Supporting North Carolina Families Facing Cancer:  
A Community-Engaged Exploration of Assets, Barriers, and Needs

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ABSTRACT

Objective

Families dealing with the cancer diagnosis of a parent face complex psychosocial challenges. Using an engaged, sustainable approach, this project aimed to explore the assets and needs of families, identify barriers to resource utilization, and enable Cancer Services, a nonprofit organization in Winston Salem, NC, to more effectively support families facing cancer.

Methods

The project involved two components: 1) an abbreviated needs assessment including focus groups, an online client survey, key informant interviews, and other outreach to identify the assets and needs of families facing cancer and the strengths and gaps in Cancer Services' current offerings for families, and 2) guided by needs assessment findings and evidence-based practices in cancer support for families, development of a comprehensive, updated family resource kit, including paper and online materials, that reflects the needs of Cancer Services clients.

Results

Identified areas of challenge for families facing cancer included family communication, finances and logistics of daily living, and emotional and behavioral health. Structural and psychosocial barriers to resource access were discussed. Six dimensions of successful family navigation of cancer were identified: connection, positivity, adaptability, control, acceptance, and resilience.

Conclusions

Beyond the local context of Cancer Services, these findings have broad implications for maternal and child health research and practice. Future study of the characteristics of families who thrive in the face of cancer will facilitate development of interventions that enable family resilience.
BACKGROUND

According to a recent population-based study, over 1.5 million adults with a history of cancer in the United States are parents of children under 18, and an estimated 2.85 million US children are living with a parent who has been diagnosed with cancer.\(^1\) Approximately 22.4% of adult cancer cases occur in individuals aged 21-55, the prime childbearing years.\(^2\) Each year, an estimated 200,000 school-age children are affected by a parent newly diagnosed with cancer.\(^3\)

Cancer transforms the whole family; its impact extends beyond the patient to other family members.\(^4\) Despite a decrease in overall cancer incidence in the US over the past decade, cancer incidence among individuals aged 20-49 is rising,\(^5\) which indicates that families with school-age children and adolescents will increasingly be affected by parental cancer diagnosis. Five-year survival rates are currently at or above 50% for most common cancers affecting individuals aged 25-54 years,\(^6\) so families are increasingly navigating the longer-term effects of chronic illness.

Families and children dealing with the cancer diagnosis of a parent or primary caregiver face complex psychosocial challenges. Disruption of family routines and roles, risk of parental loss, treatment side effects and disease symptoms comprise a multifaceted set of emotional and behavioral stressors for all family members, particularly children.\(^7\)-\(^9\) These stressors may be compounded in remote areas, where families often live far from the nearest treatment center and may have limited access to resources. For all families, a cancer diagnosis of a parent is a time of uncertainty, and it is vital to understand the influence of uncertainty on family life and outcomes during and after treatment.\(^4\) The sequelae of parental cancer vary by parental age, gender, marital status, and employment status, as well as cancer type, prognosis, and treatment plan.\(^10\)

It is well-established that a stressful life event can cause psychosocial problems in children,\(^11\) yet there is limited research on how parental cancer affects child functioning.\(^12,13\)
Although children of parents with cancer are an understudied group, there is increasing concern about their current and future psychosocial wellbeing. While many children of parents facing cancer cope well, they are at risk for poor emotional and behavioral outcomes. Children of families with poor family functioning are more vulnerable to these negative outcomes. Studies of psychosocial outcomes in children of parents with cancer have primarily been qualitative and focused on mothers with breast cancer, and have had mixed results, though most report problems across numerous domains: emotional, cognitive, behavioral, social, health, and educational.

Children of parents with cancer have an elevated incidence of internalizing behaviors, including anxiety, depression, and withdrawal. In response to parental illness, adolescents experience more psychological distress and internalizing behaviors than younger children, who are more likely to display somatic responses. Younger children may respond more to outward manifestations of illness, while adolescents are more likely to perceive the less-visible affective aspects of cancer. One study found that anxiety levels were lower in children who were more informed about their parent’s diagnosis compared to children who were less informed, although the causal relationship underlying this finding remains unclear. Another study found that children of more highly educated mothers were told less about their parent’s diagnosis. Higher anxiety was also found in boys who spent less time with friends and in leisure activities during their parent’s illness. Children of chronically ill parents also often have misperceptions about the parent’s illness, which can shape their emotional responses to the parent’s illness.

Compared to children of healthy parents, children of parents with cancer and chronic pain have been found to display significantly more externalizing behaviors, including aggression, distractibility, clingingness, and delinquency. Yet, one recent systematic review found little evidence of increased externalizing behaviors in children of parents with cancer. Behavioral
concerns may be related to limited social interaction in children of parents with cancer; the family’s focus on caring for the sick parent may limit the child’s ability to engage in age-appropriate social activities.\textsuperscript{8,16} Overall, findings on externalizing behaviors are inconclusive.

Children of parents with cancer also experience negative cognitive, health, and educational outcomes. Children develop meaning from the cancer experience, in part, through the responses of family members and peers.\textsuperscript{20} Younger children, whose cognitive responses are still maturing, may be particularly vulnerable to the effects of a parent’s chronic pain on other family members.\textsuperscript{16} Children of parents with cancer may also experience somatic complaints including headaches, stomachaches, dizziness, sleep problems, and loss of appetite.\textsuperscript{13,14,18,27} These health problems are associated with limited physical activity and increased health care utilization.\textsuperscript{16} Children of parents with cancer may also have difficulties concentrating and performing in school,\textsuperscript{28} and they may also have limited time for homework due to increased responsibilities at home,\textsuperscript{8} which can affect educational outcomes as well.

Parental coping and communication patterns correlate strongly with children’s health and coping.\textsuperscript{1,9,13,15} Maternal depression is a significant risk factor for poor child outcomes,\textsuperscript{7,14,29,30} and psychological distress in mothers with a chronic health condition is greater when they have minor children\textsuperscript{31} and can last for years beyond the completion of treatment.\textsuperscript{3,12} Parents with cancer may experience heightened distress and guilt related to the unique strain of illness on the parental role, inability to perform usual parenting activities, challenges of communication with children about their illness, and fear of not being able to see their children grow up.\textsuperscript{1,32} Parents with cancer must address their emotional needs while emotionally supporting their children.\textsuperscript{8}

Communication with their children about their illness is a primary concern for parents with cancer.\textsuperscript{3,12} Communicating with children requires considerable decision-making around
timing, wording, and amount and type of information to share, and parents may seek to protect
their children from emotional distress by avoiding discussion of the illness or withholding their
own emotional responses. However, children are aware of their parents’ emotional reactions
even when parents attempt to conceal them, and children are more resilient if given factual
information and if they have adults with whom they can communicate. In addition, children may hide their feelings and need for support in fear of burdening their parents, and may
therefore cope in isolation. Adolescents in one study also self-reported more internalizing
problems than their parents reported about them, and this discrepancy between parental
observations and children’s subjective experiences may indicate a need for improved parent-
child communication. For these reasons, there is an emerging interest in the clinical need to help
parents with cancer communicate with their children, although support around communicating
with children is rarely integrated into routine clinical care for parents with cancer.

While facing a chronic illness such as cancer can create stress for all family members, it
can also strengthen family bonds and improve family members’ ability to fully engage in family
life. Although the research literature overwhelmingly approaches the effects of parental cancer
on children from a pathological perspective, considering only the adverse effects on child
functioning, there is some evidence of positive psychological change, or posttraumatic growth, in
children as a result of a parent’s cancer. One study of children of parents with cancer found that
44% reported only positive effects and 15% reported some positive effects, including greater
appreciation for life, strengthened personal relationships, awareness of new life possibilities, and
spiritual development. Some evidence also indicates that children of parents with cancer may
have better school performance, greater social competence, and improved parent-child
relationships. Whether these experiences relate to better psychological functioning remains
unclear, but this is an area worthy of future study, as an exclusively pathological perspective on child psychosocial dysfunction is incomplete and inadequate. A strengths-based approach to understanding children’s experiences of parental cancer should encompass a consideration of the assets that enable child and family resilience and positive change in the face of parental cancer. By focusing on capacity-building and fostering resilience, researchers and clinicians can help families prevent psychosocial challenges, rather than respond to them.7

OBJECTIVE

Mutually beneficial university-community partnerships are a vital aspect of improving the health and vitality of communities across the state and reducing existing health disparities. A community-engaged approach applies institutional resources to address challenges facing communities through collaborative work and capacity-building.36 These engaged partnerships encourage public service that integrates research and best practices with specific community needs, promoting health equity and social justice and building on identified community strengths and assets.

