their wives of their attractiveness following treatment. One participant explained:

“My wife has said that the thing that was most important to her from me, in addition to just helping do the household things, was knowing that she was still sexually attractive to me. She said that I made that clear in no uncertain terms and she says there’s no way to say how important it was.” (husband, aged 71)

Some men admitted that they were worried beforehand about losing interest sexually in their wives, but were relieved to find that did not happen. A few reported it was hard to feel attracted to their wives after they lost their body hair because it made them look like young girls and raised images of pedophilia. Another man indicated: “[The loss of hair] never lessened my desire for her. The suffering did. It’s kind of hard to get cozy when the person is really wracked with pain.” On the other hand, some men said they were even more sexually attracted to their partners after treatment. One said that seeing his wife’s courage and strength in the face of death “was a turn-on.” Another noted that when his wife’s hair grew in a different color, it was something new and exciting:

“As her hair started to grow out, I thought it was really different because she was always blonde— and now we’ve got this dark-haired gal around the house. So I think those kinds of things, bringing them up and talking about them, helped her through it. And it helped me too because you were looking at a future again, both ways— the love affair and sexually too.” (husband, aged 52)

Many men generally agreed that what worked best in their marriages was communicating their love and commitment, reassuring their partners of their attractiveness, and approaching sexual relations slowly. One husband explained:

“She was just terribly shy and terribly reluctant and all I did was reinforce everyday that I was still attracted to her. I kept physically intimate with her in terms of snuggling and nuzzling – and made it clear to her that when she was ready, I was too. And the day came and we dealt with it when it came. But it was hard.” (husband, aged 47)

A few men said they went without sex for a long period of time while their wives were in treatment – and this was something they were able to accept. One noted:

“I’m 35-years-old and if someone had told me a year ago that I would go eight months without having sex with my wife... But once you’re through it or even in the middle of it it’s not nearly... it’s not about that. It’s something else. And you do get through it and... you don’t look back on it as some sort of negative or angry aspect of it.”

Others noted that frequency of sex was no longer important to them. In the words of one husband: “I’m just glad she’s alive. I just couldn’t care less about [sex] right now.”

c. *Issues for Adult Children/Siblings/Other Family Members*

Non-spousal caregivers indicated they were especially relieved when their loved one reached the end of their treatment. Unlike spouses who shared a permanent home with the cancer patient, many of the non-spouse caregivers were commuting to take care of their family members or had temporarily relocated to be nearby. Many young adult children, in particular, said they had put their own careers, schooling, families, and life plans on hold while caring for their loved ones. Once treatment was over, they looked forward to resuming their own lives.

However, many of these caregivers were surprised to learn that their family members still required considerable assistance with household chores, shopping, and driving in the post-treatment period. A few caregivers realized that the permanent impairments their family members endured as a result of treatment (such as removal of the larynx or neuropathy) would prevent them from living independently and necessitate long-term assistance.

Adult children and other family members spoke about the difficulty and guilt associated with trying to balance their own needs and desires along with the demands of care giving. A number of participants said they dropped plans to travel, start school, or move out of state. Social workers warned that some adult children become overly invested in caring for parents with cancer, to the point that they isolate themselves within the family and deny themselves any outside life. One participant seemed to illustrate this phenomenon:

“I used to think that some day I might move to the Southwest...I might move to the Bay area or something, or go live in Africa ... All those notions are gone. If I move again, it's just going to be closer to my mom's home.” (son, aged 28)

A few caregivers admitted feeling resentful that their “life was no longer their own.” One adult daughter said that she finally found a way to set limits on her caregiver role by coming up with a weekly plan of when she could be available to help her mother. Some caregivers noted that they felt resentment toward siblings and other family members who did not step forward to help out more with care giving.

“My mother does have one brother and two sisters that live as close to my mother as I do. And they just didn't step up to the plate. So in my particularly family, there was a lot of resentment. I was doing it all alone and I had absolutely no help—even when I asked for it.” (daughter, aged 38)

Yet, for the most part, caregivers were reluctant to describe care giving as a burden. As one man who had helped care for a father with prostate cancer explained: “I didn't find it to be a burden to take care of my father because I know that he would always be there to help me.”

Adult children talked about the role reversal that happens when a parent becomes ill and the child becomes the caregiver. The study included several young adults who said the experience made them “grow up early.” One college student said she was “no longer the party girl.” One son explained:

“Up until we went through this, my mother was clearly the caretaker and that was clearly it ... no matter how old I get... But now I definitely feel a very strong role as the caretaker, having to check in... calling her everyday.” (son, aged 28)

This participant went on to describe how emotionally difficult it was for him to see his mother undergo so much suffering:

“My mom has had every single bad effect from chemotherapy you can imagine. And she lost all the hair on her face, on her head, everything. And she just looks so broken down. And I don't know ... that's just an image that is so big to me... She was always telling me that no matter how sick I got, I'm her little baby and she would talk about when I was so helpless and had no hair and was so cute. And now I see my mom also ... is very helpless. So that has definitely had an effect on me, which I don't completely understand.” (son, aged 28)

Another participant, caring for an uncle post-treatment, described her sadness at seeing him lose the will to live.

