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A Concept Mapping Needs Assessment of Young Families with Parental Cancer

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A Concept Mapping Needs Assessment of Young Families with Parental Cancer

by

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DISSERTATION

Submitted in partial fulfillment for the degree of
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Department of Clinical Psychology

DISSERTATION COMMITTEE PAGE

The undersigned have examined the dissertation entitled:

A CONCEPT MAPPING NEEDS ASSESSMENT

OF YOUNG FAMILIES WITH PARENTAL CANCER

presented on February 10, 2011

by

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Dedication

In loving memory of my surrogate father, William Mitchinson. In many ways our journey was a disjointed one. Yet, in the face of chaos you challenged and inspired me to think critically and reflectively about myself and the world around me. Your network of friends and family became my network of friends and family. Your understanding and empathy for the human condition inspired me to live a moral and virtuous life. You were my satellite during a period of life that was truly difficult for me. I am grateful to have known you and I hope your spirit is free.

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I want to thank the staff of the Charles R. Wood Cancer Center of Glens Falls Hospital. Your commitment to this study is a testament of your dedication to the well being of your patients. You are all exceptional assets to the community you serve and I am honored to have worked with you all. I want to particularly thank Patricia Spencer-Cisek for believing in me and not wavering while challenging the organizational barriers that surely would have prevented my training and this research from ever becoming more than an idea. I also want to thank Karen Cook, Vicki Yattaw, and Paul Miller. The three of you provided me wonderful education in the area of oncology education and support. You also made this study possible by helping me

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To my friends, thank you for attending to my fears, complaints, wishes, and desires as I moved through my graduate studies and professional training. More importantly, thank you for excusing my absences from your lives at times I know you wanted me there. You all gave me so much of your time, attention, and support which deeply moves me and will not go unrewarded.

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Most importantly, I want to thank my wife, Angela, and our children, Aidan and Schuyler. Angela, there is no possible way for me to inventory and list all of the things you have done to make my academic, professional, and personal ambitions a reality. Your sacrifice, love, and commitment for me to become the person I am today have been unbounded. Without your companionship I am certain my life would have taken a different and less purposeful direction. In the love we share lays the hope that constructs the foundation and future of our life together. Aidan and Schuyler, you have both been a limitless source of joy, amazement, and inspiration. After all these years of graduate school and professional training in clinical psychology I am pleased to report I learned my most valuable professional and personal lesson from my children—to slow down and live in the moment. Thank you both so much for your unconditional love, all the rocking chair time we have had, and the gift of spending the rest of my life as your father.

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Abstract

The purpose of this research is to investigate the support needs of young families living with and beyond a parental diagnosis of cancer. The sample includes 56 participants comprised of 31 professional stakeholders and 25 patient stakeholders affiliated with the Charles R. Wood Cancer Center. It was hypothesized there would be differences in how the groups of stakeholders rated needs in terms of importance, satisfaction, and utilization. Differences in ratings are thought to be barriers to effective program development. While not a formal research hypothesis, it was anticipated other program development barriers germane to naturalistic clinical settings would emerge from the organizational, community, practitioner, and researcher domains. By utilizing an internet-based method of needs assessment known as *Concept Mapping*, the researcher facilitated discovering 125 emergent patient and family needs. An eight-cluster model of identified issues and needs was constructed. The cluster names assigned include Emotional Impact on Parents, Parents' Worries About Children, Family Adaptation to Illness, Navigation, Case Management, Emotional Impact on Children, Kids' Support Needs, and Families' Support Needs. Results indicate differences in how the patient and professional stakeholders rate the statements on all levels, indicating potential barriers to effective program development. The cluster rated lowest on satisfaction and highest on level of importance and utilization is Case Management, indicating a need for initial and on-going psychosocial needs assessment throughout the experience of a parental diagnosis of cancer. Limitations for this study are discussed in addition to recommendations for oncology support program development at the Charles R. Wood Cancer Center.

Keywords: concept map, cancer, family, needs

A Concept Mapping Needs Assessment of Young Families with Parental Cancer

Chapter 1: Introduction and Statement of the Problem

Providing psychosocial and educational support services to individuals diagnosed with cancer is paramount for effective and comprehensive care for their illness. According to the Institute of Medicine of the National Academies (IOM; 2008):

> Psychological and social problems created or exacerbated by cancer – including depression and other emotional problems; lack of information or skills needed to manage the illness; lack of transportation or other resources; and disruptions in work, school, and family-life cause additional suffering, weaken adherence to prescribed treatments, and threaten patients' return to health. (p. 1)

Therefore, psychosocial and education support services have been linked to optimal patient quality of life during and beyond treatment, as well as having a significant effect on cancer recurrence (IOM, 2008).

It is logical to conclude that as patient factors vary, so too do the psychosocial and education support needs they require for effective and comprehensive treatment. The IOM (2008) contends "research should aim to clarify the efficacy and effectiveness of new and existing [psychosocial] services, including identifying subpopulations who benefit from specific services and the circumstances in which given services are most effective" (p. 329). There is abundant psychosocial and educational support research and programming to address the needs of many cancer patient groups. There is only a limited amount of studies that investigate the psychosocial and educational support needs of young families who are living with and beyond a parental diagnosis of cancer. This limit has resulted in a lack of empirically supported psychosocial and educational programming available to address this special population's needs.

Therefore, young families living with and beyond a parental diagnosis of cancer are a subpopulation in need of effective psychosocial and education support services.

The American Cancer Society estimates that 303,150 adults ages 25 to 54 are diagnosed each year with invasive cancer (IOM, 2008). Given U.S. Bureau of Census data, that suggests that approximately 242,000 children and teens between the ages of 6 and 17 are faced each year with dealing with the cancer of a parent (Van Dernoot, 2005, p. xv). Studies have shown that when one family member is ill, the other members of the family are all affected, especially the children (Kazak, 1992). Consequently, the quality of life for the entire family can be greatly impacted (Compas, Worsham, & Ey, 1992).

On a more local level, the Charles R. Wood Cancer Center (the Center) at Glens Falls Hospital serves a large geographical region where many of the residents come from rural areas and are of low socioeconomic status. Approximately 900 new patients with cancer are diagnosed and treated each year by the Center, 250 of which are under the age of 54 with children. Of these 250 patients, over half have one or more children less than 18 years of age. The Center has implemented some exploratory programming to address the psychosocial and educational support needs of these young cancer patients and their families. Despite their efforts, they have identified large gaps in service for this special population and require assistance with researching, designing, and implementing programming that is evidence-based to meet these emerging community needs.

The Center recently conducted a focus group with the parents of a handful of these young families (N = 6) to assess their individual and family needs. This was a method that proved effective in work conducted with another chronic disease treatment program at Glens Falls Hospital; namely, the Regional Nutrition and Diabetes Center. The focus group identified needs and concerns in three illness phases: *diagnosis, treatment,* and *after treatment*, reflecting shifting patient needs over time. The small sample of participants identified a total of 48 items of significance. Most of the needs and concerns were identified within the *treatment* domain (22 items). The *diagnosis* domain and *after treatment* domain were equally represented with 13 items each.

After identifying the needs, the 48 items were rated by participants on a Likert-type scale consisting of 5 points: 1 – (Not Very Important) thru 5 – (Very Important). The top 6 items rated as most important included: (a) how to tell young kids about parent diagnosis in a way they would understand; (b) immediately after diagnosis, you need someone to discuss and educate you about the diagnosis; (c) planning for the future of my kids; (d) the emotional well-being of my children; (e) doctor engagement and/or communication of diagnosis and implications of treatment plan; and (f) fears of recurrence.

In addition to the rating of item importance, the participants rated their current level of satisfaction in getting these needs met by the Center or other services in the community. This rating was also on a 5 point Likert-type scale: 1 – (Not Very Satisfied) thru 5 – (Very Satisfied). The highest possible collective score for each statement or need was 30. The 6 items with the highest importance ranks and [total satisfaction scores] were: (a) how to tell young kids about parent diagnosis in a way they would understand [score of 12]; (b) immediately after diagnosis, you need someone to discuss and educate you about the diagnosis [score of 20]; (c) planning for the future of my kids [score of 20]; (d) the emotional well-being of my children [score of 21]; (e) Dr. engagement and/or communication of diagnosis and implications of treatment plan [score of 26]; and (f) fears of recurrence [score of 16]. While these results indicated that the Center's existing programs have had some impact, the emergence of previously unknown needs and rating of current satisfaction with some existing program components suggested there was a need for improved services.

Purpose of the Study

In summary, several significant findings emerged from the Center’s pilot needs assessment. First, participants easily identified 48 distinct needs or concerns. This suggests that young families in our region living with and beyond a parental diagnosis of cancer have many unique and significant psychosocial and education support needs. Additionally, this pilot data suggests that the Center’s current programming is not evenly addressing all of the identified needs of this population. It is anticipated that a more in-depth investigation of this special population, using a larger, more representative participant group from throughout the region, will reveal more unmet psychosocial and education support needs. With an increase in variability in patient factors, it is anticipated there will be an increase in variability in patient education and support needs, as the IOM (2008) suggests.

This project was designed to further illuminate these findings by utilizing a rigorous, open-ended, empirically supported, mixed-methodology to assess the needs of young families in the Center’s community who are living with and beyond a parental diagnosis of cancer. It was hypothesized this process would uncover that this special population has psychosocial and education support needs that are unmet by existing services. The needs assessment data will remain available for the scholarly community to use for development of interventions that address these emergent unmet needs. At the local level, this data will provide the Center program developers a starting-off point for developing strategies and interventions that address their patients’ needs. The results of the concept map can be used to develop a logic model, as a guide for program development, and as a tool for program evaluation (Kane & Trochim, 2007).

Research Hypotheses

The research hypotheses for this study were: One, several previously undocumented psychosocial and education support needs would emerge from a rigorous, mixed methods needs assessment of young families living with and beyond a parental diagnosis of cancer. Two, according to participant ratings, the CR Wood Cancer Center’s current programming components would not adequately address the emergent needs of this special population. Three, ratings of these needs on level of importance and utilization of new services to address the identified needs would vary between patient stakeholders and professional stakeholders, uncovering the existence of potential barriers to effective program development. While not a formal research hypothesis, it was also anticipated throughout the process of this investigation that various barriers to effective evidenced-based program development would emerge from the organizational, practitioner, researcher, and community domains put forth by Petosa (2001). The researcher’s anecdotal account of encountering these barriers is provided in the Discussion.

Chapter 2: Literature Review

Distress in Cancer

According to the National Comprehensive Cancer Network, (NCCN, 2008):

> Distress is a multi-factorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis. (DIS. 2)

Incomplete Cancer Care

The IOM (2008) put forward “many people living with cancer report that their psychosocial health care needs are not well addressed in their care” (p. 5). Patients often report experiencing dissatisfaction in the quality and quantity of information they are given when they are first diagnosed, in treatment, and after treatment. In addition, the President’s Cancer Panel, (2004); Maly, Umezawa, Leak, and Silliman (2005); Turner, Clavarino, and Yates et al. (2007), Epstein and Street (2007), found that many people diagnosed with cancer report that their cancer care providers do not understand their psychosocial needs or provide adequate services or referrals to address their needs.

One widely accepted reason for incomplete cancer care is care providers’ underestimation of the patients’ level of psychosocial distress (IOM, 2008; Fallowfield, Ratcliffe, Jenkins, & Saul, 2001; Keller & Sommerfeldt et al., 2004; Merckaert & Libert et al., 2005; Turner et al., 2007). This suggests there are differences between how patients and providers perceive the occurrence and or importance of the various patient psychosocial needs.

Stakeholder differences in perception of needs or their importance are often barriers to effective program development intended to address those needs (Abrahams, 2010; Graham & Kerner et al., 2008; Kane & Trochim, 2007; Quinlan & Petrucci, 2007; Trochim & Robinson, 2007; Witkin & Altschuld, 1995).

Education Support Services

This type of support includes education provided to the diagnosed parent and family concerning the type of cancer diagnosed and treatment prescribed by the oncologist. In addition, genetic testing and counseling, nutrition education, financial problem-solving, and referral services to fill other needs such as transportation and respite care are provided. Some education focuses on physical exercises patients can perform to reduce the side effects of treatment regimens (IOM, 2008).

Psychosocial Support Services

Psychosocial support services are psychological and social services and interventions that enable patients, their families, and health care providers to optimize biomedical health care and to manage the psychological, behavioral, and social aspects of illness and its consequences so as to promote better health (IOM, 2008).

Impact of a Cancer Diagnosis and Subsequent Treatment

Generally speaking, the diagnosis and subsequent treatment of cancer often causes significant levels of distress for the person diagnosed and his or her family. There are a number of patient and family characteristics that put some at more risk than others for distress at the time of diagnosis and during the treatment of cancer. These characteristics include a history of psychiatric disorder, substance abuse, depression or suicide attempt, cognitive impairment, communication barriers such as deafness, severe comorbid illness, social problems, family or caregiver conflicts, living alone, financial problems, limited access to medical care, young or dependent children, younger age, and spiritual or religious concerns (NCCN, 2008).