This project, supported by a Community Engagement Fellowship from the Carolina Center for Public Service at the University of North Carolina at Chapel Hill, used a community-engaged approach to partner with Cancer Services, Inc., a nonprofit organization in Winston-Salem, NC that seeks to enhance the quality of life for cancer survivors and their families through comprehensive support programs, including psychoeducation, patient advocacy, financial assistance for qualifying individuals,1 and wellness and lifestyle programs, all of which are offered at no charge to clients. In 2011, Cancer Services made 133,083 client and community

1 Cancer Services provides financial assistance, which covers emergency needs and medications, to clients whose income is below 250% of the federal poverty level; however, Cancer Services also connects clients with individual foundations that may use different criteria to determine eligibility for financial resources.
contacts within their primary service area of Forsyth, Davie, Stokes, and Yadkin counties, which includes both urban and rural communities. Most Cancer Services clients are female, whether survivors or caregivers, and the majority are from Winston-Salem rather than outlying areas.

Although Cancer Services offers extensive wellness programs, support and advocacy services, and financial assistance, they have had limited attendance at family support groups and other programs, and have wondered whether this reflects a lack of understanding of the needs of their demographic of survivors, a misalignment of their perceptions of family needs with the actual needs of the families they work with, or other factors. Using an engaged approach, this project aimed to explore the assets and needs of families, identify barriers to resource utilization, and enable Cancer Services to more effectively support families facing cancer through methods that continue will be sustainable beyond the completion of this project.

METHODS

The project was conducted from May to September 2012 and involved two components: 1) an abbreviated needs assessment including focus groups, an online survey of Cancer Services clients (n=19), key informant interviews (n=7), and other outreach efforts to identify both the assets and needs of families facing cancer within the four-county service area and the strengths and gaps in Cancer Services' current wellness offerings for families facing cancer, and 2) guided by needs assessment findings and evidence-based practices in cancer support for families, development of a comprehensive, updated family resource kit, including paper and online materials, that reflects the needs of Cancer Services clients. Seven key informant interviews were conducted during June and July, two focus groups for parents and caregivers were led in July and August, the client survey was distributed in August, other community meetings were attended
throughout the summer, and 100 family resource kits were assembled and ready for dissemination in September.

**Key Informant Interviews**

Seven key informant interviews were conducted with the goal of identifying perceptions and observations of relevant stakeholders within Cancer Services and the broader community who work with families facing cancer. A semi-structured key informant interview guide (Appendix A) was developed collaboratively with Cancer Services staff, and additional probing and clarifying questions were used as appropriate. The interviews were audio-recorded and manually transcribed. Key informants were identified by a non-probability snowball sampling approach, through conversations with the Cancer Services Wellness Director and other informants, and included four Cancer Services staff members, two employees of the area’s primary medical centers, and one employee of a prominent local church. Collectively, the key informants work in various capacities to meet the emotional, financial, spiritual, and wellness needs of both English- and Spanish-speaking cancer survivors. Key informants and their professional roles are described below.

- **Sally Benfield, Social Worker, Wake Forest Baptist Comprehensive Cancer Center**
  Facilitates home health and hospice referrals for patients, assists patients with applying for disability, connects patients with financial resources, and helps patients adjust to diagnosis and treatment.

- **Joanne Henley, Oncology Chaplain, Forsyth Medical Center**
  Meets families’ spiritual and emotional needs and helps people process and find meaning in the experience of cancer through individual and group meetings, as well as staff renewal programs to support the spiritual and emotional needs of staff.

- **Marissa Joyce, Associate for High School Ministries, First Presbyterian Church**
  Conducts long-term, small group and individual ministry and counseling with adolescents; also lost her father to cancer as an adolescent.

- **Julie Lanford, Wellness Director, Cancer Services**
  Coordinates healthy lifestyle, support, nutrition, and prevention programs.
• Melissa Lyle-Nipper, Patient Advocate Director, Cancer Services
  Answers clients’ questions following diagnosis, connects clients with financial resources, and provides psychosocial support.

• Lindy Milligan, Assistant Patient Advocate, Cancer Services
  Helps fit patients for wigs, describes what Cancer Services has to offer, and provides financial assistance; also a breast cancer survivor with four children.

• Iris Santiago, Hispanic Outreach Educator/Patient Advocate, Cancer Services
  Works with the Hispanic and broader communities, facilitates a monthly Hispanic Survivors support and psychoeducation group; also a breast cancer survivor.

Focus Groups

On June 28, 2012, an in-person focus group was conducted with four adult cancer survivors and one caregiver. The objective of the focus group was to learn more about families’ experiences navigating cancer; their assets and strengths; their needs during diagnosis, treatment, and survivorship; which needs have been met successfully; and what Cancer Services can do to help meet any unmet needs. A semi-structured focus group guide (Appendix B) was developed collaboratively with Cancer Services staff and was used as a framework for the focus group discussions. Additional clarifying and probing questions were asked as appropriate, and not all questions in the focus group guide were asked due to time constraints. The focus groups were audio-recorded and manually transcribed.

A second focus group with the same objectives was conducted on August 1, 2012 with four adult cancer survivors and one caregiver. Three of the five focus group participants had attended the previous focus group, and two had not. In addition, two of the attendees from the previous group were unable to attend the second group because they were out of town. A concurrent group was also held for teenagers, and five teenagers attended this group.

Client Survey
An online survey (Appendix C) was created and distributed to all self-identified parents and caregivers with email addresses in Cancer Services’ database (n=91). The goal of the survey was to help Cancer Services staff understand more clearly whether historically low attendance at family-centered programs reflects lack of interest in the content or structure of current programs, lack of provision of appropriate services for client and community needs, logistical barriers such as lack of transportation or childcare, or other factors. Staff were also interested in learning about whether families who have participated in previous programs have found them to be beneficial, as well as understanding why other families have not attended previous programs. In the past, Cancer Services has had limited feedback from program participants and non-participants.

The survey contained 24 questions, including a combination of basic demographic information, multiple-choice, Likert scale, and open-text-response questions. Entry into a drawing to win a $50 gas card was used as an incentive for survey completion.

Other Community Groups: Hispanic Survivors Group and Yadkin LIVESTRONG at the YMCA Focus Group

Two other community groups were not convened for the purposes of the needs assessment but were attended given their topical relevance to this project. Iris Santiago, Hispanic Outreach Educator at Cancer Services, facilitates a monthly support group for Hispanic survivors and caregivers. The group is held at Cancer Services and conducted in Spanish. The group met once during this project, on July 10, 2012, though this meeting was not convened for the purposes of this project and was not recorded. Notes were taken manually after the group ended. Approximately 16 survivors and caregivers attended the group.

LIVESTRONG at the YMCA, a twelve-week group for cancer survivors, is a national program that promotes physical activity and wellness and helps participants reach health goals.
through building physical strength and endurance, improving energy levels and self-esteem and providing a supportive community of fellow survivors. The YMCA in Yadkinville is about to begin this program and held a focus group on July 31, 2012 to help identify the needs, goals, and challenges of the target population for this intervention. The focus group was held at a Yadkinville event space over dinner and was led by a trained outside facilitator. Focus group attendees included YMCA staff, healthcare professionals, nutritionists, and cancer survivors.

RESULTS

Key Informant Interviews

Key informants identified several challenges for families facing cancer. All agreed that this topic is a vital and understudied area and an issue that must be considered from multiple angles, as there is no single solution to the challenges faced by families. Several informants noted that a family’s experience of cancer is shaped by the severity of the parent’s diagnosis, the ages and developmental needs of their children, and how these needs influence children’s cognitive and emotional processes. The identified areas of challenge fell into three broad categories: family communication, finances and logistics of daily living, and emotional and behavioral health.