C. Long-term Impact

1. Fear of Recurrence

According to caregivers, by far the most difficult long-term challenge after cancer treatment is living with the fear of recurrence. Years later, every visit to the doctor, every scheduled follow-up check, is cause for anxiety. In addition, every bruise, every sneeze, every slight pain generates the fear that cancer has returned. As one caregiver husband described it:

“At the end, when you think you're done, then it's every checkup, every three months, every six months, and you're like, 'Oh my God, what is it going to be this time?' And every ache, every pain becomes a gigantic question mark... And it's been two years now, and still whenever something comes up, you just have to look at each other and say, 'Ok, just one step at a time...'” (husband, aged 38)

Many caregivers agreed that fear of recurrence makes the post-treatment phase even more stressful than the treatment stage. Some said they struggle not to let fear of recurrence dominate their thinking, but find it difficult to keep their fears in check. As one participant noted, “The sense of crisis is never far away.” Another said, “There's a sort of Damocles sword about this disease, no question.” Several used the phrase “waiting for the other shoe to drop.”

It should be noted that for some of the caregivers in the study, recurrence was not an abstract fear but a reality.¹⁰ Caregivers whose family members had been through more than one treatment phase had a very different view of the post-treatment period. They tended to describe post-treatment as a short-lived, illusory period of time, after which their hopes were shattered. As one husband noted: “The disappointment is that it returns. The disappointment is really hard to deal with, knowing that you need to go through another process [of treatment].”

2. Accepting Loss

Virtually all spouses discussed the difficulty of coming to terms with serious illness and the accompanying loss of control over their lives. Caregivers talked in terms of “heartbreak,” “sadness,” and “stages of grief.” Many said they experienced anger at God or fate for cheating them out of the futures they had anticipated.

For younger women, decisions related to starting a family or having more children were particularly painful. One woman in her 20s said she was grateful her husband had banked sperm prior to his treatment. At the same time, it was still difficult to envision starting a family. A 43-year-old woman said how her husband’s cancer left her fearful about adopting a second child: “I think it’s hard to try to learn how to live again and to have hope.” Finally, another wife said she was having difficulty coming to terms with the fact that her husband’s cancer meant they would never have more children.

“One thing that I had to come to terms with earlier than I really wanted to was the inability to have any more children. I mean I wasn’t planning on it...but somewhere in the back of your mind, you still know if you really wanted to, you could.” (wife, aged 46)

Older spouses said they had confronted the real possibility of losing their dreams of grandchildren, retirement, and travel. Caregivers of all ages said they were forced to accept the realization that “the old way of life would never return.”

3. Impact on Work and Finances

In many groups, caregivers spontaneously brought up the issue of how cancer affects the caregiver’s job options as well as the family’s financial situation. A few younger wives, in particular, expressed resentment at having to go out and become the major breadwinner for the family. In the younger wives group, participants noted that “money runs out when only one person is working.” One young mother expressed sadness that she would no longer be able to stay at home part-time with her toddler. A 28-year-old wife explained that she was now locked

¹⁰ One of the early (non-spouse) groups inadvertently included a number of participants whose family members were still receiving follow-up treatment. Following that focus group, the screener was reworded and all upcoming participants were rescreened to ensure that all other participants would meet the post-treatment requirement.

into her current job and would no longer have the freedom to explore alternative career choices. Another noted that early retirement was now “out the window.”

Spouses across the age spectrum said that their job choices would henceforth be limited because of insurance concerns. Many said that switching jobs was no longer an option because of the likelihood of not being covered for pre-existing health conditions. As one wife explained:

“I’m fortunate I like my job. But if I didn’t, I wouldn’t be in the position to look for a different job, because I would still have to support us and run the health insurance through my job, because it’s taken a long time for him to get back into things. I feel resentful because of that.” (wife, aged 28)

One husband who was formerly self-employed said he had to give up his business and go work for a larger company because he could no longer afford health insurance on his own. Several women talked about going back to work mainly for the purpose of securing supplementary health insurance coverage.

4. Greater Appreciation for Life

Across the board, caregivers claimed that their experience with cancer changed them for the better by giving them a greater appreciation for life. Caregivers said they gained “sharper focus” by seeing that life is finite. Many said they were motivated to reassess their priorities and, as a result, are now determined to make the most of their lives.

“What it did for me is I went through a period of introspection and reflection...looking inward to see...who am I? What have I done? What about [my wife]? What has she done? And what is it that we want to accomplish together?” (husband, aged 66)

“It had a profound change in my life as far as realizing what was important [and what wasn’t]. I was in a job that I really didn’t like and that made me reevaluate where I was and where I wanted to be. And my wife did the same thing. We both changed jobs within a year after her treatment and we’re both doing things that we really enjoy. And with the children as well. Where we were maybe just going through the motions, we really started to enjoy getting really into our children’s lives.” (husband, aged 40)

Compared to before, many caregivers said they now have more fun in life, celebrate more, travel more, and laugh more. They said they have learned not to put off what is important:

“After that first round of chemo, we started looking at things differently. We took money we had been saving to do things, to buy things. We started looking at things differently. And we said, ‘Well, let’s do this now, because tomorrow is not really promised to us.’” (husband, aged 55)

“All our lives, we’re told to save and prepare for the future. My wife says, ‘The future is now.’ And we have, over the last few years, done some things seizing the moment because we weren’t sure that we would be able to do it in a year or two or five.” (husband, aged 71)

