Cancer Family Caregivers: A New Direction for Interventions

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Abstract

Background: Descriptive studies of cancer family caregivers demonstrate role-related psychosocial and physical burden; however, little is known about which factors contribute to or obviate burden. Systematic reviews of caregiver intervention studies demonstrate mixed results, perhaps because some caregiver needs are still unknown and not adequately addressed. The purpose of our study was to explore the lived experience of being a caregiver for an adult with lung or colon cancer, so as to guide the development of future intervention studies.

Method: Using phenomenologic methods, open-ended interviews were conducted at a chemotherapy clinic, New Haven, CT with 135 caregivers to adults with lung or colon cancer. Interviews were audio-recorded and transcribed. Thematic analysis was conducted with transcripts coded, reviewed, and recoded multiple times. The final 69 codes were reduced to 13 code clusters (thematic categories) distributed among 4 themes.

Results: Four inter-related themes emerged: 1) becoming a caregiver; 2) new and altered relationships; 3) personal responses to caregiving and 4) antecedents and social context. Caregivers describe hearing the cancer diagnosis as “life-changing”. The cancer creates the context for the caregiver’s relationships (with the patient, self, others, and the healthcare system), and cognitive, behavioral, affective, and spiritual responses. The caregiver’s antecedent experiences and social support network form the foundation for their perceptions of the diagnosis, relationships, and personal responses.

Conclusion: This study implicates several intervention components to be developed and tested as favorably supporting caregivers, namely, reinforcing positive aspects of caregiving, cultivating open communication, and acknowledging the prior experiences and social foundation of the caregiver’s life that can be supportive or burdensome.

Introduction

CANCER FAMILY CAREGIVERS are a unique population whose needs are often superseded by those of the ill family member.^{1,2} With cancer care typically defined by short hospitalizations, outpatient procedures, and extended survival, family caregivers assume responsibility for the patient’s physical and emotional care, activities of daily living, medication management, transportation, and household tasks, as well as communicating with healthcare providers and insurance companies.^{3,4}

Decades of descriptive research have identified high-risk caregivers and their needs.^{5–9} However interventions developed to address those needs have reported only modest effect.^{8,10,11} It is possible there are yet unidentified caregiver needs that are not addressed by the interventions.

The purpose of our study was to explore the lived experience of being a family caregiver for an adult with cancer re-

ceiving chemotherapy so as to guide the development of future intervention studies.

Research Design and Methods

Our qualitative descriptive study, using phenomenologic interview methods,^{12,13} was conducted as part of a multi-method instrument development study of cancer family caregivers’ perceived barriers to meditation. The quantitative survey results are described elsewhere.^{14,15} In order to increase the rigor of our instrument development,¹⁶ we also planned on conducting in-depth interviews on a subsample of these same family caregivers. However, it soon became clear that participants wanted to share their stories of caregiving, so we invited all caregivers to be interviewed. The power analysis for the parent study primary aims ($N=150$) drove the sample size for the qualitative adjunct study. Yale University and Dartmouth College Institutional Review Boards approved the study.

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Sample and setting

Open-ended in-person interviews were conducted in a private room at the Yale Comprehensive Cancer Center chemotherapy clinic, New Haven, Connecticut, with 135 of the 150 cancer family caregivers of adults with lung or colon cancer enrolled in the parent study. For the parent study, the sample was limited to caregivers to patients with lung and colon cancer to minimize the variability imposed by disease type on the caregiver experience, while also increasing the likelihood that the caregiver responsibilities would be complex. In addition, since the patient population with lung and colon cancer is fairly equally distributed among men and women, there was an increased probability that the caregiver sample would also be equally distributed among men and women.

Inclusion criteria

Individuals identified by an adult with lung or colon cancer as their primary caregiver, who were 18 years and older were included.

Recruitment

Chemotherapy clinic nurses referred patients to research assistants (RAs) who asked the patient to provide contact information for a family caregiver. The RA then contacted the family caregiver, explained the study, invited participation, and obtained written informed consent.

Interviews

Interviews were conducted by the PI (A.W.) and two RAs from May 2008 to March 2009. The RAs were trained by the PI; they each conducted 4 audio-recorded mock interviews and the PI provided immediate feedback to improve interviewer technique.