Family Communication: All key informants described communication challenges as a concern for families facing cancer. Parents want to protect their children; children also want to protect their parents, and these protective instincts can lead to withholding of information or emotions. One informant noted that parents often try to shield their children by not telling them the full story, which can have the opposite effect—particularly with older children, according to this informant, who works closely with adolescents. Children within this age group, she
observed, want to know specific information, as the fear of the unknown is invariably worse than any possible outcome. Younger children, noted one informant, often have lots of questions, particularly about death—yet, they can be reluctant to ask because they don’t want to upset their parents. Likewise, parents may hesitate to ask questions that they fear will upset their children.

The key informants felt that parents struggle with how much information about their diagnosis to communicate to their children. Parents must discern what to say to their children, how to say it, and how to say it without showing emotion, which is a perceived need among many parents. Children will assume the worst unless given clear information. The wide variance in the reliability of information found online can provoke undue fear and anxiety, yet children commonly seek information online, as do adults. Older children possess the technological savvy to find information online, yet they often lack the emotional maturity to process the information that they are able to access. As one informant explained, “They’re fact-rich and experience-poor.” Open communication within the family can help mitigate these challenges.

Key informants observed that communication challenges influence family dynamics; withholding information erodes trust in parent-child relationship. Children, particularly those from families in which they have been raised to be high achievers, often are accustomed to maintaining a persistent positive attitude through any adversity. According to one informant:

They’re trying so hard to convince their parents that they’re okay that they don’t allow themselves to actually not be okay… they’re afraid to tell their parents about their fears because they’ve never been told that it’s okay to not have a happy face on. They’ve been brought up to be great at everything, and sometimes this is the first time that life has not gone according to plan and they may not know what to do with it. Their parents may not know, either.
Some children try so hard to help their parents during this difficult time that they may be unable or unwilling to ask for what they need. Children who were young when their parent was diagnosed may not emotionally process the experience until years later, when they are developmentally ready. Parents can be surprised by this and may not know how to respond, but it may take years for some children to have the capacity to deal with what they went through.

**Finances and Logistics of Daily Living:** Key informants uniformly identified anxiety around the financial aspects of cancer as a primary concern for families. In addition to worrying about medical bills and other costs, parents fear that their diagnosis will disrupt their children’s lives. Parents often worry about whether their children will be able to continue their current activities and routines, and may also worry about how to help their kids balance additional household responsibilities with other activities. At the core of these issues are concerns about financial and logistical sustainability of both new and old routines within the family.

Within the Hispanic community in particular, financial concerns were identified as the most common challenge. Lack of health insurance and access to medical care, unemployment or loss of work due to illness, transportation, and childcare are often pressing concerns among Hispanic survivors, as is limited knowledge and understanding of their illness. In addition, some Hispanic survivors fear dying far from their native country and family members, and some worry about the financial responsibilities that will fall on other family members if they die in the US.

**Emotional and Behavioral Health:** Key informants also noted several concerns related to the emotional and behavioral health of family members. The need for peer support came up in several interviews. Although several informants felt that families often express a desire for peer support, the diverse experiences of survivors and their families can present challenges for group dynamics. While certain aspects of cancer are universal for all affected individuals and families,
the range of cancer types, severity, length of treatment, physical manifestation of illness, and other factors strongly influence the experience, which can make relatability difficult. As one key informant and cancer survivor noted, ‘my parent had cancer’ may not be enough of a common thread for children whose parents experienced different stages and manifestations of the disease.

Within the field of cancer survivorship, the concept of integrating the disease into a ‘new normal’ is commonly discussed, and, for some families, the cancer experience can be a catalyst for positive behavioral health changes and newfound appreciation of time spent together as a family. Families may seek advice about nutrition, diet, and physical activity. Yet, while cancer may compel some individuals to change their health behaviors, others may prefer to return to normal routines rather than create new ones. For these individuals, seeking support may be less appealing as they struggle to regain as many aspects as possible of their ‘non-cancer life.’

**Protective Factors for Cancer Survivors and Families:** In considering the community resources needed for families facing cancer to thrive, key informants captured six protective factors that enable families to successfully navigate cancer:

- **Connection:** All family members have someone they can talk to and who understands them. Open communication within the family also reduces the feeling of isolation. For some survivors, spirituality is an integral aspect of feeling connected.

- **Positivity:** Living with cancer in a positive way and not perceiving it as a death sentence.

- **Adaptability:** The ability to accept change easily and adjust as needed.

- **Control:** Families find a sense of control and a way to cope with stress, understand the disease, and maintain some old routines with enjoyment and without guilt.

- **Acceptance:** Finding a sense of peace with what’s happening, and not being in denial.

- **Resilience:** In the words of one informant, “you face into the challenge and come out on the other side with a sense that you’ve made it.”

Although key informants felt that all of these constructs were important, some identified a sense of connection as being particularly vital to survivorship. All family members need to feel
that they are not alone, to understand they cannot navigate cancer alone, to recognize that there are resources within the community to help them stay connected, and to take active steps toward using available supports as needed. For children, it can be hard to be in school and feel that none of their classmates understand what’s going on in their family life. Support groups can benefit children for this reason. Access to information is also essential in maintaining a sense of control, although the amount of information needed varies significantly. Some families need lots of psychoeducation and resources, while too much information can be overwhelming for others. Families also benefit from financial and logistical support to maintain elements of their normal routines as appropriate.

**Utilization of Existing Resources:** Some key informants felt that financial resources for families facing cancer—particularly those without insurance—have dwindled recently, due to budget cuts in community organizations such as United Way and Salvation Army. The volume of existing financial resources within the community is inadequate to meet all needs, and accessing resources requires creativity and savvy. Other informants felt that, despite the country’s recent economic decline and its effect on individual programs and resources, financial support is an area of strength in existing resources for families facing cancer.

Although Cancer Services’ efforts to connect clients with financial resources have been successful, social support initiatives have been more challenging, as measured by the number of families accessing these services. Cancer Services has attempted to foster community interest in Children’s Lives Include Moments of Bravery (CLIMB), a widely used six-week psychosocial and emotional support program developed by the Children’s Treehouse Foundation. However, attendance at CLIMB has consistently been low, despite efforts to modify the program structure to meet community needs. For this reason, Cancer Services identified developing a stronger
understanding of the needs of these families as an organizational priority, which was the genesis for this project. Cancer Services staff members identified several possible explanations for why families are not accessing the available resources:

- Families are unaware of existing resources due to inadequate or poorly-targeted publicity
- The existing resources and programs are unappealing to families
- Families believe that they do not need social support from the community

Key informants noted that determining which of these factors affects resource utilization is a key step in targeted efforts to serve families facing cancer within Cancer Services’ four-county area.

**Barriers to Access:** When asked to consider the issue of equitable access to cancer resources within the four-county area, key informants identified several structural and psychosocial barriers that prevent families facing cancer from using existing services. Key informants agreed that socioeconomic status and income were determinants of resource access from both structural and psychosocial standpoints.

Structural barriers to access encompass financial, logistical, organizational, and policy factors that prevent individuals or families from obtaining resources. Health insurance was named as a significant barrier, and required pre-authorization to justify resources as medical expenses can frustrate patients with insurance. Cancer Services staff noted challenges with the logistics of program planning, including considerations of scheduling programs in the day or evening, the summer or school year, the weekend or weekdays. While meeting the scheduling needs of all clients with any given program is impossible, staff members acknowledged the possible inconvenience of existing programs in terms of timing and/or location. Programs are typically held at the Cancer Services office in Winston-Salem, which could present a significant barrier to some families, particularly those in rural areas and those with limited transportation.
At the policy level, one informant noted that local hospitals have an automated referral process to connect breast cancer survivors with Cancer Services. However, this policy is not in place for other cancer types. As a result of this policy and the disproportionately broad public visibility of breast cancer, breast cancer survivors may enjoy more financial and social support than survivors of other cancers. Cancer Services also has a harder time reaching men than women, which contributes to disparities in resource utilization within the organization.

Psychosocial barriers, or barriers related to personal beliefs and values, also contribute to resource use. Some informants speculated that the prevalence of anxiety and depression among cancer survivors inhibits some people from accessing services, as does the cultural stigma of admitting vulnerability or a need for help. Cancer Services staff also doubted the accuracy of their perceptions of the needs of survivors and the best way to provide information to individuals and families—whether in person, on paper, online, or through other channels. Misidentifying the needs of the target population also presents a barrier if the resources that are most needed by the community are not offered at all or are not offered in the most accessible and desirable way.