5. Closer, Stronger Relationships

Looking back over their experience, the vast majority of caregivers in the study agreed that caring for their loved ones brought them closer together. Husbands and wives said their marriages had grown stronger as a result of becoming a team, laughing and crying together, and sharing their fears of death and dying. The following comments were typical:

“Yeah, we’re inseparable now, on a certain level. We were pretty tight before, but now there’s a level of trust and dependency that goes both ways that is hard to describe. ...All the little things that you bicker about are gone...when you face death together.” (husband, aged 46)

“And I think this has brought us more close. I think it’s made him more attentive. And I think it’s made him more honest with me about his feelings. And we’ll be married 50 years in January and I think...not that I wanted him to get cancer or be a survivor...but I think that this has done a world [of good] for our communicating with each other.” (wife, aged 69)

“The period after the treatment has changed our life dramatically. We have had a good marriage right along and [now] I really believe it’s better. We went into more of a celebratory mode when the treatment was done. And every time she goes in for another checkup we find some other way to do something. I think we’ve drawn a lot closer...the friends and family and ourselves...we may be living in a dream world somewhat, but it has just made life better for us all the way around.” (husband, aged 66)

Non-spousal caregivers also talked about strengthening family ties in the post-treatment period. Many said they had developed greater appreciation for family as a result of their caregiving experience.

6. Commitment to a Healthier Lifestyle

Finally, another long-term impact for many cancer caregivers was to adopt a healthier lifestyle. Many said they became much more health conscious with respect to diet, nutrition, and exercise after seeing their loved one battle cancer. As one caregiver noted, “I’m more cautious about what I do, what I eat, how I handle my life.” Spouses said they now felt extra responsibility to stay healthy and strong for themselves and their families. In families affected by breast cancer, colon cancer, or other cancers known to have a genetic link, adult children and siblings frequently said

they are now more vigilant about their health. Besides adopting healthier behaviors, some of these caregivers also mentioned they were taking the precaution of having cancer screening tests.

D. Strategies for Coping

Caregivers mentioned a variety of strategies that helped them better cope with stress in the initial and longer-term post-treatment period:

The three sources of support most commonly mentioned were (1) friends and family, (2) religion/spiritual faith, and (3) networking with other survivors and caregivers who had gone through the same type of cancer.

Many caregivers said they had found professional therapy to be helpful. Some said they benefited from antidepressant medication. Some caregivers sought out holistic therapies, including meditation, yoga, and tai chi. One wife joined a wellness community.

Many said that regular exercise was a release valve. Some found work to be a therapeutic diversion and colleagues to be a strong source of support.

Caregivers pointed out the importance of cultivating a positive mindset, ignoring the survival statistics, and enjoying one day at a time. One husband summed up this philosophy well:

“You need to get into the moment and get out of what could be in the future. Don’t worry about that because you can’t deal with that until it gets here. And get out of the past because it’s done and you can’t do anything about that either. So all you really have is the moment. And that, for me, was the most powerful lesson of the whole experience.” (husband, aged 47)

Several said they deliberately made future plans, so that they and their loved one would have a goal to look forward to. One caregiver said she got into the habit of taping up inspirational messages all around her home.

There was mixed opinion about the value of support groups. Some caregivers said they found information and comfort through support groups, adding that the experience helped them break through their isolation. Others said they avoided support groups either because they felt uncomfortable about sharing their feelings with a group of strangers—or because they were afraid of getting close to someone who might die. One husband summed up support groups “as a good news/bad news thing”:

“The good news is that there are people who have been through this that can give support and say, ‘Yes, this is what you have to look forward to.’ Knowing what’s coming makes it a lot easier to accept. The bad news is it condenses a pool of victims. And when one of them passes, it’s very traumatic, very stressful.” (husband, aged 56)

Some of the male caregivers expressed reluctance about joining a group. One husband, whose efforts at organizing a male caregiver support group were unsuccessful, said with some frustration: “I guess real men don’t cry or something.” On that note, one caregiver wife related sadly that she had tried to attend a support group, but was not allowed in because her husband would not attend. Several participants mentioned an especially high level of resistance to joining support groups among African American men, although some African American focus group participants spoke out strongly in their favor. One African American man specifically noted that he would have liked to have a support group like his wife had.

Many caregivers (both CARRA-affiliated and other) found that becoming actively involved in cancer advocacy organizations was a gratifying outlet. Participants said they volunteered with local or national societies and became involved in fundraising, education, and research. Several started advocacy groups, newsletters, or Web sites in order to learn more about their loved one’s disease and outreach with other survivors and caregivers. Caregivers said activism was a form of self-therapy because it helped them to feel empowered and involved in the fight against cancer. One woman said that getting involved as an activist helped alleviate the guilt of watching her sister suffer.

Finally, it should be noted that not everyone was able to obtain the support they needed during the post-treatment period. Some described battling depression. A few caregivers spoke of turning to self-destructive habits, including overeating, smoking, drinking, and compulsive spending. Ultimately, these individuals said they were able to get the help they needed and turn things around. One husband described how alcoholism crept up on him and how he was subsequently able to overcome it:

“Then it got to the point where I’m putting out the recycling bin...and I’m looking... and I’m seeing alcohol bottles in there. And I saw myself... and that was my out. I had started drinking more. So I just stopped. I went to an outpatient clinic and I haven’t had a drink in five years.” (husband, aged 55)

E. Impact on Children and the Family

Issues related to the post-treatment impact on children and the family are discussed below. By virtue of the study design, the majority of comments about children, parenting and family dynamics came from oncology social workers. These topics were briefly touched upon in the caregiver groups, but given relatively less attention.¹¹

¹¹ The limited number of groups in the study did not permit segmentation based upon parenting experience or age of children. In recruiting spouses, “having children under age 21” was a minor screening requirement that applied only to the two younger spouse groups—and, even then, only to 50 percent of participants in those groups because of the need to also include young marrieds without children. Since parent/child/family issues were relevant to some, not all, of the participants, the moderator could not spend a great deal of time on these issues in the caregiver discussions.