Impact on Parents

According to Davey, Askew, and Godette (2003) parents experience elevated distress and many unmet supportive care needs throughout their experience of cancer. Elevated distress may include depression and anxiety (Jones, 2001), whereas the unmet supportive care needs may include those in the domains of information, health care, physical functioning, relationships, emotions, socioeconomic matters, expectations, and life perspective (Hodgkinson, Butow, Hobbs, & Wain, 2007).

When these young adults are parents of dependent children they are often affected by the illness in unique ways because of where they are in the developmental life cycle (Sherman & Simonton, 2001). Typically, individuals in this group are significantly focused on attaining and maintaining their individual and family goals. A cancer diagnosis presents many physical and psychosocial challenges; it therefore often interferes with these efforts and impairs quality of life. Some of the physical challenges from both the illness and treatment that are of most concern to young parents include household management, fertility and sexual functioning, changes in appearance and body image, cognitive function, and pain (Davey, Askew, & Godette, 2003).

Some of the psychosocial challenges that are especially relevant to young parents living with and beyond cancer are concerns about their children’s well-being, managing emotional distress, insurance and employment, reduced social involvement, and changes in roles and lifestyle (Davey et al., 2003). Though these significant threats to quality of life exist, it has been long documented that cancer patients’ quality of life can be significantly improved by educational and psychological interventions that reduce the impact of those threats (Berglund, Bolund, Gustafsson, & Sjoden, 1997; Fawzy, Fawzy, Cousins, Kemeny et al., 1990; Greer, Moorey, Baruch et al., 1992; IOM, 2008).

Impact on Children and Adolescents

Recent research with children and adolescents who have a parent diagnosed with cancer has revealed compelling evidence identifying their special education and support needs (Fasciano, Berman, Moore et al., 2007; Grabiak, Bender, & Puskar, 2007; Osborn, 2007). As young as 6 years old, children are aware that cancer is a potentially life threatening illness (Compas, Worhsam, Epping-Jordan, Grant, Howell, & Malcarne, 1999). Evidence also suggests that psychosocial stress for children and adolescents is highest at times immediately following the parent's surgery, during their chemotherapy, and during times of hair loss (Compas et al., 1999). In these times of high stress parents are likely to underestimate the impact these events have on their child, resulting in failed communication between parent and child concerning cancer and its treatment (Forrest, Plumb, Ziebland, & Stein, 2006).

In addition to the presence of miscommunication, normal parent–child interactions are often disrupted due to the psychosocial and physical side affects cancer has on the parent (Lacetti & Vessey, 2007). Some of the disrupted interactions include the child's and parent's decreased attendance at school extracurricular activities such as sports, clubs, or special events. Other disrupted parent–child interactions include parental displays of affection and support for normal childhood experiences, and displayed affection and support for the child while he or she copes with the parent's diagnosis and treatment of cancer (Davey et al., 2003; Lacetti & Vessey, 2007; Van Dernoot, 2005).

Disruption of normal routine, parental affection and parental support can often result in poor mental health and behavioral problems in children and adolescents of parents diagnosed with cancer (Lindqvist, Schmitt, Santalahti, Romer, & Piha, 2007). Mental health concerns include increased depression and state anxiety (Visser et al., 2005), disrupted attachment (Quinn-Beers, 2001), and risk for peritraumatic dissociation, which is predictive of later development of posttraumatic stress disorder symptoms when these affected children reach adulthood (Wong, Looney, Michaels, Palesh, & Koopman, 2006). Behavioral problems often evident in these children and adolescents include internalizing problems such as withdrawal and somatic complaints and externalizing problems such as speech problems, nervous ticks, school truancy, delinquency, aggressiveness, and self-destructive behavior (Visser et al., 2005). With properly designed and implemented early interventions, much of the impact of a parental diagnosis of cancer on children and adolescents can be mitigated (Christ and Christ, 2006; Davey et al., 2003; Lacetti & Vessey, 2007).

Impact on the Family

Research on how the family system is impacted by a parental cancer diagnosis has also revealed some compelling information. One salient finding is that when a parent has cancer, the entire family system typically experiences increased emotional distress, less family interaction and communication, and increased social isolation (Baker & Sedney, 1996; Compas et al. 1999; Dunkel-Schetter, Feinstein, Taylor, & Falke, 1999; Sherman & Simonton, 2001). During the time of initial diagnosis, some common emotional responses include shock, anxiety, confusion, and despair. These emotional responses are often followed by nightmares and intrusive thoughts, and avoidant responses amongst family members (Sherman & Simonton, 2001). During the treatment phases of parental cancer, family members often struggle with anxiety concerning the effectiveness of treatment, the unwelcome intrusion treatment has on the family’s quality of life, and anxiety concerning unmet expectations with regards to their normal family life. During treatment, family members may also struggle with anger toward the parent with cancer or their own guilt surrounding their inability to be a perfect caregiver (Sherman & Simonton, 2001). In the final phases of recovery and survival, family members often struggle to continue with their daily routines and to find a way to live comfortably with the uncertainty they must now face due to the likely side effects of treatment and the possibility of cancer recurrence (Sherman & Simonton, 2001).

These emotional responses and behaviors are normal reactions to a parental cancer diagnosis. However, they often have a negative impact on the psychosocial well being of the family members and the whole family's quality of life. Family systems, as with parents and children who are coping with a diagnosis of parental cancer, can benefit greatly from educational and psychological interventions (IOM, 2008; Sherman & Simonton, 2001). Research suggests that interventions should focus on providing information relevant to the parent's diagnosis (Meissner, Anderson, & Odenkirchen, 1990), effective family coping strategies (Kershaw, Northouse, Kritpracha, Schafenacker, & Mood, 2004), and family system processes (Mizrahi, 2003).

Current Program Model and Interventions

The preceding Literature Review section demonstrates that a parental diagnosis of cancer can negatively affect parents, their children, and the whole family system. The impact can often be debilitating for the individual and severely disruptive to healthy family functioning. Next, the programming the Center currently has in place to address the current perceived needs of young families living with and beyond a parental diagnosis is reviewed.

As discussed in the introduction, the Center annually treats about 125 adults who are parents of young families and diagnosed with some form of cancer. These diagnosed parents and their young families have presented with varying psychosocial and education support needs throughout the different disease stages of diagnosis, treatment, and post-treatment. To address these needs the Center's Oncology Education and Support Services (OESS) staff (consisting of a licensed clinical health psychologist, a master's level social worker, two oncology resource nurses, a nurse case manager, a registered dietitian, a chaplain, a program director, and an assistant to the director) have implemented some exploratory programming with mixed results. That programming includes the *Young Survivor's Group, Cindy's Comfort Camp,* and *Family Connections.* In addition, parents and their families are eligible for *Outpatient Psychotherapy* services, *Oncology Resource Education* services, *Spiritual Care*, *Case Management*, and *Nutrition* services.

Young survivor's group. The Young Survivors support group is an open-ended support group for young women who have survived breast cancer. There are some participants who are mothers of dependent children, and some who are not. This is a new group and there is no specific programming in this group to address the specific needs of young mothers who have survived breast cancer.

Cindy's comfort camp. Cindy's Comfort Camp is a free, weekend overnight camp for children and teens ages 6 to 17 that have experienced the disease or death of a parent or sibling. Separate camps are held for those who have suffered a loss and those who have a parent or sibling with a life-threatening illness. The fundamental underpinnings of the camp are that children and teens are helped through these difficult times by having the opportunity to gently explore their thoughts and feelings while also having fun. Throughout the weekend campers participate in a series of therapeutic groups and outdoor adventure activities.

Family connections. Family Connections is a family-oriented program for children, teens, and parents facing life with a seriously ill loved one. Once every other month, it is an opportunity for families to step back from daily routines, spend some time together, and connect with other families experiencing similar circumstances and challenges. During participants' time together they share a family style meal and take part in different therapeutic activities. Some of the activities are for parents and caregivers, some are for kids and teens, and some are for families as a whole. Four themes serve as guiding principles for these activities: *Change, Feelings, Building a Network, and Moving Forward*. One major assumption of this program is that by sharing the experiences common to living with illness, families can move adaptively through the changes often common when a family member becomes seriously ill. It is also assumed that strengthening existing relationships by identifying, expressing, and validating feelings and by forming new healing connections, families are able to move forward to open new doors of hope and understanding (Durant & Florio, 2007).

Outpatient psychotherapy. To support people through their experience, there are psychosocial oncology experts on hand at the CR Wood Cancer Center. The staff includes a licensed psychologist and a licensed master social worker. This staff provides individual, couple, family, and group counseling.

Oncology resource education. Patients and family members often become confused by complex medical terms, overwhelmed by the volume of information they are given, and simply frightened by the thought of facing a potentially life-threatening disease. When this happens, Oncology Resource Education Nurses provide patients and families with the tools they need to better understand the cancer diagnosis, treatment options, and possible side effects, as well as refer them for additional support services.

Spiritual care. The CR Wood Cancer Center understands that a serious illness impacts every aspect of patients’ lives, including spiritual and religious beliefs. Therefore, the Center offers pastoral care services to help patients’ and their families identify key questions and find new meaning in their lives.

Case management. Case management services at the Center assist patients and their families in several ways. These include coordinating medical care and accessing resources including financial assistance, transportation for appointments, and referrals for additional community services. In addition, the nurse case manager provides assistance with long-term care facility placements and at home medical needs such as medical devices, equipment, and home care.

Nutrition services. The Center believes that nutrition is also an important part of cancer treatment. Therefore, they have a registered dietitian on staff to meet with patients and help set nutrition goals that are specific for individual patients. The dietitian also provides suggestions for management of treatment-related symptoms, eating plans after treatment is complete, and nutrition counseling for cancer prevention.

Six-Step Program Development Chain Model

This model is based on the foundation that programs are developed beginning with theoretical notions of participants' crucial needs. The movement from theory to the completed program requires a series of six steps (Sussman & Wills, 2001). The six steps include: (a) *assessment of the target population’s needs,* (b) *systematic pooling and warehousing*, (c) *systemization of perceived efficacy studies,* (d) *systemization of immediate-impact studies*, (e) *systemization of program construction and pilot testing,* and (f) *refinement* (Sussman, 2001).

These steps, and how they can be applied to subsequent program development, are explored in detail in the Discussion section.

Needs Assessment

According to Witkin and Altschuld (1995) a *needs assessment* is “a systematic set of procedures undertaken for the purpose of setting priorities and making decisions about program or organizational improvement and allocation of resources” (p. 4). The needs assessment process investigates the needs of a particular group or organization with the ultimate goal of uncovering discrepancies between the current state of affairs and the state of affairs sought after by the group or organization. The information collected then guides stakeholders in setting priorities for future programming or interventions.

Barriers to Empirically-Based Program Development

It is noteworthy that the oncology education and support programming offered at the Center is not based on empirical research, nor is there an ongoing program evaluation initiative to determine the effectiveness of the services offered. It is anticipated in this study that the lack of such initiatives is due to specific factors that are barriers to empirically-based program development. Petosa (2001) postulates that these specific factors fall within the categories of *organizational, community, practitioner,* and *researcher*. Petosa contends that these factors represent “the interests of groups whose participation is foundational to the success of health behavior programs….[and] each of these factors can provide resources and impose constraints on each of the other three factors” (p. 54). In Figure 1 Petosa’s (2001) *Ecology of Health Behavior Programs* framework is displayed. He suggests that, “together, these factors create a context in which health behavior programs evolve and improve or stagnate and die” (p. 55).