**Successful Community Programs for Families Facing Cancer:** Despite these barriers, key informants discussed several existing resources, both at Cancer Services and within the community, which they perceive as successful in helping families facing cancer. Key informants unanimously named Cancer Services as the best program in the area for cancer survivors. Within Cancer Services, Healing Hands massage, Patient Advocate, and yoga programs were named as areas of strength in helping parents. Cancer Services staff felt that the organization was most effective helping families connect through social activities such as baseball games. Sustaining active programs for kids and teens is challenging for Cancer Services. Even social outings may be unappealing for some kids, who might prefer to socialize with their friends rather than kids.
they don’t know. Informants felt that service-based activities such as a Komen race team or volunteer project are an effective, fun, and low-pressure way to engage kids and teens.

Within the community, the Leukemia and Lymphoma Society, CancerCare, and co-pay assistance foundations were seen as effective supports for families. Joanne Henley, Forsyth Cancer Center oncology chaplain, was named by one informant as someone who has raised awareness among staff to refer patients with children to her. However, Cancer Services has not been able to establish a comparable partnership through the Cancer Patient Support Program at Baptist Medical Center. At Forsyth, there is a wellness group for patients with gastrointestinal cancers that is a model in terms of attendance and an even gender split. Conversations with the facilitator of this group might provide useful insight into what has made this group successful.

CLIMB and Camp Kesem, a student-run overnight camp for children with a parent with cancer, were the only identified community cancer resources targeting children. One informant noted that Cancer Services has gotten occasional referrals from a local pediatrician and wished that more pediatric offices would refer children to Cancer Services when cancer in the family is identified at wellness visits. Further partnership efforts with pediatric offices would be helpful in establishing a protocol for making referrals, as well as communicating to pediatricians about what Cancer Services offers to children and families so that they are aware of these services.

Focus Groups

Key findings from both focus groups are summarized below, organized thematically.

**Facing Cancer as a Parent (Patient):** Parents felt a need to appear strong for the benefit of their children. Treatment and prognosis were reframed through a parental lens: “I kept thinking, ‘Let me just make it until she finishes high school.’” One participant has a daughter who was nine when she was diagnosed: “I felt the need to emphasize to her how lucky I was that
it was caught early. I didn’t want her worrying. She was concerned to some extent, but I could alleviate it. Chemo was hardest, because you can’t hide it from your kids. I wore a wig, but it was hot and itchy. I’d wear it to her school but then I stopped—I wore a scarf sometimes but would mostly go bald.” Another participant, a single mom, recognized her need to support her son and worried about her ability to work again given the loss of feeling in her hands from the neuropathy. Most participants expressed feelings of fatigue, lack of energy, and depression, which one participant described as follows: “It just feels like you’ve lost control of your life.” Single moms uniformly affirmed that women with partners were fortunate to have that support.

One participant remarked that she had never known other parents facing cancer: “I have cancer in my family, but I was grown when my family members had it and never experienced it as a child. I haven’t known any other parents going through it.” Participants agreed that it could be frustrating to be lumped together with others with different cancer types, with the assumption that all of them faced the same prognosis: “Everyone has a different type of cancer. It’s annoying when people compare you to those with other types of cancer and say, ‘You’ll be fine.’ I wish they would look up my kind of cancer and see that the odds are different for me.”

Facing Cancer as a Parent (Caregiver): Caregivers felt an added pressure to be positive for their kids: “I have to keep a strong face for her and for my son. I got angry and wanted to scream—but you can’t. You’re trapped… It’s really hard to be the strong one when he says he’s afraid his mom and I will die.” Caregivers noted the lack of targeted resources for them: “My wife had all these resources, but there was nothing for me. I sat in hospital for seven straight days [during her surgery and recovery], and it would have been so nice for someone to pull me aside. I refused to leave her there alone—the one night I left, she had hallucinations and tried to rip out her tubes, saying ‘My husband would never leave me.’ I only got two hours at home.” One
caregiver observed her daughter’s heightened vigilance about her [the caregiver’s] wellness: “As a caregiver, my daughter does sometimes get scared of me getting sick as well. She watches my husband like a hawk. I feel guilty for not being able to do everything that he’s not able to do.”

Parents’ Perceptions of Children’s Experiences with Cancer: Regardless of their children’s ages or their coping styles, participants widely agreed that they worried about their children and felt that their kids struggled to some degree. Some participants watched their children take on newly protective roles at home, whether it was a 15-year-old who assumes heightened responsibility for chores around the house and “goes into ‘Mom’ mode,” or a two-year-old comforting his mother by saying, ‘Mommy, don’t cry’ when she is sick or in pain. Other participants observed that their children had become visibly distraught during the treatment process: “My son [7 years old] has unraveled. He is melting down, freaking out. He was very positive, upbeat, energetic, and loving… now he is hitting himself, saying ‘I hate me, I can’t do anything right.’ The smallest thing that doesn’t go his way leads him to melt down… it’s hard to figure out what to do, hard to watch my son decompensate.” Yet, for others, the absence of a visible breakdown in their children was worrisome or difficult: “The hardest thing for me was that I didn’t really see my daughter break down. She had a lot of support from her art teacher [who had breast cancer], and she just kept going. She was more responsible, maintained straight As, and is now in AP classes. It kind of bothered me that I didn’t see her fall apart. It surprised me that she didn’t. I’m still waiting for it to come, maybe after my treatment is over.”

Most participants shared that their kids have not known other kids whose parents have faced cancer, although some have. Participants commented that it was challenging when their kids only got information from people who knew someone who died from cancer, rather than getting information from or about people who survived. One participant remarked that her
daughter struggles with alienation from her friends at school who don’t understand what she’s going through. Others observed that their children were extremely reluctant to come to support groups or other activities for kids and teens, despite the fact that none of their friends can identify with the challenges of having a parent with cancer: “It’s like pulling teeth to get my daughter to come mix with other kids in same situation—she just doesn’t want to.”

*Family Communication:* Participants described widely varying styles and patterns of family communication, both in general and related to the process of navigating cancer specifically. Regardless of typical family communication style, most participants agreed that the experience of facing cancer posed challenges for communication in one way or another. One participant didn’t sit his son down for a conversation until he realized how much his son was picking up from adult conversations. Others agreed that it was difficult to know how much their children absorbed from outside conversations or sources. Participants had a somewhat mixed reaction to books and brochures that they had been given to help them talk to their children about cancer. One parent worried that some of the children’s stories about a parent having cancer, which included talk about death and dying, may have been too much for his son, who subsequently had nightmares about both parents dying. One participant identified his family’s communication style as “very open,” but felt that the first conversation when he sat down to talk with his son about his wife’s diagnosis was “terrible... I wouldn’t wish that conversation on anyone.” Several participants noted that their children did not say much or ask many questions about the parent’s cancer. One parent wanted to answer her son’s questions, but felt that he rarely asked. Another participant, a caregiver, remarked that her daughter never discussed her father’s cancer with him directly, but preferred to talk about it with her mother, particularly in the car.
**Shifting Family/Gender Roles**: Participants agreed that the process of facing cancer as a family led to shifts in established family and gender roles. Both men and women felt that their gender roles changed profoundly. Female participants agreed that they were accustomed to being caregivers and taking primary responsibility for many household tasks. They felt strongly that they needed to do everything, and being unable to do many things as a result of cancer was quite distressing to them. Men identified as protectors and solvers who suddenly found themselves in a challenging situation that they could not solve, with a fear that they could no longer protect their family in the same way. For both women and men, these shifts felt life-changing.

Participants also remarked that their roles as parents changed significantly. Many felt too tired or sick to do household chores, and their kids took on added responsibilities at home as a result. In addition to responsibilities at home, participants’ roles in their kids’ extracurricular lives also shifted. One participant, whose daughter is actively involved in drama, commented that she had been a real “stage mom” and found it challenging to stay active in that role. Her daughter was accustomed to having her around in the theater and perceived this shift as well. Participants also expressed feelings of guilt about how much they would let their children watch television or do other things that they wouldn’t have been allowed to do before, because they felt too sick or exhausted to play with their children. In addition to guilt, participants also felt concerned that these changes would have a negative long-term emotional impact on their kids.