1. Non-Age Specific Observations

Oncology social workers confirmed that having a parent develop cancer is terrifying and confusing for children of all ages and at every stage of the disease—including but not limited to the post-treatment period. However, the post-treatment period may be a particularly reactive time for children and families because the sense of crisis that often accompanies the treatment phase has passed. During treatment, children experience a lot of their emotions but may feel they are not entitled to express them. Once treatment is over, these repressed emotions tend to erupt.

According to social workers, one of the most powerful ways that cancer affects the family system is to make children of all ages grow up faster. One of the ways this happens is that children are forced to confront sickness and death. Even from a young age, and even if they are not specifically told so, children are intuitively aware of the seriousness of the disease and the possibility of their parent dying. Social workers said (and participants confirmed) that the most common question that children ask—before and after treatment—is, “Will my mother/father die?”

In practical ways, too, children are forced to grow up more quickly in families touched by cancer. Social workers spoke of the common phenomenon of “parentification,” which often takes place during the treatment phase and can be seen even among very young children. In this situation, kids take on more of an adult role in the household, handling chores, supervising younger siblings, becoming a caregiver to their loved one, and, in some cases, even working to bring in income. Children caught up in this dynamic may deny themselves childhood pleasures, out of a sense of guilt or lack of entitlement. In some cases, they may forget how to have fun or how to act like other kids. Once the immediate sense of crisis is over, these children are often angry about the time they lost; in addition, siblings may show anger and resentment toward the parent surrogate.

According to social workers, another common post-treatment phenomenon is for children to feel uncomfortable with or even afraid of the survivor parent. Children may feel that their mother or father no longer looks or acts the same. One woman described the situation in her home:

“My husband is very tight with the kids, but ever since he’s been sick, the kids are scared to go near him. They don’t know how to react. For them, it’s a big change because they have always been close to their father and now, it’s like he doesn’t have the energy to go to the ballgames and do stuff with them.” (wife, aged 43)

Once treatment is over, social workers said it is common for children of all ages to want to forget about cancer altogether. Children often try to ignore it, because “living with it is just too scary.” Children may become impatient or intolerant if their parent is still tired, weak, or needy of special attention. Children expect to be the primary focus in their parents’ lives and may resent the illness for stealing that away. As one social worker explained: “Kids want things to be back to normal: When will you be the old mommy again? Why can’t we go on a trip?”

According to social workers, single parent families are especially at risk for problems in the post-treatment period because there is likely to be more of a burden on the older children to help out at home and with siblings. Also at risk are families where a parent has had multiple recurrences. In some families, the children cannot remember a time when the parent was not sick.

2. Special Issues Affecting Young Children

Social workers said that young children often have fears and concerns about cancer they cannot verbalize. Therefore, the warning signs that a young child is in distress may include physical symptoms such as headaches, stomachaches, or behavioral changes such as sleep problems, changes in eating, decline in school performance, fighting with peers, social isolation, emotional withdrawal, or changes in appearance.

In the post-treatment phase, social workers said, children as young as four or five may employ magical thinking to the extent of believing that they can keep mom or dad well by behaving perfectly. Likewise, they may believe that any misbehavior on their part will make the cancer return. Adult messages such as “You’re in charge now,” “Be good,” or “Be mommy’s little helper” can inadvertently drive children in this direction. The “perfect child” may experience strong feelings of pressure and guilt and later “fall apart” emotionally after treatment is over.

In the treatment or post-treatment phase, young children may display sympathetic side effects, along with the survivor, such as loss of appetite, nausea, or fatigue. In some cases, social workers indicated, young children will show signs of regression, such as bedwetting, separation anxiety, or unwillingness to sleep alone.

In the focus groups, parent caregivers confirmed many of these findings. Some said their young children handled the treatment and post-treatment experience okay. However, others said their children experienced nightmares, anxiety and/or signs of behavioral regression.

3. Special Issues Affecting Adolescents

According to social workers, the most important thing to know about adolescents is that “they just want to be normal.” For a teenager, having a parent with cancer is not only scary and upsetting; it is also embarrassing because it marks them as different from their peers.

Social workers noted that teenagers tend to be moody in general, which can make it more difficult to spot when they are in distress. Possible warning signs might include: a decline in academic performance; difficulty getting along with teachers, peers, or siblings; withdrawal from extracurricular activities (or the opposite, extreme immersion in activities); social avoidance; eating disorders; sleep disturbances; extreme impatience or irritability; or extreme emotional volatility. In very extreme cases, social workers said they have seen hypersexuality, teen pregnancy, suicide threats or attempts, and running away from home.