Participants responded to the open-ended prompt, "Tell me about your experience of caring for [patient]." If participants asked for more direction, they were told, "I'd like to hear anything you want to tell me about caring for [patient]." The interviews averaged 30 minutes. Interviews were transcribed verbatim and the PI checked the transcripts for accuracy against the audio-recordings.

Qualitative analysis

Data were analyzed using standard thematic analysis¹⁷⁻¹⁹ procedures aided by the use of AtlasTI® software (v.6.2 Berlin). The PI and co-investigator (M.B.) read the transcripts and coded key ideas, issues, and phrases. A code book of code labels and definitions was constructed to ensure codes were applied consistently and reliably. Coded transcripts were reviewed multiple times to clarify code definitions and add new codes as appropriate. All discrepancies were discussed and reconciled to mutual agreement. The final 69 codes were reduced to thematic categories (code clusters) and a summary statement resulting in 13 code clusters distributed among 4 themes. Trustworthiness and credibility was assessed by ongoing memo writing that provided an audit trail and record of emerging concepts and by conducting "member checks."²⁰

Member checks were performed by presenting a narrative summary representing the code clusters and themes to a new sample of 10 cancer family caregivers who were invited to comment on whether the summary reflected their experience

as a caregiver, and to modify, delete or add concepts. The caregivers agreed the summary represented their experience generally, although some commented that particular concepts (uncertainty, social isolation, and the pain of witnessing the patient's suffering) deserved greater emphasis and one commented that the interview biased the respondent toward expressing emotional needs rather than reporting physical and practical concerns about caregiving.

Results

Description of the sample

Of the 150 people invited to be interviewed, 135 did so. Those who did not complete interviews stated lack of time ($n=10$), did not want to be recorded ($n=1$), no reason offered ($n=1$), and technical difficulties ($n=3$). The sample of family caregivers ($N=135$), comprised predominately of women (66.7%), had a mean age of 52 years (range, 18-84 years). Nine percent of participants ($n=12$) self-identified as Latino/Hispanic and 82% as white race. Almost two thirds had attended at least some college (Table 1).

Participants cared for a person with colon cancer (43.7%) or lung cancer (56.3%) for an average of 6.5 months. They related to the patient as spouses/domestic partners, parents, adult children, other relatives, and nonrelatives (Table 2).

Thematic overview

Figure 1 illustrates the four inter-related themes emerging from the interviews: (1) becoming a caregiver; (2) new and

TABLE 1. STUDY SAMPLE DEMOGRAPHIC CHARACTERISTICS (N=135)

Characteristic	Mean	Standard deviation
Age in years (range)	52.3 (18.0–84.0)	16.2
	Median	IQR
Length of time as CG in mos	6.5	15.0
CHARACTERISTIC	N	Percent
Gender		
Male	45	33.3
Female	90	66.7
Latino/Hispanic	12	8.9
Race		
White	111	82.2
African American	12	8.9
Asian	5	3.7
Other/Not reported	7	5.2
Marital status		
Single	29	21.5
Married/Living with Partner	100	74.1
Divorced/Separated	2	1.5
Widowed	4	3.0
Highest grade level completed		
High school diploma or less	44	32.6
Some college	30	22.2
College graduate	34	25.2
Graduate school	24	17.8
Not reported	1	0.7

IQR, interquartile range.

TABLE 2. RELATIONSHIP TO PATIENT AND PATIENT CANCER TYPE (N=135)

Characteristic	N	Percent
Relationship to patient		
Spouse/domestic partner	60	44.4
Parent	7	5.2
Adult child	35	26.0
Other relative	21	15.6
Friend	10	7.4
Patient cancer type		
Colon	59	43.7
Lung	76	56.3

altered relationships; (3) personal responses to caregiving; and (4) antecedents and social context. Each theme is described in detail below, including quotations from caregivers [identified in brackets by their study number and relationship to the patient]. The themes and their definitions are summarized in Table 3.