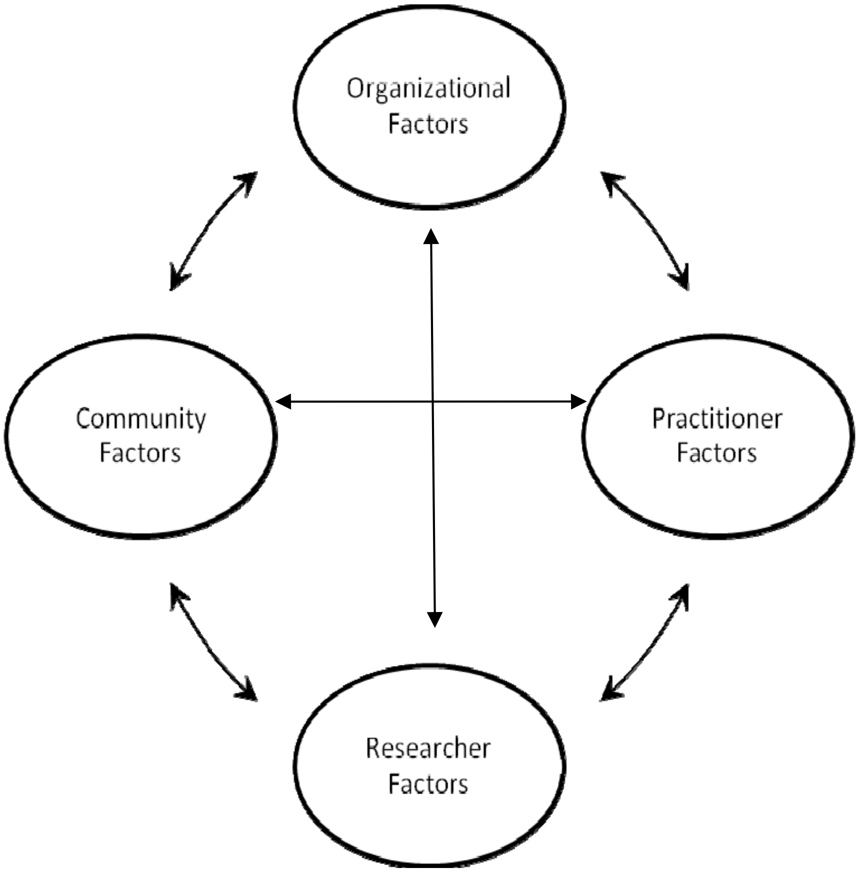


Figure 1. Depiction of Petosa's (2001) “Ecology of Health Behavior Programs” (p. 54)

Petosa contends that “factor-related barriers” (Petosa, 2001, p. 55) inhibit empirically-based program development. It was anticipated in this study there would be barriers in each of the *organizational, practitioner, researcher,* and *community* domains. Thus, *organizational, practitioner, researcher,* and *community* factor-related barriers are discussed below.

Organizational factors. Petosa (2001) defines the organization as “a functional structure for generating and coordinating the resources necessary to pursue valued goals” (p. 55). He also clarifies that the pursuit of these valued goals is the *primary purpose* for an organization. Endeavors such as empirically-based program development for psychosocial and educational services often get categorized as a *secondary purpose* (Petosa, 2001). Secondary purposes are often in direct competition for resources devoted to primary purposes. These resources often include staff, time, money, and facilities (Petosa, 2001). Therefore, resources for secondary purposes are often quite limited and as a result, organizations are more comfortable with "adopting existing health behavior canned programs that seem suitable rather than invest the time and money necessary to carefully develop and test a program tailored to their site" (Petosa, 2001, p. 55).

Another key organizational barrier to empirically-based program development is "disruption of established decision-making processes" (Petosa, 2001, p. 56). Petosa proposes that the process of making decisions within organizations requires equilibrium between "administration, practitioners, and community members" (p. 56). The crux is that researchers investigating programming may seem like they are thrusting themselves into the decision-making process in a way that disrupts the natural and accepted flow of an already existing process, thus causing potential threat and disruption to the organization and its way of doing business (Petosa, 2001).

Community factors. Petosa (2001) defines a community as "a collection of people identified by mutually held concerns for the development and well-being of their group (e.g. neighborhood, a geographic region, or a collection of people who share a common identity)" (p. 57). Similar to organizations, competition for resources within the community for empirically based program development is high. According to Petosa (2001) "ultimately community members must impose constraints on the time, money, and other resources available to any particular program. In this context it is often difficult to garner resources for empirically-based program development models" (p. 57). The amount of resources allocated will depend greatly upon the weighing-in of four specific groups within a community. Those groups include *general* *citizenry, special interest groups, private sector-vendors of behavior program materials,* and the *target population*.

Practitioner Factors. Practitioner factors exist within groups of associated program service providers. According to Petosa (2001) this is primarily because:

> The training of these professionals is diverse. There are few models or theories shared among these professional groups. Many of them do not receive formal training in health behavior program planning. Only a small percentage receive training in health behavior theory, and even a smaller number receive training in behavioral and educational research methods necessary to empirically validate the effectiveness of health behavior programs. (pp. 58-59)

Since these practitioners have varied training experiences and expertise, it is likely many of them will rely on their understanding of different programs they are familiar with that do and do not work. According to Petosa, (2001) as "a consequence, practitioners develop implicit heuristics for making judgments. Often, judgments regarding effectiveness and efficiency of programming are based on impressions of cursory reviews of program materials….they [reviews] can be inherently conservative and serve as a barrier to program innovation" (p. 59).

Another practitioner barrier is that "practitioners are often more comfortable as consumers of educational research rather than as participants in the research process" (p. 59). The feelings and resistance that often emerge from their levels of comfort "are not conducive to teamwork or commitment to use an empirical program method" (Petosa, 2001, p. 60). A final barrier that exists within the practitioner category is that practitioners tend to be person-focused. "They are trained to focus attention on the social, educational, and emotional needs of their program participants….[and] practitioners are concerned that their program participants' needs may become subservient to the demands of the program-planning and research process" (p. 60).

Researcher Factors. According to Petosa (2001) barriers that exist at the researcher level of empirically-based program development include *few commonly accepted theories, limited exposure to practitioners and target populations*, and most researchers who engage in primarily theory-based research *generally focus their energies on summative evaluations*. A frequent outcome of a few commonly accepted theories across the professional groups involved in the research is that "common assumptions, approaches, and even language are lacking across disciplines. This can increase the communication gap between researchers and practitioners" (Petosa, 2001, p. 60). One consequence of limited exposure to target populations and practitioners includes a "lack of experience [that] can dampen researchers' willingness to commit the time necessary for extended collaboration in the context of a team of health professionals" (Petosa, 2001, p. 60). Finally, the frequent outcome of researchers focusing too much of their energy on summative evaluations is the researcher's reluctance "to make needed adjustments in fear of compromising their research or their reputations" (Petosa, 2001, p. 61). This reluctance becomes evident when researchers recognize that "empirical program development methods would need to be less intrusive and focus on rapid-cycle feedback. To accomplish these goals, the evaluation methods would focus on process and may have to sacrifice some degree of rigor to enhance feasibility" (Petosa, 2001, p. 61).

Ethical Considerations and Informed Consent

It is important to ensure that treating research participants ethically includes the stipulations of confidentiality and anonymity. According to Mertens (2005) "confidentiality means that the privacy of individuals will be protected in that the data they provide will be handled and reported in such a way that they cannot be associated with them personally" (p. 333). In addition, Mertens (2005) indicates that "anonymity means that no uniquely identifying information is attached to the data, and thus no one, not even the researcher, can trace the data back to the individual providing them" (p. 333). To ensure participant confidentiality in this study all tape recordings, transcripts, and ancillary data media were kept in a combination-lock filing safe. To ensure participant anonymity, all data gathered was coded with a unique identifier. Only the primary researcher had the combination for the safe and no person knows the relationship between the identity of the participants and the data gathered.

Participation in this study was voluntary. Each participant completed an informed consent form (see Appendix A). The form specified the nature and purpose of the research. Participants were informed of the risk for harmful emotions as a result of participating in this study. They were assured if they experienced harmful emotions in this study; they would be referred to qualified mental health service providers. The form also indicated that participants could discontinue with the study at any time without risk of penalty.

Chapter 3: Methods for Needs Assessment

Concept Mapping

Assessment of the target populations' needs was conducted by way of *Concept Mapping*. Concept mapping is a social research method that enables researchers to collect the thoughts and ideas of groups of people, build consensus within and between these groups, and develop a pictorial map of how the thoughts and ideas of group members come together to create concepts. These *concept maps* can then be used to develop group relevant programs and to establish critical benchmarks for evaluating the effectiveness of the programs developed (Kane & Trochim, 2007).

According to Kane and Trochim (2007) "planning and evaluation are essential human activities, aided by the intelligence, knowledge, and experience that individuals bring to the creation of a common approach to any issue" (p. vii). Typically, individuals bring different levels and types of intelligence, knowledge, and experience to any issue that is studied. With this diversity comes much difficulty for researchers, program developers, and program evaluators to collect and manage clear, concise, and neatly packaged resolutions for problems. The Concept mapping process prevails over this major barrier because it is action research oriented and emphasizes stakeholder-driven data. This, in conjunction with the quantitative analysis procedures, multi-dimensional scaling and hierarchical cluster analysis, create viable resolutions for the issue being studied (Kane & Trochim, 2007).

Concept mapping is a systematic process that integrates numerous structured group processes. The qualitative results of these processes are then analyzed with multivariate statistical methods to produce quantitative results. The results of these analyses can then be used to develop objectives for the program development endeavor, in addition to being used as program evaluation metrics or outcome measures. This collaborative, mixed-method research procedure involves stakeholders directly in the initial idea generation as well as in the interpretation of results.

This study adhered to the six Concept Mapping steps recommended by Kane and Trochim (2007). The six steps included *preparation, generating ideas, structuring statements, concept mapping analysis, interpreting the maps*, and *utilization.* Each of these important steps contains their own sub-steps, and each is discussed in relation to this study in more detail below.

Preparation. The preparation step requires the facilitator or primary investigator to help manage the beginning of the process. This involves the facilitator “working with a group of key participants to set the structure, expectations, and desired outcomes” (Kane & Trochim, 2007, p. 8) of the concept mapping project. For this study, the researcher facilitated several meetings with the program director, program consumers, and the program champion. In these meetings we discussed the focus of the project, identification of stakeholder-participants, and the scheduling and logistics of the project as a whole. From these meetings emerged the structure, expectations, and desired outcomes sought from the study.

While discussing preparation, it is also important to acknowledge the necessity of a program champion. This necessity has been established by many program development and evaluation researchers (Goodman & Steckler, 1989; Kane & Trochim, 2007; Sussman, 2001). Program champions are paramount in program development because they are credible and have influence on the decision making processes of both administrators and line staff of organizations (Sussman, 2001). The program champion’s importance is woven throughout each phase of the concept mapping process, beginning with the important steps of developing the focus of the project.

The focus of a concept mapping project is achieved through creation of two types of *focus statements* (Kane & Trochim, 2007). The first focus statement is used in the *brainstorming* activity, which is discussed in more detail in the *Generating Ideas* step below. This first focus statement is designed to give the specific instruction or instructions intended for the project. Kane and Trochim (2007) offer the following focus statement example, "One specific thing Organization XYZ needs to do in order to address its mission is…" (p. 10). This statement is determined via a collaborative process among stakeholders and the champion within the organization undertaking the project. The focus statement for this study, developed by the primary investigator and program champion was, *"Generate statements that describe the issues, problems, concerns, or needs that young families with a parental diagnosis of cancer are faced with."*

The second focus statement, also referred to as a *focus prompt*, was also developed by the principal investigator and program champion. This focus prompt is directly connected to the *rating* activity to be discussed in the *Structuring Statements* step below. The focus prompt is "arrived at through a facilitated inquiry as to the desired outcomes and requirements of the initiative" (Kane & Trochim, 2007, p. 10). An example of a focus prompt, according to Kane and Trochim (2007) is "rate each potential outcome on a five point scale in terms of its importance to the program, where '1' means 'Not very important', '3' means "Moderately important", and 5 means 'Extremely important'" (p. 10). This specific example would be used if understanding level of importance was a desired outcome of the project.

For this study there were three focus prompts designed to evaluate three areas of interest. The first focus prompt elicited the importance participants assigned to each of the statements generated in the brainstorming process. It read *"Rate the importance of each of these issues,* *problems, concerns, or needs on a scale from 1 to 5 where 1 equals Not Very Important, 3 equals Moderately Important, and 5 equals Extremely Important".* The second focus prompt elicited how the participants' rate patients' current level of satisfaction with having these identified needs addressed by current programming. This focus prompt read *"On a scale from 1 to 5 where 1 equals Not Very Satisfied, 3 equals Moderately Satisfied, and 5 equals Extremely Satisfied, rate what you think young families' current level of satisfaction is in having these issues, problems, concerns, or needs addressed.* The third focus prompt elicited the likelihood a young family with a parental diagnosis of cancer would utilize services that address the identified needs. This prompt read *"On a scale from 1 to 5 where 1 equals Not Very Likely, 3 equals Moderately Likely and 5 equals Extremely Likely, rate what you think is the likelihood that a young family with a parental diagnosis of cancer would seek and utilize services to address these issues, problems, concerns, or needs."*

Sampling and participants. Selecting participants is a significantly important part of any research project, including concept mapping. Kane and Trochim (2007) argue that concept mapping is most effective "when it includes a range of people whose knowledge or experience is relevant to the question, although some situations (e.g. product development planning) call for smaller, more homogenous groups because the map's use is very targeted" (p. 10). Therefore, the participant selection process is very much dependent upon the nature of the project. For example, if a health care agency wants to learn more about the health care needs of a specific population, let's say elderly African American community members, the selection process would call for only that demographic. Whereas, if the same health care agency was trying to understand the differences in perception of current health program effectiveness it would be beneficial to include stakeholders from within the organization, possibly health management organization members or hospital clinical staff, in addition to community members.