The post-treatment can be especially difficult for adolescents who are graduating high school and heading to college. Social workers explained that this is ordinarily a time for experiencing

separation anxiety; but in families where a parent has had cancer, the child is often torn between wanting to leave home yet wanting to remain close by. A few of the parent caregivers in the focus groups cited that their college students wanted to change schools to be closer to home. Social workers also noted they have seen heartbreaking situations where kids had to delay going to college because the family's savings were needed to pay a parent's medical bills.

Social workers indicated that post-treatment is often a difficult time for parents and teens. During the treatment phase, parents are often preoccupied, giving a teenager the opportunity to assume more independence. Once treatment is over, when one or both parents try to regain their authority, the teenager often does not want to give up his or her newfound freedom – and clashes may ensue. Social workers said they also commonly see parents becoming upset in the post-treatment period when their teenagers no longer stay on “best behavior.”

Parent caregivers in the focus groups reported varied experience with their adolescent children. It was interesting to note that within families, reactions often varied widely from one child to another. Many parents reported that one child accepted the illness, while another remained in denial—or that one child became overprotective, while the other became aloof. The following comments illustrate this phenomenon.

“I have two boys. The young one was 12 when my wife was diagnosed and we used to take him to the chemotherapy sessions. We didn't want to hide anything from him. And he was right there with everything that was said and done, helping me take care of her. And the 18 year old disappeared for two years; he couldn't deal with it. He took off on his own little journey somewhere. He's back in the family now. He's very apologetic for it, but he just couldn't cope with it.”
(husband, aged 47)

“I have two older sons and a younger daughter – and she is adopted. ... And the reactions were very interesting. The two boys distanced themselves and my adopted daughter hovered.” (husband, aged 69)

While a handful of parents cited extreme examples – a teenager running away or attempting suicide—most said their teenagers were able to cope through the treatment and post-treatment phases. In fact, several parents commented, with slight irritation, that their older children carried on as if everything was normal.

“I saw teenagers just continuing their lives with this sort of minor problem going on on the sidelines. There could have been things deep down; I'm not a therapist, so I don't know what was really going on. But, from all appearance, they still expected somebody to put dinner on the table. They expected to be able to go and do whatever they wanted...” (husband, aged 55)

“It's almost like treatment is over...dad's cured...we don't have to worry about this any more. And, as far as they're concerned, life is back to normal. Everything is fine.... They just don't necessarily see that it's been very difficult.”
(wife, aged 52)

4. The Importance of Communication

Social workers and caregivers alike strongly emphasized the importance of open, honest communication throughout all stages of the cancer process and no less so in the post-treatment stage. Social workers emphasized that information empowers people of all ages. Children need to be informed about what is going on in the family. The communication of information “empowers them,” “normalizes the experience,” and “helps cut down the isolation” no matter what the age of the child.

Social workers said they are shocked by the number of parents who maintain “a cult of silence” about cancer in an effort to protect their children from the truth. Protecting the child inevitably backfires, they said, because kids sense there is a problem and find out in other ways, leading to anxiety, resentment, and loss of trust. On the other hand, they said, talking with children about cancer opens up a whole new level of trust within the family. Talking with children tells them they are not alone; they can go to adults for answers, support, and comfort. As one social worker so elegantly stated:

“And what I like to say to parents is that you can really give your child this gift of a lifelong way of coping: this is what we do in this family. ...In this family we're going to share this, we're going to talk about it. And I think it's just a model for future life problems.” (oncology social worker)

Social workers urged parents to establish an atmosphere of open communication and trust with their children from the very beginning of the cancer experience, when the parent is first diagnosed. Post-treatment communication should be a continuation and extension of the dialogue that has hopefully taken place all along. Most important is for children to know they can ask questions at any time. They should also be reassured that all feelings are safe to bring before the family. Social workers said there is no “magic bullet” of information that should be given to children in post-treatment. Parents should take their cues from the child. However, children are most likely to have the following concerns:

- *Will my mom/dad/(other family member) die?*
- *Are they going to get sick again?*
- *Who's going to take care of me?*
- *Was it my fault? Did I do anything to cause it?*
- *Is it contagious? Can I get it, too? Should I be worried?*
- *(Young children): My stomach/head/(other body part) hurts. Does that mean I have cancer, too?*

Caregivers were asked to describe their approach in talking with their children and grandchildren about cancer. Communications styles were clearly personal. Some parents and grandparents

said they had tried to be open and honest in talking with their children and grandchildren about cancer. One husband proudly recounted the scene in which he told his three sons their mother had cancer.

“The first question the youngest one asked was, ‘Is she going to die?’ And I said, ‘Yes, but not from this.’ It was one of my prouder moments during the whole illness. And it kind of set the tone.” (husband, aged 47)

Another woman described the way she spoke very directly to her grandchildren about their grandfather’s cancer. She indicated that this was the same way she had talked to her own children when they were growing up:

“I was very comfortable mainly because of the way I raised my own children. I’ve always been open with them. As I said, [their dad] suffered from clinical depression since my children were babies and I had never hidden that from them. ... So I was very comfortable in dealing with the grandchildren in the same way. And I guess, in some ways, their parents were glad because they were afraid. They didn’t know how to deal with the children and I just was very matter-of-fact about it.” (wife, aged 52)

A grandfather recalled both the serious and silly discussions he had with his grandchildren:

“With the grandchildren ... it became a series of very thoughtful questions about ‘Are you going to die’? Our six-year-old granddaughter... now that my wife has some hair back ... when she does wear her wig, she says ‘Oh, I see you’ve got your big hair on today.’ And so our experience was that you do, in fact, need to be up front and explain everything ... answer all questions ... and they will handle it.” (husband, aged 67)

On the other hand, some caregivers admitted to being more reticent about divulging information. One husband admitted that withholding information from his children had backfired.