Theme 1. Becoming a caregiver

Caregivers referred to the cancer using aggressive terminology such as "devastating," "tough," "rough," "brutal," "awful," and "horrible." Several caregivers used physical references to describe hearing the cancer diagnosis ("... a blow out of nowhere for us", "... hit us right between the eyes", "... it's like a bullet in your heart") and notably included

themselves in the diagnosis with the words "us," "we," and "our." Shock was a common response to the diagnosis.

When he first announced this had happened to him, I thought he was talking about somebody else. This is how shocking it was. [079 mother]

Theme 2. New and altered relationships

Relating to the patient. Several caregivers expressed deep admiration and respect for how their family member was handling the illness. A brother commented:

There are some days when he [the patient] brings out the best in me....he's a fighter. To me he's in better health and peace of mind than I am. And, that's why I can never, ever stop doing for him. [105 brother]

Other caregivers despaired at the caustic or hostile relationship they had with the patient. The wife of one patient commented on how unappreciative the patient seemed:

When he was going through chemo he went through emotional spells...there was nobody else to show his frustration or anger so he has to show it on me. That was very difficult. ... I am sacrificing so much and going extra miles to do all this and he is showing that attitude on me." [063 wife]

Communication was an important feature of the relationship. As described in the following quotes from three caregiver spouses, they often expressed a need to be "up" around the patient, cheering him/her on and hiding their own feelings so the patient wouldn't worry about them:

FIG. 1. The cancer family caregiver experience.

TABLE 3. THEMES AND DEFINITIONS

<i>Theme</i>	<i>Definition</i>
Becoming a caregiver	Hearing the diagnosis is the germinal event that changes the caregiver's life, alters the caregiver's perceptions, awareness, attitudes, beliefs, and behaviors, and necessitates their becoming a caregiver.
New and altered relationships	As a result of the caregiving role and responsibilities, the caregiver's relationships with self, the patient, others, and the health care system change.
Personal responses to caregiving	Each caregiver responds to the caregiving role and responsibilities on a personal level involving cognitive, behavioral, affective, and meaning-making/spiritual responses.
Antecedents and social context	How the caregiver responds to the caregiver role and responsibilities and relates to themselves and others, is influenced by the context of the rest of their lives, especially their antecedent experiences as a caregiver and their social support network.

I try to be the cheerleader to encourage him to go on with the treatments—to try to soften the blow a little bit for our children. [099 wife]

I can't let him see me cry...He has worked very hard all his life to make my life perfect so I have to be very careful, happy, and cheerful. [112 wife]

We feel that if we show any sort of depression in front of A., it would affect her badly. You know, because she's trying to be optimistic...[085 husband]

Caregivers frequently described how difficult it is for them to witness their family member's suffering:

It's been hard to see him disintegrate—losing weight. I see him depressed....it's just overwhelming to see someone who you care for going through something like this. [115 domestic partner]

Some say they would rather be the patient than have to witness their loved one in pain.

I just feel helpless. I mean she has to come and get stuck all the time and I kind of just sit there. You wish that it were you instead of them. [067 husband]

Relating to others. Several caregivers mentioned that in addition to caring for the patient, they also cared for other ill or disabled family members and/or young children. The additional responsibilities caused some to feel overwhelmed by the constant need to attend to someone or something as described by this caregiver:

I don't take the time to calm down and relax because I think if I sit down and think about all the bills and all the mortgage due, this one has to go here tomorrow, and B. has to go to the doctor, and I have two appointments scheduled at the same time...I need to check his creatinine level, you know, and all his medications. Dinner. Breakfast, lunch, dinner...Who's taking what pill? [068 daughter]

Relating to self. Caregivers described changes within their own life as a result of assuming the caregiver role. Some realized the importance of caring for themselves in order to be an effective caregiver; however it was much more common for caregivers to neglect their own needs as these three caregivers noted:

...since he got diagnosed we've been to doctor after doctor and, you know, I dropped everything and it's just all about him. [037 wife]

There's no time for myself. ... I don't even get to shower during the day because I'm running around...doing this for him, doing that for him. [104 wife]

I was always very able to give myself some me-time, and lately I feel guilty when I do that...Right now I feel like I have to be there all the time. [017 domestic partner]

A few caregivers expressed resentment at being thrust into the role of caregiver by obligation rather than personal choice. For example, one daughter commented:

It's my responsibility to be there for her now. But it's become more of a chore and not a choice...it's become extremely overwhelming, and it's become who I am. ... I am my mother's caretaker and I'm kind of losing myself. As much as I want to help her there are days when I don't...and I resent it. [059 daughter]

Several expressed a feeling of isolation and difficulty maintaining social ties since their time was relegated to the patient. This contributed to a sense of loss of their former lives, a grieving for the activities and pleasures that are no longer available. A son and domestic partner stated:

You have to drop your own personal life and be there...I can't really go out when I want to go out because somebody has got to be there for him. [140 son]

He doesn't do as much with his friends because he can't do the stuff...so I don't see my friends as much. It's a choice I've made because I know if I'm with a friend, he's home alone. [147 domestic partner]

Relating to health care providers and systems. Many caregivers talked about the complexity of the health care system, encompassing physicians, nurses, staff, and insurance companies. Most were grateful for the care they were receiving, as this wife describes:

I will say I feel the people...are fantastic. I mean I have not seen so much kindness in my life. [112 wife]

Some expressed anger about a delayed diagnosis, inadequate or inappropriate treatment, and struggles with insurance companies. For example, a husband states:

I get a bill yesterday. I owe them a \$75 co-pay....every day I get a different surprise....I got a letter from [insurance company] yesterday questioning me about why did she have x-rays on her shoulder and neck....I said, "The doctor wanted it!" [120 husband]

Caregivers lamented a lack of time with health professionals, paucity of care coordination, and poor bedside manner/communication skills. For example, a daughter commented:

I think a lot of people need to work on their bedside manner, and in the case of like two of these doctors...arguing about convincing her and me that she was going to die, you know I really don't see the benefits of that...the term he [the doctor] used was a "dead duck." I mean, come on, can we work on our manners a bit more! [149 daughter]

Theme 3. Personal responses to caregiving

Cognitive. Caregivers described coping techniques used to navigate caregiving roles and responsibilities. They emphasized remaining positive, optimistic, and hopeful. Two caregivers provided representative comments:

We never try to be the "pity-party family" or "why me?" or whatever. We try to use humor and always have something to look forward to. [103 wife]

Everybody in our family is really positive. I mean we understand that it's a serious situation, but I think we all really believe that if you don't think that you're going to reach the end in a positive way then you won't...if you think bad thoughts then bad things are going to happen to you. [001 wife]

Caregivers described immersing themselves in information, trying to use knowledge as a tool to combat the disease, as demonstrated by these quotes from a wife and a daughter.

I bought the book on eating well through cancer so I can make the right meals for him, and I did all the internet studies for him. So, I feel like I'm on top of the game. [037 wife]

...we just have learned so much. I just feel that once you get the educational piece behind you it's not such a panic. [073 daughter]

Caregivers also distracted themselves with trivial activities completely unrelated to the illness in an effort to keep from being overwhelmed.

... I would rather go sit and have a latte with a friend than have too much time to myself to be thinking about the future and 'what if'...I don't want to go there. [004 wife]

We tend to do better when we just keep ourselves occupied and busy and try to be positive and do a lot of social stuff. Even though it's tiring it feels better than sitting with the elephant and thinking about what's really happening. [004 wife]

Behavioral. Caregivers assumed new activities or tasks, such as physical care (bathing, wound care), medication management, symptom management, and providing emotional support—things they would not have done if not for caring for their ill family member. Some caregivers had a dominant feeling of accomplishment, while others just felt overwhelmed. Two spouse caregivers provide examples of the tasks they assumed:

... I take care of all the scheduling, making sure all the major medication is taken on time, talking to the doctors, and going to all the appointments and everything else—it just became my life...[069 husband]

I had to learn how to give injections and monitor his blood, give fifty different pills, and deal with the fact that he is extremely depressed. [099 wife]

Affective. Many caregivers referred to their experiences as "life-changing." They felt awakened to a new world—some of which was dreadful and some of which was surprisingly supportive and expansive. Some caregivers related a sense of

pride in newly discovered abilities like providing physical care and emotional support, and finding a depth of emotion and compassion. A husband described his discovery:

It is interesting the way...that I found resources within me to help my wife through the emotional trauma of this...to be a good person beyond I suppose what I had been in life. It was really surprising, and I suppose in a way gratifying that I had those resources, that I could rise to the occasion and provide her with the help that she needed...[047 husband]

Caregivers felt like they were on an emotional rollercoaster. They described a spectrum of emotions (e.g., hopefulness, bitterness, anger, resentment, fear, depressed mood, anticipatory grief, and compassion for others.) A daughter describes her feelings of hopefulness:

Now that she's started treatment, I'm hopeful. It's hard for me to get really upset right now—all I feel is hope and positive....[149 daughter]

A wife provides an example of anger:

He had to leave work...I was angry that—oh my God, now it's all on me. Now I have to go to work...pay all the bills...the mortgage. [060 wife]

A wife expresses her bitterness and depressed mood:

...it's the holiday season so we put up the tree, get the Christmas music on...my daughter, it was all she wanted to do. In the back of my head I'm like, "God this sucks." [103 wife]

They also described a constant worry about the uncertainty of their circumstance and the patient's prognosis, as represented by quotes from two spouse caregivers.

The uncertainty, the shock, the fear of losing someone you have loved for so long, who is...[crying] so much of your life. [116 husband]

There are times when the enormity of something like this can be almost staggering....I think, 'How is this all going to be resolved?' I do have great worries and I do have great concerns about the future. I don't have answers yet. [097 wife]

Some caregivers expressed anger and resentment toward the patient for engaging in a lifestyle which may have contributed to their disease or not presently optimizing their chance for recovery. Two quotes from spouses provide examples:

I got over the anger...I said, '...if he decides next week to pick up a cigarette there is nothing you're going to do to stop him because that's what he feels his quality of life is.' [060 wife]

I'm ashamed of feeling angry at B...but I was angry with him because for so many years he smoked despite my nagging...my thought was – 'if you didn't smoke, you wouldn't have this right now.' [080 wife]

Meaning-making/spiritual. Caregivers spoke of positive outcomes from the cancer experience, including the opportunity to reflect on life, prioritize relationships, meet new people, collaborate as a family, be kinder and more communicative, and get to know each other better. Caregivers expressed appreciation for time to "celebrate life." A husband and a daughter provide examples of recognizing positive outcomes:

... this experience...it put our family all together. It bonded everybody together - especially with the kids and me...It opens your eyes to what is more important in life. [069 husband]

We actually look at this as a gift because not everybody has a chance to reflect on their life before they die...it makes you look at things differently. [073 daughter]

Caregiver's struggled to find meaning in the experience, wrestled with uncertainty, and confronted mortality. For almost all caregivers, the uncertainty of what comes next was a tremendous strain impeding their ability to enjoy the present.

Existential questions about the purpose of suffering and mortality weighed heavily on their minds. A wife and a daughter provide examples:

When you have a week like this, it's hard because you went from a really good place to an unknown place, which is the worst. Once you know what you're dealing with, it's crappy, but it's something tangible...Unknowns...make it worse, and it's frustrating. [052 wife]

...it's getting harder and harder to cope with it and to understand why it's happening...[009 daughter]

Many caregivers expressed belief in something larger than themselves – a confidence in a greater design, as expressed by a husband and a son.

I think you sort of accept that life is fate and what's going to happen is going to happen. [049 husband]

You always ask yourself, "Why my mom...?"...but I think that everything happens for a reason. Maybe it's happening because God wants my family to get together...[106 son]

Several said they felt fortunate to be out of work so they had time to devote to caregiving.

I'm blessed because I'm between jobs...the right job hasn't come up...I believe there's a reason that happened. [073 daughter]

I feel very lucky that my job situation has worked out...it would be a much worst situation if I were not available to them. [070 daughter]

I'm laid off. I'm not working, and this has been an opportunity for me...to be friendly, to be helpful, to be of use. [110 friend]

Many caregivers describe finding solace in religious practices, especially prayer. Two spouse caregivers provide examples:

... he was very sick...I went to church and I said, "I can't do this by myself anymore." Next I said, "You've got to do it, I can't do it!" The next day his lab levels started to improve...I considered it my miracle...I don't think we ever do it by ourselves, but you know we don't really realize that. [035 wife]

I just can go and pour out everything that I feel...and I am strengthened beyond words...I have so much peace in such an upheaval...I get my strength from a new day because of the Word...[062 wife]

Theme 4. Antecedent and social context

Most caregiver's recognized their response to their current caregiving role was influenced by the context of antecedent caregiving experiences and how other people in their lives, their social support network, could be helpful or burdensome.