This study investigated the support needs of a specific population. It also investigated the perceived differences in importance of these needs and perceived utilization of developed services that address the identified needs between the patient population studied and professional stakeholders. Therefore, the participants in this study were comprised of a sample of participants consisting of patient and professional stakeholder groups. According to Kane and Trochim (2007), data saturation is usually achieved with a sample of 100 participants. The researcher was not able to recruit 100 participants due to emergent barriers to program development identified by Petosa (2001). These barriers are summarized in the Discussion section.

The researcher utilized a *snowball approach* (Mertens, 2005) to recruit study participants. This respondent-driven approach enabled the researcher to discover who had the information that was important in the study. By asking key informants who were knowledgeable about the topic, the researcher learned of others who were knowledgeable about the topic. In this study, the researcher interviewed potential participants identified by Center staff as meeting criteria.

There were three types of participants in this study; patients, caregivers, and professionals. The patients and caregivers comprised the *Patient Stakeholder* group and the professionals comprised the *Professional Stakeholder* group. The inclusion criteria for the patients were: (a) the patient must have been between the ages of 25 and 54 at the time of diagnosis of any form of cancer and (b) the patient must have had at least 1 dependent child (age 18 and under) living in the home at the time of their cancer experience. The inclusion criterion for caregivers was: (a) the caregiver could be a spouse, partner, or family primary care giver of the patient who met the two criteria above. The professional stakeholder criteria required those participants to be: (a) Clinical Oncology staff, (b) Oncology Education and Support staff, (c) Cancer Center Volunteer staff, (d) School Teaching or Support Staff, or (e) Cancer Grant Agency or Fund Raising staff. Upon interviewing qualified individuals, the researcher asked for the names of other potential participants from each demographic who she or he thought would be similarly qualified and interested in participating in this study. This demographic data was important to collect for this concept mapping project because it allowed for subsequent analysis of the results based on the demographic criteria.

Each patient stakeholder participant household received a $25 gift card as incentive for participation. The professional stakeholder participants did not receive an incentive due to limited funds. Initial participant recruitment efforts secured a total of 63 participants. Seven patient stakeholder participants dropped out of the study or rejected participation after reading the informed consent. The reason they dropped out or rejected participation is discussed in the Results section. A total of 56 participants were recruited for the study (see Table 1). Participants entered their demographic data on their computer screens via the Internet-based Concept Systems Incorporated (2010) © program. A total of 45 females and 11 males participated. Participants' age ranges were as follows: 18 to 24 (1), 25 to 35 (3), 36 to 54 (41), 55 to 65 (10), 66 or older (1). 34 participants indicated they have experienced their own parental diagnosis of cancer, either their own parents were once diagnosed, or they as parents have been diagnosed.

The participants included 25 patient stakeholders and 31 professional stakeholders. The patient stakeholder group was comprised of 18 patients between the ages of 25 and 54 who have been diagnosed with cancer. These participants varied in disease stages comprised of *diagnosis* (*n* = 2), *treatment* (*n* = 5), and *survivorship* (*n* = 11). The patient stakeholder group also contained 7 participants that met the caretaker criteria (*n* = 7). The *professional stakeholder group* totaled 31. It was comprised of 7 cancer center volunteers, 14 oncology clinical staff, 6 oncology education and support staff, 2 school staff, and 2 grant agency staff members.

Table 1

Participant Demographics

Variable	Response	*N*	%
Primary Role	Patient	18	32.14
	Oncology Clinical Staff	14	25.00
	Program Volunteer	7	12.50
	School Staff	2	3.57
	Education &Support Staff	6	10.71
	Spouse / Partner of Patient	7	12.50
	Grant Agency Staff	2	3.57
Gender	Male	11	19.64
	Female	45	80.36
Parental Cancer Experience	Yes	36	64.29
	No	20	35.71
Age Range	18 to 24	1	1.79
	25 to 35	3	5.36
	36 to 54	41	73.21
	55 to 65	10	17.86
	66 or older	1	1.79
Illness Phase	Not applicable	19	33.93
	Diagnosis	2	3.57
	Treatment	5	8.93
	Survival	30	53.57

Scheduling and logistics. The scheduling of the project steps such as generating ideas, structuring statements, analyzing concept maps, and interpreting the data were planned out early. Kane and Trochim (2007) suggest that concept mapping facilitators develop a written schedule for “the concept mapping process….a plan for communicating responsibilities and time frames within this schedule to affected parties…[and] the format for completed deliverables” (p. 38). This study was online so participants were notified via email when each phase (brainstorming, sorting, and rating) began and ended. The processes of analyzing concept maps, and interpreting and utilizing data began a week after data collection ended. Originally, a series of focus groups and follow up activity meetings were going to be conducted. However, due to unforeseen inhibiting factors proposed by Petosa (2001) in the organizational, community, practitioner, and researcher domains, the researcher had to resort to online data collection and synthesis. The specific inhibiting factors included a small sample size and participation convenience. These factors are elaborated on in the Discussion section.

In addition to developing a schedule, it is equally important to have a thorough understanding of the resources required for the project. According to Kane and Trochim (2007):

> As with most projects, one should be generous in the estimates of time and money required – and in particular, those involved should expect to spend more time in planning a concept mapping study than in actually executing it. Resource use must then be assessed throughout the project, both to check against initial resource projections and to adjust the project scope or negotiate further resources as needed. (p. 43)

Resource management for this project was a team effort consisting of the researcher, the project champion, and the director of the Center. The researcher and project champion calculated a preliminary figure of $3,500 for this project and it did not exceed that figure. The funds for this project were provided by the Class of 2008 Dissertation Research Award from Antioch University New England Department of Clinical Psychology ($700) and the Glens Falls Hospital Foundation ($2,800).

Generating Ideas. The first step of the study required patients to be assigned a unique user name and password to login to the Internet-based Concept Systems Incorporated (2010) program. Participants then accepted or declined participation after reading the online Informed Consent (see Appendix A). Participants were then directed to a secure webpage where they entered answers to demographic questions that inquired about their: (a) P*rimary Role (patient, spouse/partner, oncology clinical staff, school staff, OESS staff, grant agency staff, or program volunteer)*, (b) *Gender (male or female)*, (c) *Parental Cancer Experience (I have experienced—*

or—I am experiencing a parental diagnosis of cancer), (d) *Age Range (18-24, 25-54, 55-65, 66 or older)*, and (e) *Illness Phase (diagnosis, treatment, survival)*.

Next, participants entered the *generating ideas* phase. During this phase participants generated both ideas and statements elicited by the focus statement. For this project, participants generated statements pertaining to the issues, problems, concerns, or needs that young families with a parental diagnosis of cancer are faced with. Each participant was free to generate as many statements or ideas they could come up with and they were able to view the statements entered by the other participants on a master list. This allowed for patients to search the list and reduce the chance they would generate redundant statements.

The process the group engaged in to generate ideas or statements is often called *brainstorming*. Brainstorming (Osborn, 1948) can use any number of processes, such as a live, on-site meeting, or remotely via traditional mail, fax, or the Internet. It can a group process in the manner of a focus group (Stewart & Shamdasani, 1990) or involve people submitting individual inputs over a period of time as in the nominal group technique (Delbecq, 1975). This project used an Internet-based approach for the brainstorming because of convenience and because participants were geographically dispersed. If participants did not have Internet access at home, they were provided access at the Center Library. Participants were able to login as many times as needed to generate statements and were required to generate a minimum of one statement to participate.

As the *statement generation* process continued online the researcher monitored participant progress via the internet. Emails were sent to participants throughout this step to gently remind them to complete this phase within a period of 30 days. The purpose of a 30-day deadline was to adhere to a 3-month schedule for the three phases of data collection and a 3-

month schedule for data analysis and manuscript preparation. The researcher imposed this six-month deadline to complete the study in the time allotted by the Glens Falls Hospital Institutional Review Board.

Once the statements and ideas were generated in the brainstorming process, the researcher then analyzed them. This process is called *idea synthesis,* and its purpose is to reduce and edit the resulting set of ideas. According to Kane and Trochim (2007) this process is important because it results in “a list of unique ideas, with only one idea represented in each statement, ensuring that each statement is relevant to the focus of the project, [and]…reduction of the statements to a manageable number for the stakeholders to sort and rate” (p. 59). It is important to understand this process is not meant to change the order of priority or to remove any one generated idea or statement. It is simply a process designed to eliminate redundancy in statements and create relevant statement lists for sorting and rating, which is discussed in the Structuring Statements section. For the *idea synthesis* step, the researcher reviewed the final list of statements. Statements that were similar in theme to other statements were either consolidated into one statement or removed from the list.

Structuring statements. After idea synthesis was completed the *statement generation* phase was locked online with no further access granted to participants. At this time, participants were invited by email to structure the statements. This phase involved the participants sharing their own perceptions of any similarities between statements. Participants also rated each individual statement on the following previously discussed dimensions: (a) level of importance, (b) current satisfaction level, and (c) level of utilization.

The first step in the online statement structuring process is *sorting*. Sorting occurred before rating because it calls for the participants to attend to “the semantic similarities between statements, regardless of how each participant might feel about the importance or priority of each statement….if the rating task is done first, it is likely that it will influence how the participants sort the piles" (Kane & Trochim, 2007, p. 74). In this step, participants sorted the statements they generated online by dragging and dropping them into piles based on statement similarities. Kane and Trochim (2007) indicate that "the grouping, or sorting, of disparate statements or ideas into piles helps identify a stakeholder's view of the interrelationships of the ideas" (p. 71). At the beginning of this phase participants were presented with the following standardized Concept Systems Incorporated (2010) instructions on their computer screen:

> In this activity, you will categorize the statements, according to your view of their meaning or theme. To do this, you will sort each statement into piles in a way that makes sense to you. First, read through the statements in the Unsorted Statements column below. Next, sort each statement into a pile you create. Group the statements for how similar in meaning or theme they are to one another. Give each pile a name that describes its theme or contents. Do NOT create piles according to priority, or value, such as 'Important', or 'Hard To Do' (or Agree, Disagree, True, False, No Opinion, etc..,) Do NOT create piles such as 'Miscellaneous' or "Other" that group together dissimilar statements. Put a statement alone in its own pile if it is unrelated to all the other statements. Make sure every statement is put somewhere. Do not leave any statements in the Unsorted Statements column. People vary in how many piles they create. Usually 5 to 20 piles work well to organize this number of statements.

As the *sorting* process continued online the researcher monitored participant progress through the administrator porthole. The participants were given a 30-day time limit for this phase and were able to login as many times they needed to complete it. The researcher sent an email to participants once per week to remind them to participate.

After pile sorting was completed and statement sorting results were recorded, participants performed *statement rating*. The rating activity required participants to rate the statements in accordance with the *focus prompts* developed in the earlier stage of the concept mapping process. As already discussed, these focus prompts investigated level of importance, current level of satisfaction with existing services, and utilization of services implemented to address the perceived needs. This process, which proceeded online via the online Concept Systems Incorporated (2010) program, involved participants reading the list of statements on their computer screen and then rating each on the five-point rating scales by clicking the appropriate circle.

Concept Mapping Analysis

After all the demographic, sorting, and rating data were collected, the concept map was developed. Below, the analysis processes of *multidimensional scaling, hierarchical cluster analysis, bridging analysis, pattern matching* and *bivariate plots (go zones)* are discussed. Each level of analysis served a specific function and yielded specific results that were crucial to this needs assessment process.

Multidimensional scaling. According to Kane and Trochim (2007), multidimensional scaling analysis is a result of the statement sorting process and situates each statement as a separate point on a map. Multidimensional scaling clusters those statements most often grouped together by participants closer to each other spatially on the concept map. It does this by taking a table of similarities (or distances) as input and iteratively placing points on a map so that the original table data are as fairly represented as possible (Kane & Trochim, 2007). The map of points that was created clearly represents the set of statements created during the brainstorming session. This analysis created coordinates for each statement and each dimension desired, which comprehensively created a map of the concept(s) under study (Kane & Trochim, 2007). So, the issues, problems, concerns, and needs identified by the participants as most alike appeared closer on the map to each other, and those least alike are situated further apart.

Hierarchical cluster analysis. After the map was generated, a *hierarchical cluster analysis* of the map was performed from which the averages were computed for each statement generated. This produced clusters of statements. The cluster's center is the average of all the points in the cluster — that is, its coordinates are the arithmetic mean for each dimension separately over all the statement points in the cluster. According to Kane and Trochim (2007) this level of analysis "groups individual statements on the point map into clusters of statements that aggregate to reflect similar concepts" (p. 98).

Ward's Algorithm was the mathematical procedure used in the hierarchical cluster analysis, because it makes the most sense with distance-based data (Kane & Trochim, 2007). The primary reason for this is "at each stage in the hierarchical merger of clusters, the algorithm minimizes the sum squares of the distances between all statements in any two hypothetical clusters that might be joined" (Kane & Trochim, 2007, p. 99), resulting in a more well-defined cluster of concepts for the map (Hair, Tatham, & Black, 1998). The hierarchical cluster analysis in this study revealed clusters of like statements as they appeared spatially on the map. These clusters were made up of similar issues, problems, concerns, and needs identified by the study participants.