“When my wife was first diagnosed initially, we tried to keep everything from the kids. But as the kids have gotten older, they told us they had a little animosity against [us for] that because they wanted to know up front what was going on. They didn’t like the fact we were trying to keep things from them.” (husband, aged 55)

Another husband said his impulse had been to hide information from their children about his wife’s cancer, but she had overruled him. Later, he said, he agreed that being open with the children had strengthened their relationship.

“I think it made it stronger, to tell you the truth. ... My children get angry if they are not told things. They don’t like to be kept in the dark. They know how I am but they don’t like it. They like to know everything that is going on.” (husband, aged 47)

F. NCI Resources for Caregivers

1. Affirming the Need

Participants overwhelmingly affirmed the need for more information and support on the topic of caregiving. Caregivers commonly said they simply fell into the role by necessity, without any information, preparation, or training in how to handle the responsibilities. Virtually everyone agreed they would have wanted more support and a better sense of what to expect. The following comments are representative:

“I found that I didn’t even realize that I was a caregiver until afterwards. I just knew that I had to do it. I didn’t even look at myself as a caregiver. But we are caregivers. I think it would be nice to have some type of literature on that because you don’t know what to do. You just kind of go off ad hoc.” (wife, aged 57)

“They have pamphlet after pamphlet about every type of cancer and what to expect from your therapy... There’s almost nothing that deals with what you’re going to go through as the caregiver and how you can help yourself get there.” (wife, aged 52)

Participants strongly felt that NCI caregiver resources should focus on the entire continuum of care giving, from diagnosis, through treatment, and on into post-treatment. As one participant explained, post-treatment is an important period, “but I don’t think it’s the key period.” They suggested that, regardless of format, the NCI resource be divided into diagnostic, treatment, and post-treatment phases, so that caregivers can focus on what is pertinent to them at the time and can anticipate the transitions from one stage to another.

2. Content

Participants believe it is important for NCI caregiver resources to address both (1) how to care for a loved one throughout the cancer process, and (2) how to care for oneself. Caregivers were not ashamed to say that they, too, need support. Many echoed the comment: “You can’t be an effective caregiver for someone else if you’re not healthy and you’re not well.”

a. *Caring for the Patient/Survivor*

Under the patient care section, participants said NCI should offer suggestions as to how the caregiver can best support his or her loved one through diagnosis, treatment, and post-treatment:

- Caregivers should be instructed to help the patient prepare for medical visits by preparing a list of questions. They should accompany their loved one to appointments,

where they can listen, ask questions, and take notes. Between medical visits, caregivers should help the patient keep a log, calendar, or journal, writing down questions and concerns.

- Caregivers should be instructed in techniques for researching cancer on the Internet and provided with a list of reputable sites.
- Caregivers should be informed about the importance of getting a second opinion and instructed in what to do when two opinions differ.
- Caregivers should be told what to expect through treatment and given tips on how to make their loved ones more comfortable.
- Caregivers should be told what to expect post-treatment: that recovery typically takes place slowly over a period of months, that treatment may have long-term physical and emotional effects, and that the survivor requires a great deal of emotional support, love, and patience.

Social workers added the following recommendations:

- It is important to educate caregivers and families about the challenges they are likely to face post-treatment. Unrealistic expectations can lead to a sense of failure, which then creates a deepening spiral of guilt and disappointment.
- It is important to explain that cancer is a process that does not end when treatment has ended. They should also know that cancer is unpredictable and inconsistent.
- Caregivers need to know ahead of time that it will take awhile for the survivor to get his physical and emotional strength back.
- Caregivers should be told that the post-treatment stage is a “now what?” phase and that the accompanying uncertainty and loss of control are difficult to handle. Their feelings of frustration and disappointment need to be validated.
- It is important to let caregivers know that support is available.

b. *Caring for the Caregiver*

The caregiver care section should explain how a loved one’s cancer can impact the caregiver and what the caregiver can do to help himself.

- Caregivers should be given an understanding of the various emotional stages they are likely to go through as they accompany their loved one through the cancer process. They should be told that these emotions are normal and healthy.

- Caregivers should be told that it is important to take care of themselves. They should be encouraged to make time for themselves everyday—to keep up with exercise, friends, and outside activities—and not feel guilty about taking time off from care giving.
- Caregivers should be urged to network with other caregivers, either individually or in a support group setting. They should be given a list of national support groups and organizations, along with helpful tips for seeking out organizations in the local community.
- Caregivers should be encouraged to talk about cancer, not hide it. Talking about cancer helps caregivers link up with others in the community who have been through the same experience.
- Caregivers should be encouraged to seek out support and practical assistance from family, friends, neighbors, church or synagogue, and community.
- Caregivers should be warned about the risk of depression and should be urged to seek professional help if they feel they may be suffering from it.
- The NCI materials should touch upon some of the financial, insurance and work concerns that caregivers and their families sometimes face post-treatment, and offer referrals to helpful resources.
- Finally, caregivers should be given information on how to become more involved in cancer volunteerism and/or advocacy, along with an explanation of how that can be a source of personal empowerment.