Past experiences: Good and bad. Caregivers described their prior experiences with loss and caregiving. For some, prior losses and experiences contributed to a sense of weariness or despair, reminding them of deep sorrow or anguish from the past that tainted or weighed down the present caregiving experience. A wife states:

There's always been some kind of crisis, basically for my entire life. I had a father...had a drinking problem...two of my brothers died...so this is just one other in a series of things to juggle. [108 wife]

For others the prior losses reminded them of their personal strength, self-efficacy, competence, familiarity with the health care system, and how much they could endure. A husband and a sister provide examples:

It just hit me— I had been through this. My mother had it [cancer] for 5 years...I had some experience in it. Certainly not as much as I'm having now, but...I guess I can't see why I would have any difficulty with it on a personal basis. [085 husband]

I'm kind of like at ease in doing it because it's not my first time having to deal with someone with cancer....the day after my friend died, my sister was diagnosed...as far as knowing how the chemo procedure works and the amount of time you have to come, and being able or trying to be able to get my sister to just not be so anxious about it - so in that aspect it's good that I've been through it before. [065 sister]

Interfacing with the social network. The larger social and family unit beyond the patient/caregiver dyad was sometimes helpful and sometimes burdensome. When caregivers could draw strength from their network of family and friends, they expressed satisfaction at the depth of caring and support they received, as described by these three caregivers:

...as far as a support group, our Christian family and our Christian friends of 39 years. They've all been there for us—through phone calls, through personal visits—that has been great for both of us. [062 wife]

My children are a big help—they come all the time...And grandkids...they come too after work. They could be tired but they'll stop by...It makes a big difference. [078 wife]

...in terms of family, it has pulled us together...You know you have a lot more phone calls. You have a lot more visits...All of a sudden someone will show up with groceries...just to kind of say, "Here I am."...I guess that's a good side to it. [101 son]

In contrast, some family and friends added to the caregiving burden. At times the caregiver acted as a buffer between the patient and the rest of the social network. For example, the caregiver shielded the patient from the fact that other family members were not interested in his/her well-being. A wife comments:

You know it's hard on the spouse alone. You need a little support from your kids. There's none on that end, none at all. And I can't tell him [patient/husband] because I don't want him to get upset and then not want her [daughter] at the house. [104 wife]

In other cases, the caregiver shielded the other family members from the extent of the patient's symptoms, as noted by a nephew:

I have a lot of siblings that are kind of, you know...they're kind of out there....They can't function on their own, let alone help somebody else...so it all falls on me. [121 nephew]

Discussion

Four inter-related themes emerged from this group of cancer family caregivers of patients receiving chemotherapy: (1) becoming a caregiver; (2) new and altered relationships; (3)

personal responses to caregiving; and (4) antecedents and social context. Member checks support these themes as representative of the cancer family caregiving experience. The themes are consistent with and extend the existing literature,^{21–23} and provide implications for intervention development. The link between our findings and future intervention components are highlighted in Table 4 and described below.

There was abundant overlap between the expressed sentiments of our caregivers to patients receiving chemotherapy and those caring for someone receiving exclusively palliative²⁴ or end-of-life care²⁵ relative to attitude, emotional range, sense of responsibility, and relationships. For example, a qualitative study of nine caregivers providing palliative home care described lifestyle restrictions, a sense of isolation, the need to be a font of hope and optimism, guilt and frustration over competing demands, difficulty witnessing the patient's deterioration, and bitterness when they felt their caregiving efforts were not appreciated²⁴—all of which were noted by our sample. A study of 29 cancer caregivers to an adult at end of life revealed caregivers: have a “just-do-it” attitude, are challenged by uncertainty, believe they must be positive and hide their emotions from the patient, have a sense of responsibility and obligation to the role, note interdependence between their well-being and the patient's, and observe changes in the quality of their relationships.²⁵ The similarities between caregivers to patients receiving chemotherapy with those at end of life may indicate important components of the experience endure over time. Possibly, interventions aimed at caregiver challenges early in the disease process will mitigate the presence or intensity of those challenges later in the disease trajectory.