According to Florio et al. (1998) "a problem common to cluster analysis pertains to deciding the number of clusters that are present in the data set" (p. 229). In their study of work-related stress and coping among oncology nursing staff, Florio et al. recognized that it is effective to examine a wide range of clusters before determining a number for the final map. The researchers decided "using both an item content and quantitative goodness-of-fit criterion" (p. 229) to determine the number of clusters for the final map. According to Florio et al. (1998) in evaluating item content:

> The range of cluster solutions should be examined in reverse order. At each reverse step, two clusters are merged. The clusters that are merged at each step are examined, and a subjective determination is made as to whether the two merged clusters obscure an important distinction preserved by retaining the separate clusters. When the entire range of solutions is examined in this way, a judgment can be made about the cluster solution that yields the fewest number of clusters but still preserves the maximum amount of substantive detail. (p. 229)

The item content analysis was performed via the Concept Systems Incorporated (2010) program by generating a *cluster replay map*. This is the analysis recommended by Kane and Trochim (2007) and is a built-in proprietary feature of the program. The researcher created a cluster relay map starting with a 20 cluster solution and ending with a 2 cluster solution, as recommended by Kane and Trochim (2007) for program development projects. The researcher and the project champion then reviewed only those clusters being merged as we moved through the cluster levels. We based our cluster solution decision on our discovery of the solution that retained the most useful detail between clusters while at the same time merging the detail within clusters that most sensibly belonged together when considering the context of this study (Kane & Trcohim, 2007).

Florio et al. (1998) also provided a succinct description of the goodness-of-fit measure found to be effective at determining the cluster solution:

> A goodness-of-fit measure known as a bridging value is used to analyze the range of cluster solutions quantitatively. A bridging value can be computed for each item, and an average bridging value can be computed for each cluster. The bridging value for an individual item indicates whether the item was sorted more frequently with other items that are close to it on the map. The cluster-average bridging value is the mean of the individual item values and indicates how clearly a cluster reflects the content in its specific portion of the map. Bridging values range from 0 to 1, and decisions about the final cluster solution should try to minimize the cluster-average bridging values while still providing sufficient substantive detail. (p. 229)

In this study, the principal investigator utilized the Concept Systems Incorporated (2010) program to analyze the cluster-average bridging values in all cluster solutions created in the cluster relay map process. By doing so, the researcher was able to discover the cluster solution that made the most quantitative sense based on the bridging values. This cluster solution was determined by selecting the one which minimized the within cluster variance while maximizing the between cluster variance (Florio et al., 1998; Kane & Trochim, 2007).

Bridging analysis. A bridging analysis evaluates whether a statement acts more as an *anchoring statement* or a *bridging statement*. In terms of a concept map of statements, an anchoring statement is one that most represents the content of the other statements in its vicinity. The bridging statement is the one that represents the point most in-between the content of two different vicinities or most distant points on the map. The algorithm places any statement appearing to bridge two concentrated areas in this position (Kane & Trochim, 2007). Kane and

Trochim (2007) suggest it is important to know about and understand anchoring and bridging statements because they "will help explain both the meaning of each area of the map and the dynamics across areas…which help better understand the map in anticipation of the interpretation session" (p. 101). In this study, the anchoring and bridging statements and their values were calculated. The numerical bridging and anchoring values were calculated by performing the proprietary *bridging analysis* function in the Concept Systems Incorporated (2010) program. The numerical values were reviewed by the researcher and project champion and a better understanding of each area of the map and dynamics across areas of the map was obtained.

Pattern matching. Pattern matching allows concept map analysts to evaluate how two sets of ratings compare with each other. It is a very useful tool for investigating consensus and consistency across groups of participants (Kane & Trochim, 2007). Pattern matching is derived from cross referencing any combination of data such as participant demographic data, statement generation data, sorting and rating data, and different points in time for the same variable—such as cluster ratings across two separate planning meetings (Kane & Trochim, 2007). "The facilitator presents these pattern matching displays to the group following the presentation of the concept maps and uses them as a basis for group discussions about the differences and areas of consensus highlighted by them" (Kane & Trochim, 2007, p. 126). The researcher engaged in the pattern matching analysis process by cross referencing several variables. This level of analysis helped us learn about the similarities and differences between ratings across these variables.

Bivariate plots (go zones). *Go Zone* displays "are bivariate X-Y graphs of ratings, shown within quadrants constructed by dividing above or below the mean for each variable. Statements in the upper-right quadrant or 'go zone' normally represent the most actionable ideas within each cluster" (Kane & Trochim, 2007, p. 128). These are the statements within each cluster that are rated above the mean and are agreed upon by all participants. The lower-right and upper-left quadrants contain the statements that are rated above the mean by one group and below the mean by the other. The lower-left quadrant contains the statements rated below the mean by both groups of participants.

The researcher was interested in discovering differences in statement ratings on level of importance and level of utilization. Therefore, bivariate plots were created for these ratings at the cluster level, comparing the patient and professional stakeholder groups. Interpretation of these bivariate plots focused on the lower-right and upper-left quadrants. The researcher was also interested in understanding levels of satisfaction for having the emergent needs met. Therefore, bivariate plots were created for each cluster so statements rated below the mean on level of satisfaction could be examined. Interpretation of these bivariate plots focused on the upper-left and lower-left quadrants.

Program Development Prioritization Strategy

The intention of conducting a concept mapping project is to develop a conceptual framework for program development and or evaluation (Kane & Trochim, 2007). Each statement represents a specific need area to which a specific service can be connected. In this study, the concept map resulted in a categorized set of specific issues or needs of the target population. Each categorized set is a cluster and these clusters collectively become the conceptual framework for the service areas to be considered for program development.

The rating information pertaining to each statement and cluster serves as a guide for prioritization in program development. In this study, the patient stakeholder ratings on importance, satisfaction, and utilization are all relevant for determining priority. For targeted intervention or service development to address one or two needs, the rating information for a couple of statements can be reviewed. For developing interventions or services for a categorized set or sets of specific issues, the rating information for one or more clusters can be used.

To determine priority for program development the researcher developed two patient stakeholder, cluster-level pattern matches, and two all-cluster bivariate plots. The variables used for one pattern match and one bivariate plot were satisfaction and importance. The variables used for the remaining pattern match and bivariate plot were satisfaction and utilization. If a cluster name appeared in the upper-left and lower-right columns of both pattern matches, it was considered an actionable area for program development. If a statement appeared in the lower-right quadrant of both bivariate plots it was considered an actionable area for program development. Clusters and statements in the positions described above are considered to be low on satisfaction, yet high on importance and utilization by the patient stakeholders.

Chapter 4: Needs Assessment Results

Statements

A total of 168 statements were initially generated by participants. Kane and Trochim (2007) indicate that data saturation is usually achieved at 125 statements and this is the maximum amount of statements allowed for calculation in the Concept System software. After completing the *idea synthesis* process discussed earlier, the researcher was able to reduce the statement list down to 125 statements (see Appendix B, Table B1). In comparison, the pilot study generated a total of 48 statements (see Appendix B, Table B2). A content analysis of both lists of statements revealed that the statement list from this study included a close match or variation of approximately 31 of the statements developed in the pilot study, resulting in a total of 94 new needs or issues emerging from this study. The statements from the pilot study that were similar in content to those generated in this study are indicated in bold type in Appendix B, Table B2.

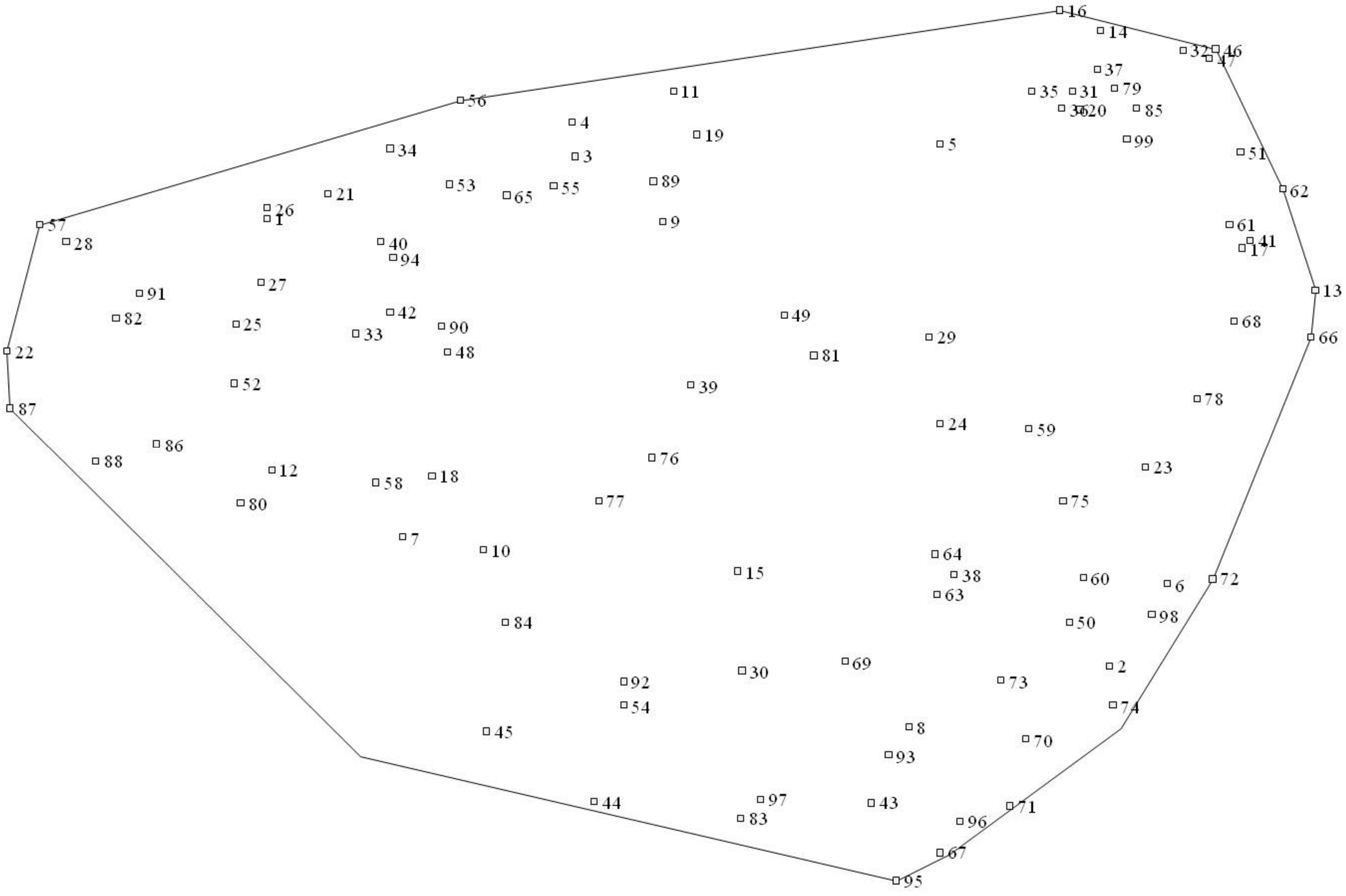
Multidimensional Scaling

The 125 statements were then analyzed in a two dimensional non-metric multidimensional scaling or MDS. According to Kruskal and Wish (1978), the most important diagnostic statistic in multidimensional scaling analysis is the stress index or stress value. Kane and Trochim (2007) indicated that "stress measures the degree to which the distances on the map are discrepant from the values in the input similarity matrix" (p. 97). It is basically a goodness-of-fit measure indicating whether or not the map is cohesive and representative of the input data.

In this study, the MDS analysis of the perceived similarity of the statements produced a final stress value of .244 after 23 iterations or repetitions of the calculation. This final value falls on the low end of the range of stress values recommended by Kane and Trochim (2007). Their review of meta-analytic studies revealed that “approximately 95% of concept mapping projects are likely to yield stress values that range between 0.205 and 0.365.” (p. 98). This equates to an average stress value of 0.285 with a standard deviation o 0.04. They also reported that a concept map is considered a better statistical fit as the stress value approaches the lower end of this range, as the stress value from this concept map does.

Point map. The point map resulting from MDS analysis of the 125 statements is presented in Figure 2. The MDS analysis assigned each of the statements an identifying number which is used for nothing more than statement identification (Kane & Trochim, 2007). In Figure 2 a point indicates each participant generated issue or need with the MDS assigned statement identifying number beside it. It is important to remember that items close together should show a high degree of similarity in meaning. Analysis of Figure 2 reveals that this is generally true. For example, in the upper center portion of the map statement 11 (*Families need to keep the lines of communication open*) and 19 (*Some parents shield children from diagnosis making it hard for child to understand*) are located very close together given their similar content or theme, as opposed to these two statements and statement 95 (*Families don't always know what financial assistance is available or how to access it*) in the bottom center of the map. Again, the farther apart the points are from one another, the more dissimilar they are in content or theme.