There was a moderate level of agreement in the male groups that some of the content may need to be gender-specific. Men pointed out that women are the ones who usually assume the care-giving role in the family. Thus, it can be especially difficult for men to learn how to give support. One husband explained:

“It was very difficult for me, at least to understand just what sort of support I needed to give, at the time I needed to give it. And should I ignore the fact that my wife was extremely worried about the reoccurrence, or should I sit and really talk to her about it?” (husband, age unknown)

Another quipped:

“Men are warriors. That’s the way we handle our work and God made us that way. But there is a nurturing side to us that has to be raised up...and it’s different with men. Men are from Mars and women are from Venus.” (husband, age unknown)

3. Format

Participants suggested that NCI offer caregiver support in a variety of formats to suit everyone. Generally speaking, they expressed a preference for formats that can offer personalized support—especially if it can come from other caregivers.

a. *For Adults*

Print: Participants agreed that print information is easy to use and easy to disseminate through physician offices and hospitals. The problem, however, is that this information is not personalized. Moreover, many said they would not have been in the mindset to do extensive reading. Men were especially critical of print publications. One participant noted: “No matter what you say, people don’t read very well and people don’t interpret the printed word very well.”

Telephone: Many participants liked the idea of accessing information by telephone. Advantages of this format are its anonymity, ease of use, and universal accessibility.

Social workers envisioned a state-by-state support program, where survivors and families could call in and network with others who have had the same cancer experience.

Participants suggested that NCI establish a telephone contact information line whereby caregivers could call in and be directed to appropriate resources in their local community.

It should also be pointed out that both oncology social workers and male and female caregivers of all ages had an overwhelmingly positive response to the telephone focus groups. Many participants commented that they found the calls to be enormously supportive and therapeutic. A number of male caregivers, in particular, commented on how comfortable they felt sharing their feelings with other men—something they had never done before. Their positive experience in a telephone focus group led some participants to suggest that periodic telephone support groups or “town meetings” might be an excellent way to support the caregiver.

“This phone call alone is amazing! To know that there are other people out there that feel the way I feel and have been through the things that I have been through.” (wife, age unknown)

“Too bad we can’t do this once a week.” (wife, age unknown)

“One of the things I’m realizing sitting here tonight with all these guys is that this is the first time since she was diagnosed – and that’s over three and a half years—that I’ve sat and talked with a bunch of other caregivers, male or female.” (husband, aged 40)

Online: Participants said that the online format offers a “safe,” anonymous channel for connecting with other caregivers. Men, in particular, said they would like online support because “you don’t have to share your feelings face to face.” The obvious disadvantage is that Internet access is not available to all.

Participants envisioned a variety of possible online resources. NCI could help caregivers hook up with caregiver mentors who would agree to provide one-on-one email support.

Participants also suggested online support groups in the form of small, moderated chat rooms that would allow caregivers to network with one another, share experiences, and find support.

Finally, they also suggested that the NCI Web site include an electronic bulletin board for caregivers to post questions and responses, review past threads, read the “topic of the week,” and review frequently asked questions. One participant suggested that NCI check out “Web Whispers,” a Web site that offers this type of support for laryngectomy survivors and their families.

Video: Participants generally liked the idea of a video format for its easy accessibility and also for its ability to show interactive communication between the survivor and caregiver.

b. *For Children and Teens*

Print: Social workers said that storybooks are a useful way to reach young children, but claimed that print is generally not the best way to reach older children and adolescents.

Online: Social workers recommend the online format as perhaps the best way to reach older children and teenagers. Both social workers and parents confirmed that kids are already using the Internet to research cancer on their own. In some situations, kids are more comfortable getting answers from the computer than from their own parents. The Internet is an ideal support tool because it puts kids in charge, puts them in touch with a peer group with similar needs and interests, and gives them information on demand. Social workers identified the Web site “Planet Cancer” as a useful example.

Social workers suggested that a portion of the NCI Web site be set aside for children. They also suggested an online peer support group for teens, as well as a Listserv to reach this audience.

TV/video/CD-ROM: Social workers agreed that other electronic media, such as television, videotapes, and interactive CD-ROMs are also good potential formats for reaching older children and teenagers. Any approach that portrays other teenagers dealing with cancer is likely to help normalize the experience, and is therefore likely to be effective.

Other strategies: Social workers also suggested a number of other strategies for reaching young people. These may be beyond the scope of what NCI can offer; nevertheless they offer insight into effective ways for reaching a younger audience.

- Schools should be seen as an outreach channel for young children and teens. Information should be given to teachers and school counselors to help them understand the special needs of children and teens in families affected by cancer. One social worker explained that she visits high schools and presents a special program to the entire class.

- Individual or group therapy can be very effective for teens. Teen support groups are often highly effective because talking to other teens helps normalize the cancer experience.
- Some teens greatly benefit by participating in cancer advocacy events like “Race for the Cure,” particularly when these events involve a teen component.
- Art or recreation/play therapy works well for young children

4. Special Needs of Minority Subgroups

Social workers pointed out that there is a dearth of patient information written for minority communities. They requested that materials not only be available in translation, but also that they portray family situations that reflect racial and ethnic diversity. For example, they said, many of their clients are in extended, not nuclear, families. It is important for caregiver resources to reflect these considerations.

A few African American participants suggested that there is a special need in the African American community to encourage people to talk about cancer. One African American participant described the difficulty he had encouraging African American men to sign up for support groups. Another participant explained that, within her family and her community, talking about cancer—either inside or outside the home—is still largely taboo.