**Role of Faith-Based Support**: Many participants considered their church community to be a “family” who they could rely on for emotional and logistical support, and this was a powerful source of strength for many families. Beyond emotional support, church members helped with day-to-day needs. One participant’s church youth group cleaned out her basement, while another’s Sunday school teachers took her children to lunch after church. Participants were
overwhelmed by the generosity of their church communities and found them to be a valuable source of peer support for themselves as well as positive adult support for their kids.

**Helpful Resources for Parents:** Beyond their church communities, participants valued the support they received from friends, neighbors, and community organizations that helped out with various needs. Small gestures, such as mowing the lawn without being asked or re-lighting the pilot light on the stove after it went out, were affirming for participants and truly made them feel seen and acknowledged by those around them. Friends also helped by taking participants to chemotherapy so that their caregivers didn’t have to miss as much work. Several participants commented that asking for help required grace and humility, and that it took some time to get over the feeling that they were a burden. One participant noted that creating a CaringBridge site was a saving grace for her. She was able to put her needs on the site and people could see them and help as needed, without having to call her to ask how they could be helpful.

**Helpful Resources for Children/Adolescents:** In addition to the support they received for themselves, participants identified several valuable sources of support for their children. Participants felt that their children benefited from adults giving them space to share their feelings and permission to be angry and ask ‘Why me? Why my mom/dad?’ Participants agreed that it was important for their children to have space to talk and trusted people to talk to. Several participants found that familiarizing their teenagers with the treatment process and setting was valuable for making the experience more tangible and safe for them. One felt that touring her daughter around the Forsyth Cancer Center was a huge help. Another said that her daughters found it helpful to accompany her to treatment, even if they just stayed briefly. Numerous participants mentioned support from teachers as another important source of support. When teachers checked in on kids during school after one participant emailed them to share updates
about her treatment, it showed that they were aware of what was going on. Another participant said that her daughter’s teachers stopped by the house, which went a long way toward making her daughter feel supported. Participants had mixed experiences with attempts to bring their children and teenagers to counseling. One participant’s daughter was receptive to counseling and has benefited from the experience. Others stated that their children refused to see a therapist, despite strong recommendations from their pediatricians and other healthcare professionals.

**Unmet Needs:** Several participants expressed a desire for more financial counseling—particularly someone who could explain about bankruptcy, as well as help clients apply for support from agencies that can help with medical bills and medication costs. Some participants felt a sense of shame in needing such extensive financial support and noted that financial stress filtered down to their kids as well. As one participant, who struggled to make her mortgage payments during treatment, described, “It’s humiliating. My kid was wondering if she would have a place to live.” Another participant remarked, “For me, the financial aspect has been worse than the cancer.” One participant remarked that, medically, she was given plenty of information and resources, but felt less equipped to meet her other needs. Yet, another participant expressed a need for additional medical information about coping with neuropathy.

Numerous participants experienced unmet needs around social support from their friends and neighbors. One participant observed that friends regularly brought meals over for her family while she was getting chemo, but this slowed down despite the fact that she was still exhausted after recovering from radiation. Another participant said, “Everyone is like, ‘We’ll be there for you,’ but they’re not.” Participants agreed that they wished their friends would show up and help with household tasks rather than asking what they could do, as accomplishing seemingly simple tasks was a significant source of stress for most participants. Participants also expressed a need
for a community of other survivors who they could ask for advice about navigating the day-to-
day of treatment and survivorship. Some participants felt that their friends disappeared after they
got their cancer diagnoses and suspected that these friends felt unable to deal with the stress of
the illness. Others noted that their friends wanted to help but didn’t know how to be helpful.

Participants agreed that they would like to see more resources available for caregivers—
whether a spouse, parent, other family member, or friend. Numerous participants acknowledged
the tremendous sacrifices that their caregivers have made, often with limited or nonexistent
support. One male caregiver suggested that it would be more helpful for me to gather in a room
with television, coffee, and food, explaining, “We’ll talk in that setting, without calling it a
support group.” Some participants also felt that it would be nice to have a place for kids and
teens to socialize together in a relatively unstructured setting.

Client Survey

The survey was distributed to 91 self-identified parents in Cancer Services’ database. 19
respondents (21%) completed the survey. Respondents were 84% female and 16% male. 89% of
respondents were aged 31-50, and 11% were older than 50. Respondents were from Winston-
Salem (9), Kernersville (3), Madison (2), Ridgeway (1), Clemmons (1), High Point (1), Pilot
Mountain (1), and Mocksville (1). 63% of respondents had breast cancer, and the remaining 37%
was split between other cancer types. All respondents had been diagnosed between 2005 and
2012, with the majority (68%) having been diagnosed within the past two years.

26% of respondents had children age 5 and under, 26% had children ages 6-9, 53% had
children ages 10-13, 42% had children ages 14-17, and 26% had children age 18 and older. At
the time of their/their partner’s diagnosis, 32% of respondents knew another parent with cancer,
while 68% of respondents did not know any other parents with cancer. 21% reported that their
children knew other children whose parents had been diagnosed with cancer, while 79% reported that their children did not know any other children who had parents with cancer.

53% of respondents told their children about their/their partner’s cancer diagnosis as soon as they found out, 26% told their children once the treatment plan was decided, and 5% told their children right before treatment began. Several participants had young children (under 3) and did not talk to them about the diagnosis. 68% of respondents received some advice or resources about how to talk to their children about cancer, while 32% did not receive any such resources. Among participants who did receive resources or advice, 92% found them to be helpful, while 8% did not find them to be helpful. Respondents who received advice or resources named the following sources: books (31%), internet (23%), and pamphlets (15%). 46% received resources from their medical care teams, 15% from Cancer Services, 8% from teachers and counselors at their child’s school, and 8% received faith-based support. One respondent commented that there were “too many different people involved… difficult to figure out who to call for what.”

90% of respondents had participated in at least one program offered by Cancer Services, including Healing Hands (42%), Survivors Day (32%), Wigs (32%), Support Groups (26%), Families Group (21%), CLIMB (16%), and Patient Advocates (11%). 95% of respondents who attended programs reported that they enjoyed the programs and found them helpful and worthwhile, while 5% did not find the programs helpful. 37% of respondents had also participated in programs offered through organizations other than Cancer Services, including LIVESTRONG, Look Good Feel Great, massage, yoga, online groups, and Relay for Life. 84% of respondents indicated that they and/or their family had not been able to attend a program that they were interested in, for the following reasons: inconvenient time (32%), cost of gas (26%),
unaware of program (26%), inconvenient location (16%), no childcare (16%), too tired (16%),
children didn’t want to attend (11%), too sick (11%), and too busy (5%).

47% of respondents were able to find a program that met their needs, and 53% identified
unmet needs, including:

- People to help with upkeep around the house
- Group for people of similar ages and with similar cancers
- General information about talking with teenagers
- Programs held after 5:00 p.m.
- Group for single parent survivors
- Summer programs for children
- Financial resources
- Support groups in outlying areas beyond Winston-Salem

The majority of respondents (74%) indicated a preference for learning about resources,
groups, or programs for cancer survivors and families by email. Other preferred communication
channels included healthcare providers (53%), pamphlets (47%), friends/word-of-mouth (37%),
online (26%), church (16%), and phone (11%).

11% of respondents described their ability to meet their children’s needs following
their/partner’s diagnosis as excellent, while 33% described it as very good, 22% described it
as good, 22% described it as fair, and 11% described it as poor. 58% of respondents did not feel
that they needed any additional support or resources to meet their children’s needs, while 42%
identified additional resources that would help them meet the needs of their children:

- Mental health support to deal with depression
- Activities for children
- Support for single-parent families
• Financial assistance
• Breaks for caregivers
• Information on how to communicate with kids/teens about illness
• Information on how to cope with stress
• Counseling resources for children and adolescents

Respondents also shared numerous comments about what the time following their/partner’s diagnosis has been like for them as parents, as well as their perceptions about what this time has been like for their children. These comments are included as Appendices D & E.