Figure 2. Point Map

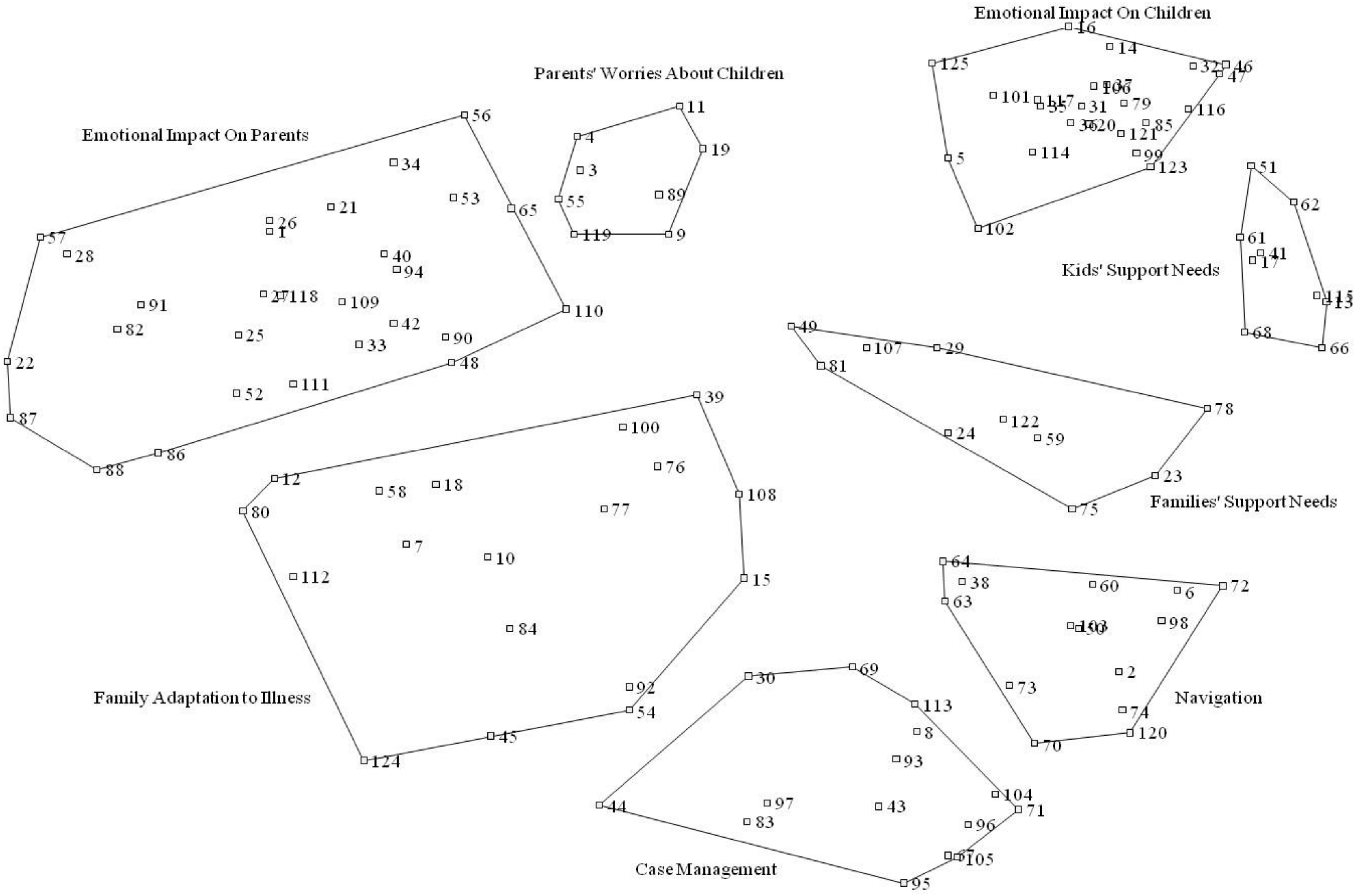


Hierarchical Cluster Analysis

Hierarchical cluster analysis was the next statistical method applied in this study. As discussed earlier, the purpose of this analysis is to group the statements into internally consistent clusters which constitute the conceptual framework. The clusters are the groups of statements that are clearly close to one another on the point map and result from the pile sorting tasks performed by the larger pool of participants during the statement structuring phase. The researcher and project champion utilized the item content and quantitative goodness-of-fit criterion discussed in the methods section to evaluate all potential cluster solutions between 2 and 20 in terms of their bridging values and item content respectively. The original plan was to recruit an advisory board of participants to assist with this analysis; however, unforeseen barriers prevented this from happening. These barriers are discussed in the Results and Discussion sections.

An eight-cluster solution was chosen because it minimized the average cluster and solution bridging values, while at the same time maintaining the item content cohesiveness of each of the clusters. The Eight Cluster Oncology Education and Support Needs Concept Map are presented in Figure 3. In Figure 3 the clusters are the white polygonal objects surrounding the individual statement points. The item content and bridging values of each of the eight clusters are presented in Appendix C. Each of the eight clusters was also assigned names based on careful examination of the items in each cluster. The statements with lower bridging values were weighted more heavily when considering the names of their respective cluster as lower bridging values are indicative of overall cluster content and theme (Kane & Trochim, 2007).

Figure 3. Eight Cluster Oncology Education and Support Needs Concept Map



Cluster names. The cluster names developed for this study include *Emotional Impact on Parents, Parents' Worries About Children, Family Adaptation to Illness, Navigation, Case Management, Emotional Impact on Children, Kids' Support Needs,* and *Families' Support Needs.* As shown in Appendix C, statement 94 (Parent's may not always know how to experience their own fear and anxiety without worrying their kids) and statement 109 (Parents may feel guilty for the disruption in their family's life) clearly represent the cluster *Emotional Impact on Parents*. Similarly, statement 119 (Parents want to know how kids feel, but it can be hard for them to actually hear about how their illness is impacting them) and statement 9 (Overwhelming concern with how kids are handling the diagnosis) most significantly represent the content of the cluster *Parents' Worries about Children*.

The third cluster, *Family Adaptation to Illness*, is noteworthy. The central location of this particular cluster on the map is important because it reflects the primary relationship between family adaptation to illness and all other clusters. This cluster is significant not only for its central position, but also because the items within it represent core aspects of family functioning when faced with parental illness. This cluster includes such items as "Pre-existing family issues (e.g. addictions, depression) are exacerbated w/ the stress of cancer, making family life more difficult", "Difficult for parents to know how to prepare themselves and their kids about what to expect from treatment", "Parents need information about how to help their kids emotionally", and "Families need support in adapting / coping when fertility cannot be preserved." Altogether, there are 18 items in this cluster.

In cluster four, *Navigation*, statements 70 (Help with household management) and 63 (Families need follow-up after an initial supportive contact because their needs and readiness change frequently) are most representative of the content in that cluster. Cluster 5, *Case*

Management, is comprised of statements most similar to 105 (Financial assistance to help family keep up with normal activities and secure necessary things like school supplies) and 104 (Transportation assistance for the multiple family household needs).

At first glance, the Case Management and Navigation clusters appear similar in their item content. However, these clusters (and services) are conceptually different. According to the IOM (2008) “case management consists of a variety of activities necessary to coordinate some or all of the health-related care needed by patients…[that] include assessment of the patient’s needs for supportive services; individual care planning; referral; and connection of the patient with other necessary services and supports…” (p. 191). Patient navigators provide similar functions. However, navigators focus their energies on helping lower socio-economic patients participate more effectively in their overall cancer care (IOM, 2008). This is accomplished by acting as a sort of *concierge* throughout cancer care, guiding more vulnerable patients in the direction of comprehensive service utilization. Patient navigators “assist patients and their families throughout the period of care by, for example, arranging various forms of financial support, scheduling transportation to appointments, and organizing child care during appointments” (IOM, 2008, p. 194).

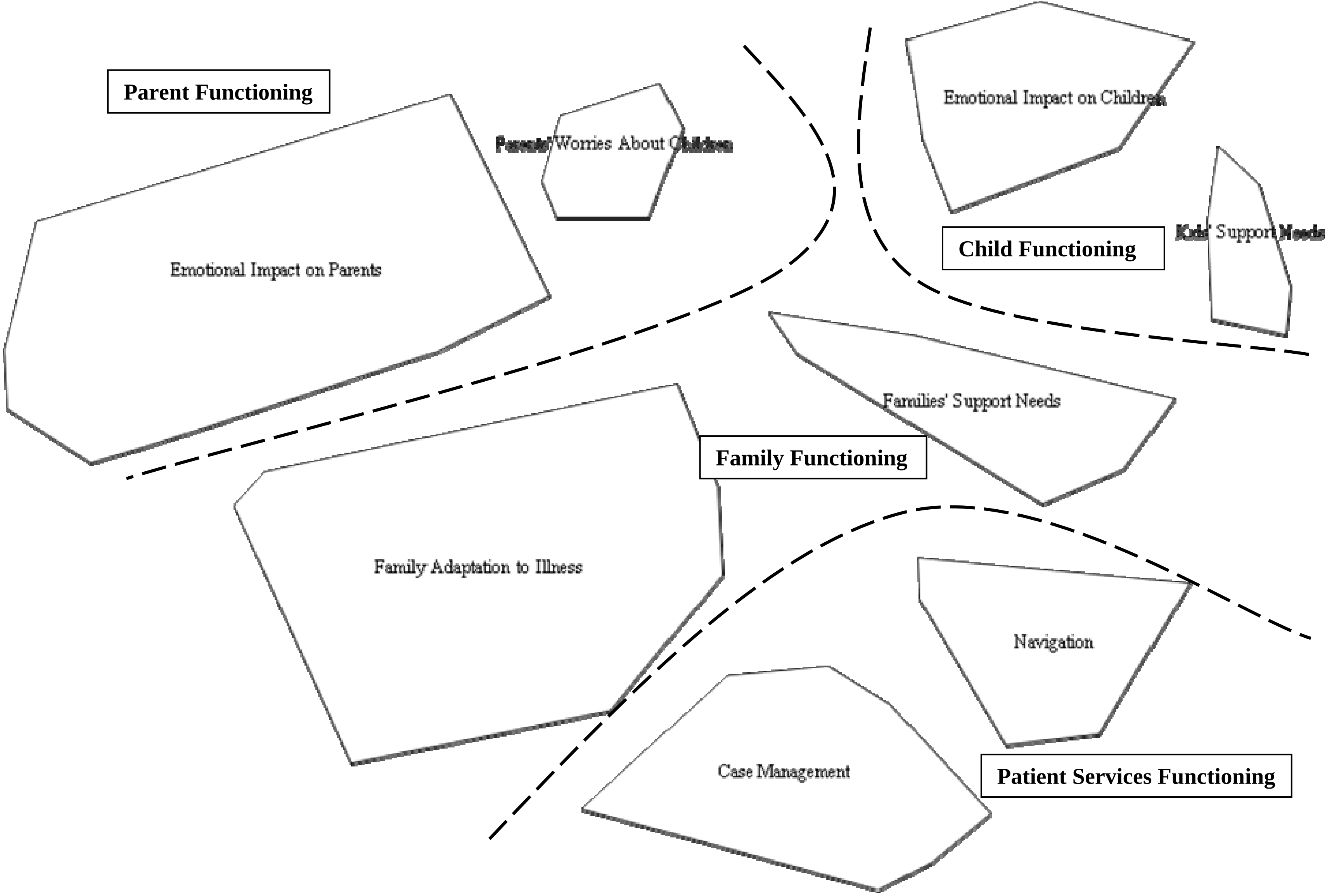
While each of these clusters contains statements that may be more representative of the other, those that have the lowest bridging values are contained within the cluster they most represent. In addition, an attempt was made to collapse these clusters together via the cluster replay map. The next lower solution (7-cluster map) collapsed two other clusters (Kids Support Needs and Families’ Support Needs). The 6-solution map collapsed Navigation and Case Management. These two levels of cluster collapsing increased the within cluster variance while decreasing the between cluster variance of the map, resulting in higher over-all cluster bridging values for the four collapsed cluster.

In cluster 6, *Emotional Impact on Children*, statements similar to 79 (Kids sometimes feel guilty when they enjoy themselves or do normal things) and 106 (Kids experience emotions that can be tough to deal with) prevail. Statements 51 (Kids lack peer support) and 61 (Kids need opportunities to connect and communicate with peers who are having similar experiences) are most representative of the content within cluster 7, *Kids' Support Needs*.

Finally, *Families' Support Needs* is also a noteworthy cluster. Like cluster 3 it is more central on the map indicating a bidirectional relationship with other clusters on the map. Example statements for this cluster include number 81 (Family members don't always know how to talk about the situation) and 49 (Family members often experience anger and don't know how to deal with that). By reviewing Appendix C you can see that the statement examples given above have the lowest stress values within their clusters, indicating cohesive content representation within each cluster.