While positive effects of caregiving are infrequently described,²⁶ our results indicate caregiving can have positive outcomes, including time to reflect, prioritize relationships, and express appreciation and kindness. These positive aspects are related to the developmental tasks of remembering and reconciling advocated for patients at end of life.^{27,28} Innovative interventions can potentially be developed that support the positive aspects of caregiving and integrate the developmental tasks of the patient. Based on research with caregivers to people with dementia, positive aspects of caregiving measurement tool²⁹ and conceptual framework³⁰ have been developed. The experiences of dementia caregivers and cancer caregivers differ, primarily driven by the patient's cognition, physical deterioration, illness acuity, and length of time caregiving. The positive aspects measurement tool and

conceptual framework will need to be tested and validated in the cancer caregiver population.

Positive aspects of caregiving must be distinguished from maintaining a positive attitude and defending against negative input. Pervasive in the caregiver literature^{31–33} including the data presented here, is the caregiver's expressed belief that s/he must maintain a shroud of silence around all negative emotions and doubts. Some of our caregivers committed to a cheerleader role—ever cheerful, optimistic, and encouraging. The cheerleader stance, however, can undermine the prospect of authentic communication. While well-intentioned, it may create feelings of isolation from the patient. Several caregivers said they adopted the upbeat façade to protect the patient. The façade also appears to be a mechanism by which the caregiver safeguards their own concerns, sense of despair and hopelessness. Interventions aimed at cultivating open, genuine communication may assist the caregiver and the patient.

Our results show the foundational importance of antecedent caregiving experiences and social support network. This foundation may be the difference between caregivers who are able to have a positive, fulfilling, growth experience from caregiving, and those who are encumbered by the role and tasks. Future interventions for caregivers should assess antecedent experiences and social networks in order to identify those who might be at high risk for caregiving difficulty and thus require additional support. Obviously, prior experiences cannot be changed—but if identified they could be processed such that they become a resource rather than an inescapable misery. Also obvious is the fact that social support networks take years to cultivate and reinforce. It is unrealistic to think an intervention can help a caregiver form a social support network; however, it is reasonable to consider an intervention that might help caregivers identify and communicate effectively with key people who can assist them.

Our study is limited by the cross-sectional design, especially since the caregiver experience is dynamic.¹¹ The four expressed themes are a function of time. For example, the personal responses a caregiver has to the demands of caregiving change depending on how ill the patient is and whether the caregiver has had time to adapt to the role and learn new skills. Future research will benefit from ongoing dialogue with caregivers at different times during the illness, especially to inform intervention development.

As a qualitative study, our sample is unique due to the number ($N=135$) and diversity of caregivers (45 men, 24 people of color, 35 adult children) who provide a rich, multivocal dataset describing a breadth of experiences. The large sample allows for future analyses of the influence of caregiver's gender, ethnicity, and relationship to the patient.

TABLE 4. POSSIBLE FUTURE CANCER CAREGIVER INTERVENTION COMPONENTS

<i>Future Intervention Components</i>
Support positive aspects of caregiving.
Integrate developmental tasks of patient (remembering and reconciling).
Cultivate open, genuine communication skills—especially within the patient-caregiver dyad.
Recognize and learn from the influence of prior caregiving experiences.
Identify and communicate effectively with key people who can be supportive.

Conclusion

The cancer family caregiving experience has unifying features endorsed by a broad spectrum of diverse caregivers. For some caregivers the experience is largely gratifying and positive, while for others it is stultifying if not crushing. This study implicates several intervention components to be developed and tested as favorably supporting caregivers, namely, reinforcing positive aspects of caregiving, cultivating open communication, and acknowledging the prior experiences and social foundation of the caregiver's life that can be supportive or burdensome.

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