Hispanic Survivors Group

At the Hispanic Survivors Group meeting, Robin Chancer, LCSW, a bilingual therapist, gave a presentation about depression, including symptoms of depression; types of depression; the effect of depression on the body, emotions, spirit, and thoughts; treatment; and resources with bilingual services. After the presentation, the group shared their experiences coping with depression. Participants willingly shared their stories, and many participants spoke to the unique challenges of navigating cancer far from their extended family in their home country. In addition to distance from family, financial needs appeared to be a primary source of stress for this group.

After the group ended, the participants ate lunch together. Participants brought food to share, and their families and children joined them for a lunch of salad, chicken, vegetables, fruit, and freshly-made smoothies. Given the enthusiastic family attendance at the lunch portion of the group, this group seems to be a model for involving the whole family in ongoing cancer support.

Yadkin County LIVESTRONG at the YMCA Focus Group

Participants in the focus group described transportation as a significant barrier to group participation and noted that even the small cost of public transportation, which serves a limited
area to begin with, can be problematic. Although transportation can present a barrier for families in urban areas as well, this issue seemed to be especially concerning for this rural community. Participants preferred meeting on weekdays rather than weekends, and faith-based communities seemed to be a prominent source of strength and socialization for participants. Some participants spoke to the fact that caregivers are often overburdened with additional responsibilities and in need of someone to take care of them and/or specific programs targeting the needs of caregivers.

Focus group participants also spoke about the value of sharing personal goals with a group to help sustain their momentum in making lifestyle changes, as well as the empowerment that comes with group participation rather than individual efforts. Participants also noted the importance of ensuring that changes that occur during the twelve-week program are sustainable for participants over the long term, rather than lasting only the course of the program itself. Both the inherent value in shared group participation and the importance of providing participants with tools for continued growth are essential considerations when planning future groups.

**DISCUSSION**

Several key themes emerged from the needs assessment. Although there is no ‘one size fits all’ approach to meeting the needs of families facing cancer—different family structures, dynamics, personalities, and diagnoses lead to different experiences for parents and children—parents share a common experience of navigating cancer through the lens of being a parent. Parents want to survive for their children’s benefit, perceive symptoms as they affect their children as well as themselves, and are motivated to persevere largely because of their children. Peer support appears to be a vital need for both parents with cancer and their children, yet many families do not know other parents or children who have faced cancer as a family. Helping
families connect with other families who have navigated similar situations could help alleviate some feelings of isolation and anxiety. The primary importance of financial needs for families facing cancer can also create unmet needs around social support if parents are not prioritizing social support for themselves or their children due to other priorities or financial constraints. Both kids and parents need peer support from other families facing cancer so that parents can normalize what they and their kids are going through and so that kids, in the words of one focus group participant, “know that there’s another kid like them.”

While challenges around peer support have broad relevance for many families facing cancer, other concerns are unique to specific groups: single parents, caregivers, families in rural areas, and Hispanic families. Single parents face a distinct set of challenges as cancer patients and survivors, and those needs should be addressed directly through targeted future programs, resources, and groups. The unique and varied needs of caregivers are frequently overlooked throughout treatment and survivorship, as most of the attention is focused on the patient. Caregivers may feel burdened by a need to be strong for their family, and may neglect their own physical, emotional, and social needs due to the demands of the difficult caregiver role. For families in rural areas, transportation is a significant barrier to program attendance and can lead to an increased sense of isolation. Addressing the unique needs of these groups through targeted resources and programs is integral to promoting wellbeing for all family members in the face of parental cancer. Cancer Services has a strong existing outreach program for Hispanic families, and continued provision of culturally relevant resources for these families is essential to ensure ongoing support for the Hispanic community.

The needs assessment identified the importance of peer and professional support for children of parents. Although the research literature supports child-centered interventions as
important in promoting positive outcomes for children of parents with cancer, these findings are not widely applied in clinical practice. If research findings are not adequately translated into clinical settings, their potential impact is significantly limited. Clinical practice should both inform and reflect the existing research, and both researchers and clinicians should adopt a translational, collaborative approach in order to best meet the needs of families facing cancer.

**Recommendations to Cancer Services**

The following recommendations to Cancer Services are based on an integration of needs assessment findings and evidence-based best practices in supporting families facing cancer:

- Given the barriers related to transportation, particularly for rural families, it would be worthwhile to explore ways that Cancer Services could extend their program delivery into communities, rather than relying on individuals to come to Cancer Services. Cancer Services already models this approach through their two Patient Advocates who work within local hospitals. A lay health advisor model would train cancer survivors as peer leaders who could facilitate support groups or other programs in their communities. If a group of volunteers could come to Cancer Services to get trained as peer facilitators, their reach could extend more broadly to those unable to travel to Winston-Salem and those in rural areas who lack the availability of resources found in urban settings.

- Future efforts to address the needs of caregivers should consider the logistics of how and when to best support them. While caring from someone in active treatment, a support group is unrealistic, but outreach to caregivers could occur in the hospital. Caregivers could be matched with a caregiver “buddy” of a similar age who has been through the process and could visit them in the hospital or check in regularly by phone or email.
• Social events, rather than structured groups, might be a more effective way of increasing attendance and interest among kids and teens. Social activities give kids “a chance to be kids,” in the words of one key informant, and may also provide an opportunity for them to do things their family cannot afford during their parent’s treatment. Many kids also participate in myriad extra-curricular programs, which poses attendance challenges. While a peer support group could be valuable for kids, they may not attend due to conflicting activities. Less structured programs and use of social media or online tools are potential examples of low-key and appealing options for busy kids and teens who may feel intimidated by a more formal support group. In addition, programs held off-site (at a sporting event, bowling alley, or restaurant) may be more enticing to kids, given that these locations are often seen as more neutral venues. A partnership with the YMCA or a similar agency could be worth exploring. Developing familiarity with Cancer Services staff in a low-pressure environment that feels fun rather than obligatory allows kids to establish trust and helps them know they can talk about issues if they want to.

• Because many parents indicated how helpful they found it to have friends and neighbors assist with household tasks and upkeep, it might be helpful to create a brochure of ideas for ways that friends and neighbors can help during treatment and recovery, and include this list in family resource kits so that clients can share it with their friends and neighbors. Ideas for ways to help could be solicited from current clients by email and Facebook.

• Community service activities are another successful way to attract participants—both adults and kids. Adults see service as an important way to give back, and kids connect when they are helping other people and being active. Developing meaningful hands-on service projects could be appealing and fulfilling for family members of all ages.
• For many cancer survivors, members of their chosen family may include individuals who are not biologically related to them. Language in Cancer Services’ literature, website, and other communication should reflect a broadly inclusive definition of family structure that incorporates fictive kin, as well as same-sex couples and multigenerational families.

• Because many parents struggle with how to talk with their children about cancer, it might be useful to invite an expert clinician from the community to lead an interactive seminar for parents to learn how to maintain effective ongoing communication with their kids about cancer and have an opportunity to practice these skills.

• In-service education for healthcare providers to help them work more effectively with patients could be beneficial to ensure that patients receive appropriate psychosocial and financial support throughout diagnosis, treatment, and survivorship. This could be a valuable opportunity for cross-agency collaboration between Cancer Services and providers at the local hospitals, potentially serving two purposes: 1) helping providers communicate with patients more effectively and sensitively, and 2) increasing awareness of Cancer Services among medical providers, thus potentially increasing referrals for families with cancer types other than breast cancer.

• Although Cancer Services primarily serves a female client base, it is also predominately staffed by women. More male staff or volunteers could facilitate outreach to male clients.

• It might also be worthwhile to consider outreach to schools about how to support kids whose parents are facing cancer. Cancer Services staff could meet with teachers, social workers, and counselors at school or create a handout to distribute to an affected student’s teachers. In the future, Cancer Services could consider adding a paid or
volunteer Child Counselor to their staff, who could both conduct this type of outreach and work with children onsite.

- Given that several of the identified unmet program needs from the survey are programs that do currently exist either at Cancer Services or within the broader communities of Winston-Salem and beyond, consideration should be given to effective promotion of existing programs to families through a variety of media (newsletters, mail, flyers, social media, advertisements, email, in-person) to ensure the broadest possible reach.