“I think especially in the African American community, we think for the most part that when someone says ‘cancer,’ it’s a death sentence. I think it needs to be put out, especially in our community, that if a person is diagnosed with cancer, they’re not going to die.” (wife, aged 57)

One social worker related the following:

“I’m African American and in African American families there are still people that do not talk about those cancers. My mother still refers to cancer as ‘the Big CA.’ I have family members who have passed away and I didn’t find out that they had cancer till after the fact because of the fact that it’s still sort of a taboo kind of thing to discuss. So that still exists.” (oncology social worker)

One participant said that this effort needs to be directed at the next generation, also.

“I don’t know what we think. I really don’t. But it needs to be definitely put out there in little pamphlets from an early age ... [from the age of] about five years old.” (wife, aged 57)

Social workers explained that this is a problem in other minority communities as well. According to one participant: “Depending on how culturally assimilated a family is, they may revert to traditional cultural ways of handling the crisis of cancer.” Often these traditional approaches avoid discussing cancer directly.

5. Other Distribution Channels

Participants suggested that other potential distribution channels for caregiver resources include physicians, hospitals, community organizations, libraries, churches, and schools (as mentioned above).

6. Timeframe

Virtually all of the participants, including both social workers and caregivers, recommended that caregivers be given post-treatment information before they reach that stage in the process.

Many said they would prefer to receive this information at the very start, when the patient is first diagnosed. As one participant suggested: “Make it part of the treatment plan.” One participant even suggested that giving post-treatment information up front could be very encouraging to the caregiver and family “because it reinforces the idea that you will get through the treatment.”

Others said they would not look at post-treatment material until midway through treatment, but agreed there would be no harm in receiving the information sooner. Everyone agreed that some amount of advance information would have helped them to plan and prepare for the post-treatment period. Men were particularly outspoken about their desire for advance information:

“Guys are like that, we like to be forewarned.” (husband, age unknown)

“I think the old Boy Scout adage would fit: Be prepared.” (husband, aged 40)

IV. Conclusions and Recommendations

The focus groups provided a wealth of information and insights about the challenges faced by caregivers and families once a loved one has completed cancer treatment. In addition, they offer specific direction for developing resources aimed at caregivers and their families. The findings support the following conclusions and recommendations.

- There appears to be a strong, largely unmet need for information and support on the topic of cancer caregiving. Clearly, caregivers feel they need better information about what to expect after treatment ends. However, they also feel they need more information and support about caregiving throughout the cancer process.
- Informational resources are especially needed in some minority communities where cancer may remain largely a taboo topic. Every effort should be made to make materials available in different languages and to design them in a way that is sensitive to the specific needs and concerns of various minority subgroups.
- NCI's care giving resources should give approximately equal weight to caring for one's loved one and caring for oneself. Under the topic of patient care, caregivers wish to know:
 - How to prepare for medical visits
 - How to research cancer on the Internet
 - How to seek and reconcile different medical opinions
 - What the patient/survivor is likely to experience physically and emotionally throughout the cancer process
 - How the caregiver can best support the patient/survivor at each stage
- The section(s) pertaining to "caregiver care" should include:
 - A description of the various emotions caregivers commonly experience
 - Tips on self-care: keeping up with exercise, friends, activities
 - The importance of networking with other caregivers
 - The importance of seeking support and assistance from family, friends, and community
 - Warnings about signs of stress and medical risks, including depression
 - General advice about financial and insurance concerns
 - Information about the value of cancer volunteerism and advocacy
- Caregivers are particularly interested in resources that offer personalized support from other caregivers. Telephone and online resources are ideal. Telephone offers the advantages of anonymity and accessibility. Online resources are also anonymous, with the additional advantage of providing information on demand; however, the obvious disadvantage is accessibility.

- For reaching the adult caregiver audience, NCI should consider establishing one or more of the following:
 - A telephone resource line that caregivers could call to find appropriate resources in their local community
 - A program that puts caregivers in touch with other caregiver mentors who agree to provide one-on-one support via telephone
 - Periodic telephone support groups or “town meetings” for caregivers to share common concerns and strategies
 - A section of the NCI Web site for caregivers. This space could sponsor various resources, including an electronic bulletin board for caregivers to post questions and responses or review past topic threads; small, moderated chat rooms that would allow caregivers to network with one another; guest “speakers” discussing a “topic of the week”; and more.
 - Videotapes showing scenarios that provide a role-model for effective communication between spouses/partners or parents and children as they confront common post-treatment concerns
 - NCI should further explore the need for separate caregiver resources for men and women

- For reaching older children and teenagers, NCI should consider the following:
 - An online Web site aimed at older children/teenagers whose parents are survivors. Similar to the adult Web site, this space might include a bulletin board; small moderated chat rooms; past threads; and guest speakers.
 - Television, videotapes, and interactive CD-ROMs that help normalize the cancer experience by portraying other children/teenagers facing the same challenges

- Caregiver resources should be designed in a modular fashion, with separate sections on diagnosis, treatment, and post-treatment issues, so that caregivers can easily find the information they are looking for at the time. Information about post-treatment should be offered to caregivers no later than midway through the treatment process. Some caregivers would prefer to have this information earlier (i.e., at the point of diagnosis or start of treatment).