Concept map regions. Another important process is to identify and discuss *regions* or "super dimensions" (Florio et al., 1998, p. 41) on the concept map. As discussed earlier, identification of regions assists in the implementation of program planning and evaluation (Kane & Trochim, 2007). After careful review of the eight-cluster oncology education and support needs concept map the researcher identified four super dimensions (see Figure 4). Region 1 *Parent Functioning* is comprised of the clusters *Emotional Impact on Parents* and *Parents' Worries About* Children. Region 2, *Child Functioning*, is comprised of the clusters *Emotional Impact on Children*, and *Kids' Support Needs*. Region 3, *Family Functioning*,

Figure 4. Super Dimension Cluster Map



is comprised of *Family Adaptation to Illness* and *Families' Support Needs*. This region is most central on the map and spans all of the other regions. The centrality of Region 3, *Family Functioning*, is a serendipitous occurrence in this study and is discussed in the Future Directions section of this manuscript. Finally, Region 4, *Patient Services Functioning* is comprised of the clusters *Navigation* and *Case Management* and represents the more pragmatic education and support needs of families.

Point Rating Map

As discussed earlier, this needs assessment methodology involved a rating process. Also remember the ratings were of importance, level of satisfaction, and level of utilization of services to address the identified needs. This data is presented on the point rating maps in Figures 5, 6, and 7. Figure 5 is the point rating map that represents the level of importance these statements hold for all stakeholders. On this map, each point is now represented by a bar that indicates the average rating for that statement with regard to level of importance.

The scale used for this rating was as follows; *"Rate the importance of each of these issues, problems, concerns, or needs on a scale from 1 to 5 where 1 equals Not Very Important, 3 equals Moderately Important, and 5 equals Extremely Important"*. If you look at statement 15, "family members need to be a part of planning for the future, regarding the patient's personal health choices", in the lower center of Figure 5, you will see it is represented by three vertical levels of a bar. As indicated in the key, three levels are equivalent to an average rating that falls in a range from 3.52 to 3.85. Thus, stakeholders rated this statement's level of importance on the average between 3.52 and 3.85, which falls in the *moderately important* range on the rating scale.

Figure 5. Level of Importance Point Rating Map for All Stakeholders

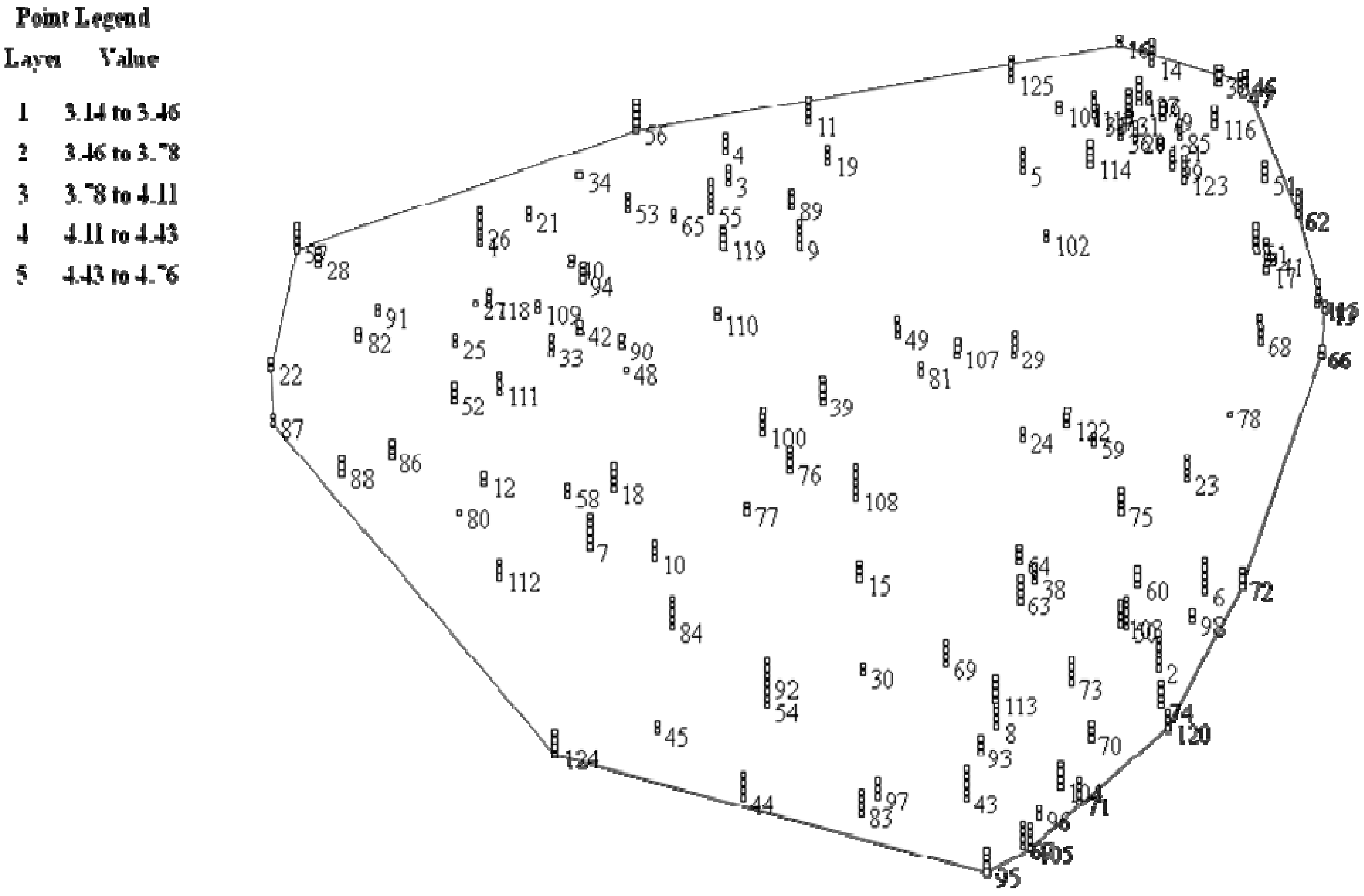


Figure 6 is the point rating map that represents level of satisfaction ratings for all stakeholders. Each point is represented by a bar that indicates the average rating for that statement with regard to level of satisfaction. The scale used for this rating was as follows; *"On a scale from 1 to 5 where 1 equals Not Very Satisfied, 3 equals Moderately Satisfied, and 5 equals Extremely Satisfied, rate what you think young families' current level of satisfaction is in having these issues, problems, concerns, or needs addressed.* If you look at statement 15 as an example again, "family members need to be a part of planning for the future, regarding the patient's personal health choices", in the lower center of Figure 6, you will see it is again represented by three vertical levels of a bar. As indicated in this figure key, three levels are equivalent to an average rating that falls in a range from 2.74 to 3.08. Thus, the combined stakeholders rated this statement's level of satisfaction on the average between 2.74 and 3.08 which distributes across the rating scale as *somewhat* to *moderately satisfied.*

Figure 6. Level of Satisfaction Point Rating Map – All Stakeholders

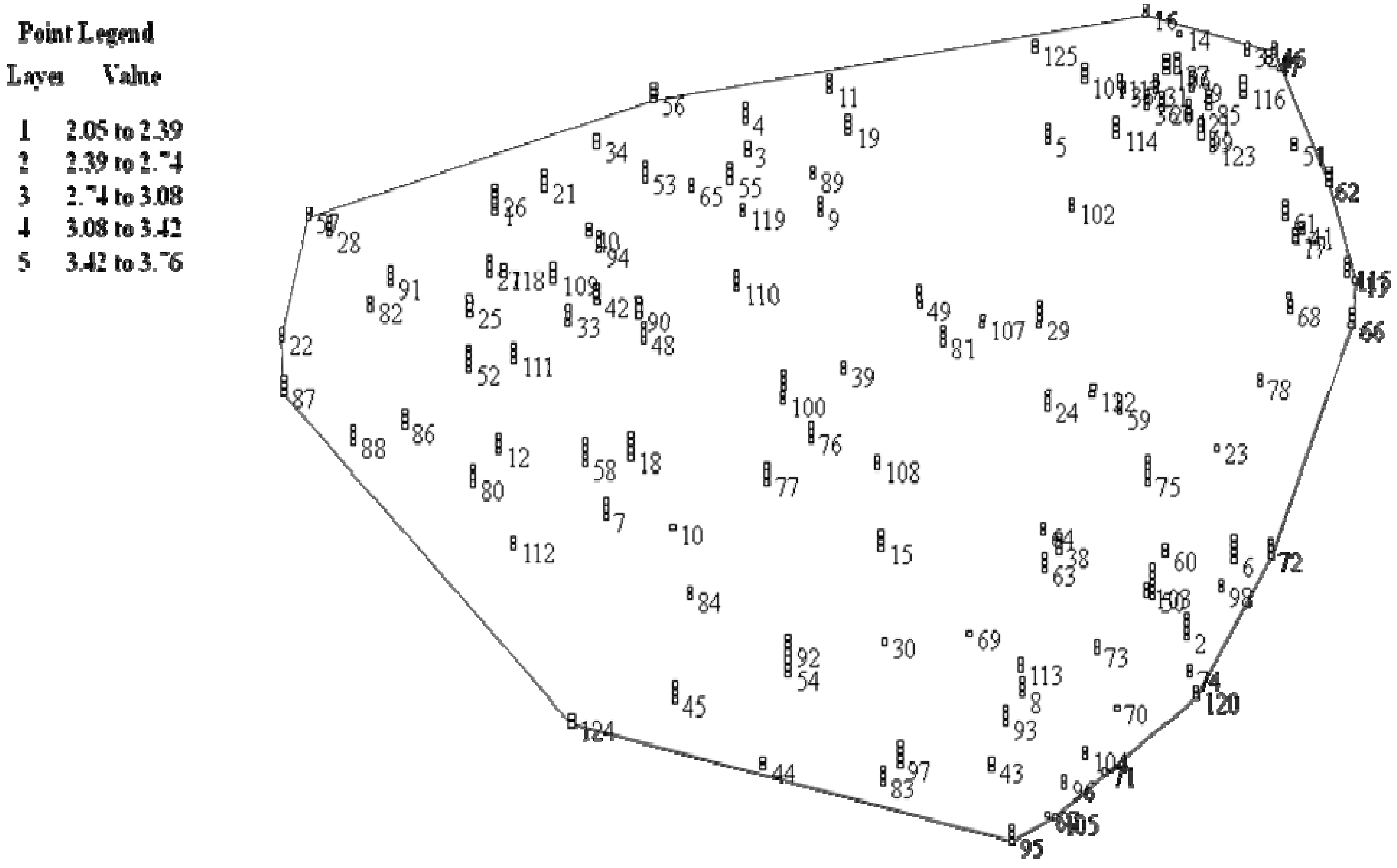


Figure 7 is the point rating map that represents the ratings that indicate the likelihood a young family with a parental diagnosis of cancer would utilize services that address the identified needs. This rating prompt was “On a scale from 1 to 5 where 1 equals Not Very Likely, 3 equals Moderately Likely and 5 equals Extremely Likely, rate what you think is the likelihood that a young family with a parental diagnosis of cancer would seek and utilize services to address these issues, problems, concerns, or needs”. Using statement number 15 as an example again (in the bottom center of the map) you will notice it is now represented by only one bar. On this map the key indicates that one bar is equivalent to an average rating that falls within a range from 2.86 to 3.19. This range distributes across the rating scale as *somewhat* to *moderately likely*.

Based on the three rating map examples given above, it can be concluded that all stakeholders believe it is moderately important for family members to be a part of planning for the future, regarding the patient's personal health choices. Their overall satisfaction for having that need currently met ranges from somewhat to moderately satisfied. Finally, the combined group somewhat to moderately agrees that families would seek out and utilize a service that addressed the need.