- Connecting parents with professionals who can help identify appropriate literature for the child’s age, maturity, and type of parental cancer is critical, as parents may find it hard to determine how much information is too much for their child. Online resources might be an effective outreach approach for older kids and teens, and could be a teaching opportunity around media literacy and the distinction between reliable and unreliable information. Teens benefit from resources that are accessible, but not forced upon them.

**Family Resource Kits**

Based on needs assessment findings, the following resources were included in the family resource kits. These resources reflected the emergent needs for information targeting caregivers and tools for improving family communication about cancer. Although a clear need for Spanish language resource kits emerged from the needs assessment, Spanish language resource kits were not made at this time. This would be a valuable future project for an intern or volunteer. It would also be helpful to include specific resources for single parent families facing cancer; however, despite extensive online research, virtually no such resources were identified beyond small,
grassroots nonprofit organizations in a handful of cities across the country. The lack of targeted resources and services for this population reflects a striking unmet need.

At Cancer Services’ Family Picnic on August 25, 2012, families painted brightly colored tote bags to use for the resource kits, so that families will receive a bag made by another family who has faced a similar situation. If, at upcoming Cancer Services events or groups, family members can continue to paint bags for other families, this will enable families to pass forward a supportive gesture that they received when they first came to Cancer Services and received their resource kit. The ongoing process of painting bags will ensure the sustainability of this project beyond the summer timeframe. The resource kit materials are listed below.

- Helpful Resources for Families Facing Cancer (brief, user-friendly guide developed in response to needs assessment findings; includes links and descriptions of local and national resources for families, survivors, kids, teens, and caregivers; Appendix F)
- Helping Children When a Family Member Has Cancer (CancerCare)
- Talking to Your Kids About Your Diagnosis (CancerCare)
- Questions Commonly Asked by Children Who Have a Parent With Cancer (KidsKonnceted)
- 10 Tips for Talking With Children About a Parent’s Life-Threatening Illness (article)
- Cancer In the Family: Helping Children Cope With a Parent’s Illness (American Cancer Society)
- Caregiving for Your Loved One With Cancer (CancerCare)
- Coping With the Stress of Caregiving (CancerCare)
- 10 Tips for Family Caregivers
- Small stuffed animal (for younger children only)
- Helping Teens When a Parent Has Cancer (CancerCare; for older children only)
LIMITATIONS

Several other individuals and agencies were contacted for key informant interviews, but were unavailable: Wake Forest Baptist Health Cancer Center’s Cancer Patient Support Program, Greater Cleveland Avenue Christian Church (a predominately African American church), and Tres Fordham, Executive Director of the Yadkin Family YMCA in Yadkinville. Despite being unable to interview the YMCA Executive Director, attendance at the focus group for the LIVESTRONG at the Yadkin YMCA included the views of both Mr. Fordham and other individuals within the rural counties in Cancer Services’ service area. However, the absence of lengthier interviews with this community leader, as well as the Baptist Cancer Patient Support Program and an African-American church such as Greater Cleveland Avenue, presents limitations for the needs assessment findings. These perspectives would be useful to integrate into further exploration of strengths and gaps in existing services for families facing cancer.

CONCLUSIONS

Beyond the local context of Cancer Services, these findings have broad implications for maternal and child health research and practice. The Institute of Medicine’s call to identify the psychosocial needs of cancer patients and their children to connect them with needed services is an important step, but this initiative must be linked to both clinical practice and population-based survey data. The use of population-based data would increase reliable information about cancer survivors with children. Doing so could facilitate screening and referrals to help survivors manage the unique stressors of facing cancer as a parent. Expanded awareness of the public health impact of cancer on families and children would help health organizations develop programs and partnerships to better target the needs of these families.
Using a strengths-based approach to build community capacity, future research should address both the characteristics of families who are at greatest risk for poor psychosocial outcomes associated with parental cancer, and those who are doing well. Understanding risk factors is important, but learning more about the characteristics, beliefs, and health behaviors of families and children who thrive in the face of parental cancer is also essential to planning interventions that enable resilience within the family of a parent with cancer. Longitudinal studies will help illuminate how these behaviors and beliefs evolve over time, and translational research will evaluate the effectiveness of program implementation in clinical practice settings.

Thoughtful development of research questions is also essential to understanding the impact of parental cancer on family and child health. Although the existing research base demonstrates the negative psychosocial, educational, and health effects of parental cancer on children, research questions specifically target these harmful effects. It is worth considering whether a research lens pathologizing children’s experience of parental cancer creates a self-fulfilling prophecy of finding further evidence of adverse outcomes. There may also be positive changes in children of parents with cancer, but the right research questions must be asked to identify these effects. Further study of the qualities that enable families to navigate cancer well—connection, positivity, adaptability, control, acceptance and resilience—will enable development of interventions that foster these strengths and help families face cancer successfully.
References


Appendix A: Key Informant Interview Guide

1. Describe your professional role and the role of your agency within your community. Who do you serve? Are clients referred, mandated, or voluntary? For how long do you typically work with clients (and how often do the same clients return for subsequent visits)?

2. Describe a typical interaction with a client. What kinds of things do you do or discuss together?

3. Based on your professional expertise, what are some of the most common challenges, fears, or concerns faced by cancer survivors and their families in the community you serve?

4. In your opinion, what does it mean to thrive or do well as a cancer survivor or the family member of a cancer survivor? What services do cancer survivors and families need to thrive? Do those services exist within the community? Who utilizes them? Are there barriers to access (and who experiences these barriers most often)?

5. What are some programs in the community that you think (based on your opinion and/or conversations with clients) are doing a good job helping adult cancer survivors and their children? What makes these programs successful?

6. What are some of the unmet needs of adult cancer survivors and/or their families? Is the community making efforts to meet these needs? What else could be done?

7. In your work with cancer survivors, what has been surprising to you? Why?

8. How could Cancer Services better meet the needs of parents with cancer and their families? Are there existing programs that could be improved, or new programs that could be added? What else do you think would make a difference in the lives of these families?

9. Any other thoughts, ideas, or suggestions that we haven’t discussed?
Appendix B: Focus Group Guide

1. Describe what the time in the first several weeks following your/your partner’s cancer diagnosis has been like for you as a parent. As more time passed, what changed?

2. What resources did you need after your/your partner’s diagnosis to support yourself?  
   • What made your life easier during this time?  
   • Have you found it most helpful to access resources through the internet, written/paper materials, someone to talk to (a professional, a friend, or a fellow survivor)—which resources have you used most to support yourself?  
   • Did you receive a CLIMB kit, and how was it helpful if so?

3. How have your needs for resources or support changed over the course of your/your partner’s diagnosis and treatment?

4. What do you think the time following your/your partner’s diagnosis and treatment was like for your child(ren)?  
   • Before cancer, describe how you and your child(ren) communicated.  
   • What kinds of changes or responses did you notice in them, in terms of behaviors, emotions, physical symptoms, or anything else?

5. What resources did you need after your/your partner’s diagnosis to support your kids?  
   • What helped you make their lives easier during this time?  
   • Have you found it most helpful to access resources through the internet, written/paper materials, someone to talk to (a professional, a friend, or a fellow child of a survivor)—which resources have you used most to support your child(ren)?

6. What kinds of resources or support did your child(ren) need for themselves to cope with what was happening? (Distinction: things they did for themselves, not through you)

7. How have your children’s needs changed over the course of your/your partner’s diagnosis and treatment?

8. How well did you feel able to help meet your child(ren)’s needs? What, if anything, would have enabled you to be more helpful in meeting these needs?

9. Have you and/or your family participated in support or educational programs for cancer patients, survivors, caregivers, or families (either through Cancer Services or through the hospital, church, or other organizations in your community)? If so, how was your experience?

10. If there were programs that you and/or other members of your family wanted to attend but were unable to, what got in the way and kept you from being able to attend?

11. Were there other kinds of resources/programs/groups that you would have liked for yourself or your family but couldn’t find in your community (or online) during and after your cancer
treatment? If so, please describe the kind of program, resource, or group that you would have liked to find but couldn’t.

12. Do you have any suggestions for programs/services that Cancer Services could offer to families affected by cancer in the future? These could be programs for parents, caregivers, children, and/or whole families. Please describe any suggested programs/resources in as much detail as possible! (type of program, meeting day/time/location, etc.)
   • Would you be interested in a program at the site where you/your partner receive treatment (where kids could tour the facility and meet the doctors/nurses/other staff)? Would this be helpful, or does it not matter that much?

13. Do you have any other comments or suggestions?
Appendix C: Client Survey

1. Name

2. Age

3. Gender

4. City/Town

5. Cancer type

6. Date of your/your partner’s diagnosis

7. How old are your children? Please select all that apply.

8. When you/your partner were diagnosed, did you know other parents who had been diagnosed with cancer?

9. When you/your partner were diagnosed, did your child(ren) know other children whose parents had been diagnosed with cancer?

10. When did you first talk to your child(ren) about your/your partner’s diagnosis?
   - As soon as I found out
   - After the treatment plan was decided
   - Right before treatment started
   - When signs of illness became visible (hair loss, etc.)
   - When my child(ren) asked about it
   - Other:

11. Where did you get resources to talk to your child(ren) about your/your partner’s diagnosis? What was helpful? What was not helpful?

12. What advice do you wish someone had given you about talking with your child(ren) about cancer?

13. Have you, your partner, or your children participated in any programs offered through Cancer Services? Please select all that apply.
   - CLIMB
   - Families Group
   - Healing Hands
   - Patient Advocate
   - Support Group
   - Survivors Day
   - Wigs
   - Other:
14. Were these programs helpful and/or enjoyable? Why or why not?

15. Have you, your partner, or your children participated in any cancer-related programs offered through other organizations? If so, please describe.

16. If you or your family did not attend a program that you were interested in, why not? Please select all that apply.
   • The program was at an inconvenient time
   • The program was at an inconvenient location
   • Cost of gas/driving to the program
   • Lack of childcare
   • I was too tired
   • I was too busy
   • My child(ren) didn’t want to attend
   • I didn’t learn about the program until after it happened
   • Other:

17. If you were unable to find a program to meet your needs, what were you looking for? Please describe the kind of program, resource, or group that you would have liked to find.

18. How do you prefer to learn about resources, programs, or groups for cancer survivors and their families? Please select all that apply.
   • Handouts or pamphlets
   • Internet search
   • Email
   • Phone
   • From my healthcare providers
   • Friends/word-of-mouth
   • Church/place of worship
   • Other:

19. What has the time following your/your partner’s diagnosis been like for you, as a parent?

20. What do you think the time following your/your partner’s diagnosis has been like for your children?

21. How would you describe your ability to meet your child(ren)’s needs following your/your partner’s diagnosis?
   • Poor
   • Fair
   • Good
   • Very Good
   • Excellent
22. Is there something that would have enabled you to be more successful in meeting your child(ren)’s needs following your/your partner’s diagnosis? Please describe.

23. Do you have any suggestions for resources, programs, or groups that Cancer Services could offer to families? These could be resources for parents, caregivers, children, and/or whole families. Please describe any suggested programs/resources in as much detail as possible!

24. Is there anything else that you would like to share about your family's journey through cancer? Your reflections and ideas will help us meet the needs of other families facing a cancer diagnosis, so we would love to hear anything that you think would be helpful for us to know!
Appendix D: Responses to Client Survey – What has the time since your/your partner’s diagnosis been like for you as a parent?

• “It was an eye opener, because I was always the caretaker in the family.”
• “Extremely taxing emotionally and physically.”
• “Difficult financially… felt like a complete loser. My kid had to watch chemo, mastectomy, radiation, and the tears as my car got repossessed.”
• “Focused on health and lifestyle changes for myself and my child.”
• “I was very optimistic with my diagnosis… I was thinking only to get well and to be there for my kids.”
• “Very stressful and hard because they don’t understand how you feel and just want things to continue as usual.”
• “Very difficult—I want to see them growing.”
• “Day to day tasks difficult alone with three kids. My youngest is 3, oldest only 10. I was very active at school, PTA, etc. Kids miss me there.”
• “I am through treatment successfully and living a relatively normal life again.”
• “Same, just a little more loved.”
• “Extremely difficult to maintain a household and support two children while facing cancer.”
• “Very hard. My six-year-old couldn’t understand that I was too tired to play. My older kids had a hard time the past two summers because of not being able to have any fun, since I haven’t worked since May 2011.”
• “Tough, low energy and patience, short-tempered at times.”
• “I prayed to God to help me through this. I wrote a journal every time I took chemo. When I lost all my hair I thought I would cry. But when it came out I saved it AND PUT IT IN A BAG!!! And thank God for life everyday. Because my hair will grow back and wouldn’t be able to get another life. My family has been right there for me every step of the way. This sickness grew my husband and I closer together. Not only that, my husband and my daughter (his stepdaughter) have a better relationship now as well. That was an answer prayer. Just want to say you can make it through with family support and keep the faith with God, cause only God can bring you through. I have so many people tell me they are inspired by me because through it all I always have a smile on my face. But it was by the Grace of God. God gets all the credit!!!”
• “This is the hardest thing that I have ever gone through. A year and a half later I am still struggling financially.”
• “Initially, I thought, cancer means death, but when I met the survivors and heard their stories, I went back to life again. I accumulated all my strength to make my life normal for my family.”
Appendix E: Responses to Client Survey – What do you think the time following your/your partner’s diagnosis has been like for your children?

- “Scary.”
- “Anxiety and denial.”
- “Stressful and worrisome.”
- “They actually took it pretty well after the first week, because I didn’t let it get me down.”
- “Not a change for them.”
- “I honestly don’t think he’s noticed. He’s only six.”
- “It wasn’t very difficult.”
- “Pretty normal.”
- “It was hard, but they managed really good.”
- “Lots of changes… difficult with how Mommy looks and is always tired.”
- “They wonder if they are next, if they inherited it, and when it will get them.”
- “We rarely discuss it. They know it may come back, but we intend to live our lives without that threat.”
- “A little stressful.”
- “It was horrible. Both acted out as a way of dealing with the shift in our everyday normal.”
- “Very hard.”
- “Confusion around death, sadness.”
- “My 7-year-old has had behavioral difficulties and bad dreams despite open communication and check-ins.”
- “Great learning, trusting, healing, life changing.”
Appendix F: Helpful Resources for Families Facing Cancer

Helpful Resources for Families Facing Cancer

Resources for Families

American Cancer Society
www.cancer.org
1-800-ACS-2345 (1-800-227-2345)
Cancer information, support, free printable guides for patients, survivors, kids, teens, and caregivers

CancerCare
www.cancercare.org
1-800-813-HOPE (1-800-813-4673)
Free information, financial assistance, and support for patients, survivors, kids, teens, and caregivers

National Cancer Institute
www.cancer.gov
1-800-4-CANCER (1-800-422-6237)
Current information, live chat, and free printable guides on various topics for all family members

Resources for Caregivers

National Family Caregivers Association
www.nfcares.org
1-800-896-3650
Information, education, and support for caregivers

When Someone You Love is Being Treated for Cancer
http://www.cancer.gov/cancertopics/coping/whensomeone-you-love-is-treated
Free, detailed, printable booklet and resources for caregivers from the National Cancer Institute

The American Cancer Society, CancerCare, and National Cancer Institute websites (see links above) all include specific information for caregivers.

Resources for Kids/Teens

Kids Konnected
www.kidskonnnected.org
Support, resources, and reading lists for kids and teens who have a parent with cancer

Someone I Love Is Sick
www.someoneiloveissick.com
Resources to help young children cope with cancer

Telling Kids About Cancer
www.tellingkidsaboutcancer.com
Includes a tool to help families communicate about cancer, age-appropriate conversation guides, audio stories from parents and teens, and a resource list

Staying Connected

These sites allow you to create a free, private online space where you can connect and share messages with family and friends, as well as coordinate helpful tasks such as bringing a meal or taking care of pets:

CaringBridge: www.caringbridge.org
CarePages: www.carepages.com
MyCancerCircle: www.mycancercircle.net

Other Resources

The resource libraries at Cancer Services and your cancer treatment center have many of the books and videos listed on these websites—just ask!

Cancer Services, Inc. • 3175 Maplewood Ave., Winston-Salem, NC 27103 • (336) 760-9983
www.cancerservicesonline.org