Figure 7. Level of Utilization Point Rating Map All Stakeholders

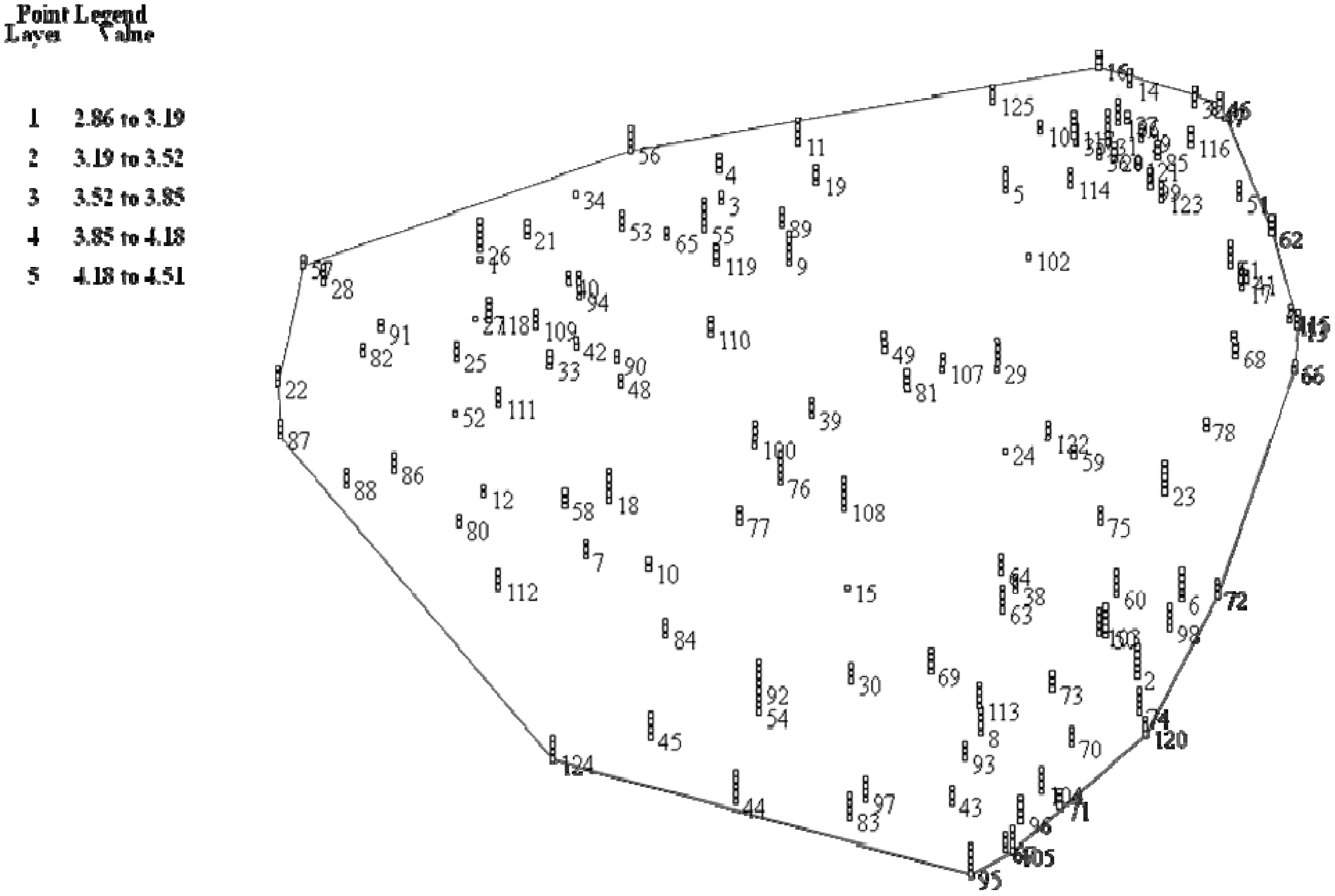


Table 2

Point Rating Map Key Layer Differences

Layer	Level of Importance Value	Level of Satisfaction Value	Level of Utilization Value
1	3.14 – 3.46	2.05 – 2.39	2.86 – 3.19
2	3.46 – 3.78	2.39 – 2.74	3.19 – 3.52
3	3.78 – 4.11	2.74 – 3.08	3.52 – 3.85
4	4.11 – 4.43	3.08 – 3.42	3.85 – 4.18
5	4.43 – 4.76	3.42 – 3.76	4.18 – 4.51

Another important aspect of the point rating maps is the difference between their respective keys. For each map the levels 1, 2, 3, 4, and 5 represent a different average range of rating (see Table 2). This is important information because it reveals that overall participants' level of importance ratings were higher than level of utilization ratings. In addition, level of importance and utilization ratings were higher than level of satisfaction ratings. From a program development perspective this information is valuable as it is an immediate indication of the discrepancies between needs identified as important, the current satisfaction with having those needs met, and the degree to which potential services would be utilized to address those needs.

To gain understanding of how the patient and professional stakeholder groups rated each of the 125 statements on level of importance, satisfaction, and utilization see Appendix D. It is important to examine the statements at this in-depth level in order to get an understanding of how individual statements were rated by these two groups. From a program development perspective it provides a quick snapshot of potential single program components to be considered for development. Review of Appendix D reveals that the differences between the patient and professional stakeholders' average ratings on level of importance, level of satisfaction, and level of utilization are less than 1.00, with some exceptions presented below.

On level of importance, the patient stakeholder group rated statement 42, (All family members (including ill parent) have problems adjusting to ill parent's body image changes), 1.03 points lower on the average than the professional stakeholder group. This indicates the patient group felt this issue was *moderately important* while the professional stakeholders felt it was *significantly important*. Also on level of importance, the patient stakeholder group rated statement 110, (Parents don't always know to help children preserve memories of ill parent when diagnosis is terminal), 1.20 points lower on the average than the professional stakeholder group. This indicates the patient stakeholders felt this issue was also *moderately important*, while the professional stakeholders felt the issue was *significantly important*.

On level of utilization, the patient stakeholder group rated statement 87, (Illness disrupts normal sex life of the parent–partner couple), 1.05 points higher on the average than the professional stakeholder group. This indicates the patient stakeholders felt a young family with a parental diagnosis of cancer would *significantly utilize* services to address this issue, whereas the professional stakeholder group felt services that addressed this issue would be *moderately utilized*. Also on level of utilization, the patient stakeholder group rated statement 88 (Parents are concerned about fertility and reproductive issues), 1.03 points higher on the average than the professional stakeholder group. This indicates the patient stakeholders felt a service addressing this issue would be *significantly utilized*, while the professional stakeholder group felt it would be *moderately utilized*.

The top ten rated statements for the patient and professional stakeholder groups can be viewed in Table 3. Review of this table reveals that the two groups share three statements in their top ten rated statements on level of importance. Those statements included #2 *Families need to be directed to resources*, #6 *The family needs to be made aware of programs and services available to the children*, and #50 *Patient and family need education about illness and treatment*. All of these statements were grouped by all participants in the *Navigation* cluster which is discussed in more detail in the cluster rating map section below.

Table 3

Top 10 Level of Importance Ratings – Patient vs. Professional Stakeholders

	Patient Stakeholders		Professional Stakeholders	
Rank	Statement	Rating	Statement	Rating
1	Families need to be directed to resources.	4.67	The family needs to be made aware of programs and services available to the children.	4.90
2	Parenting support and assistance when patient is a single parent.	4.67	Families need to be directed to resources.	4.86
3	The family needs to be made aware of programs and services available to the children.	4.53	Family members are afraid parent / patient will die.	4.71
4	Need for spousal/partner individual or group support.	4.53	Teenagers need someone to turn to for help with coping healthfully.	4.67
5	Uninsured and underserved "fall through the tracks" and may not seek treatment or help.	4.53	Patient and family need education about illness and treatment.	4.67
6	Child care assistance during treatment, when coming into clinic and at home after treatment recovering.	4.53	Parents may have to give up parental rights or plan for custody after death, due to their illness.	4.67
7	Respite is needed for care giving parent / partner.	4.53	Parents are afraid to tell kids about negative prognosis or dying.	4.62
8	Lack of knowledge about services available for the patient.	4.47	Age appropriate information needs to be shared with the kids at all times to keep them in the loop.	4.57
9	Parents worry about ability to get or keep health insurance for their family in the future.	4.47	Families need to keep the lines of communication open.	4.57
10	Patient and family need education about illness and treatment.	4.47	Emotional impact on children	4.57

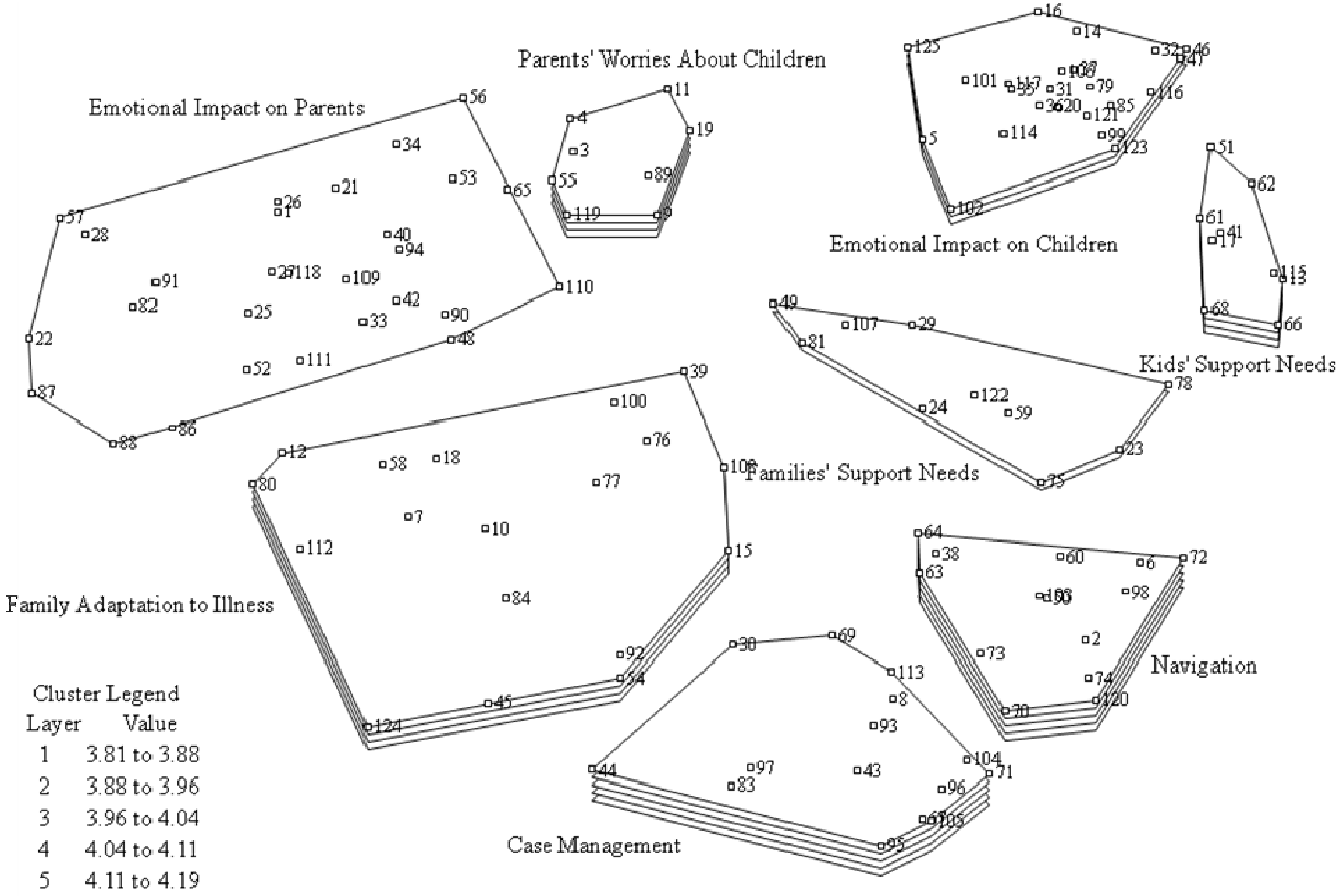
Cluster Level of Importance

The cluster rating map is similar to the cluster map (Figure 2) in how it is a visual representation of how the statements were grouped together by participants. However, the cluster rating map is also a visual representation of how each cluster was rated on levels of importance, satisfaction, and utilization.

Figure 8 is the cluster rating map that illustrates how both stakeholder groups rated the 8 clusters on level of importance. Each cluster of points is stacked in layers from one to five. The layer of any single cluster is dependent upon how important participants rated the statements within the cluster. As per the cluster legend, single layer clusters have an average importance rating ranging from 3.81 to 3.88. Clusters with two layers have an average importance rating raging from 3.88 to 3.96. Clusters with three layers have an average importance rating ranging from 3.96 to 4.04. Clusters with four layers have an average importance rating ranging from 4.04 to 4.11 and clusters with five layers have an average importance rating ranging from 4.11 to 4.29.

Based on this legend, no single cluster was rated below *moderately important* by participants. The clusters rated most important by participants (5 levels) were *Case Management* and *Navigation*. The statements within these clusters were rated on average as *significantly* to *extremely important* by participants. The *Family Adaptation to Illness*, *Kids' Support Needs,* and *Parents' Worries About Children* clusters all have four layers. The statements within these clusters were rated on the average as *moderately* to *significantly important*. The *Emotional Impact on Children* cluster has three layers, indicating that participants rated those statements in the *somewhat important* to *moderately important range*. The *Families' Support Needs* cluster has two layers indicating participants rated the statements within that cluster in the *not very*

Figure 8. Level of Importance Cluster Rating Map – All Stakeholders



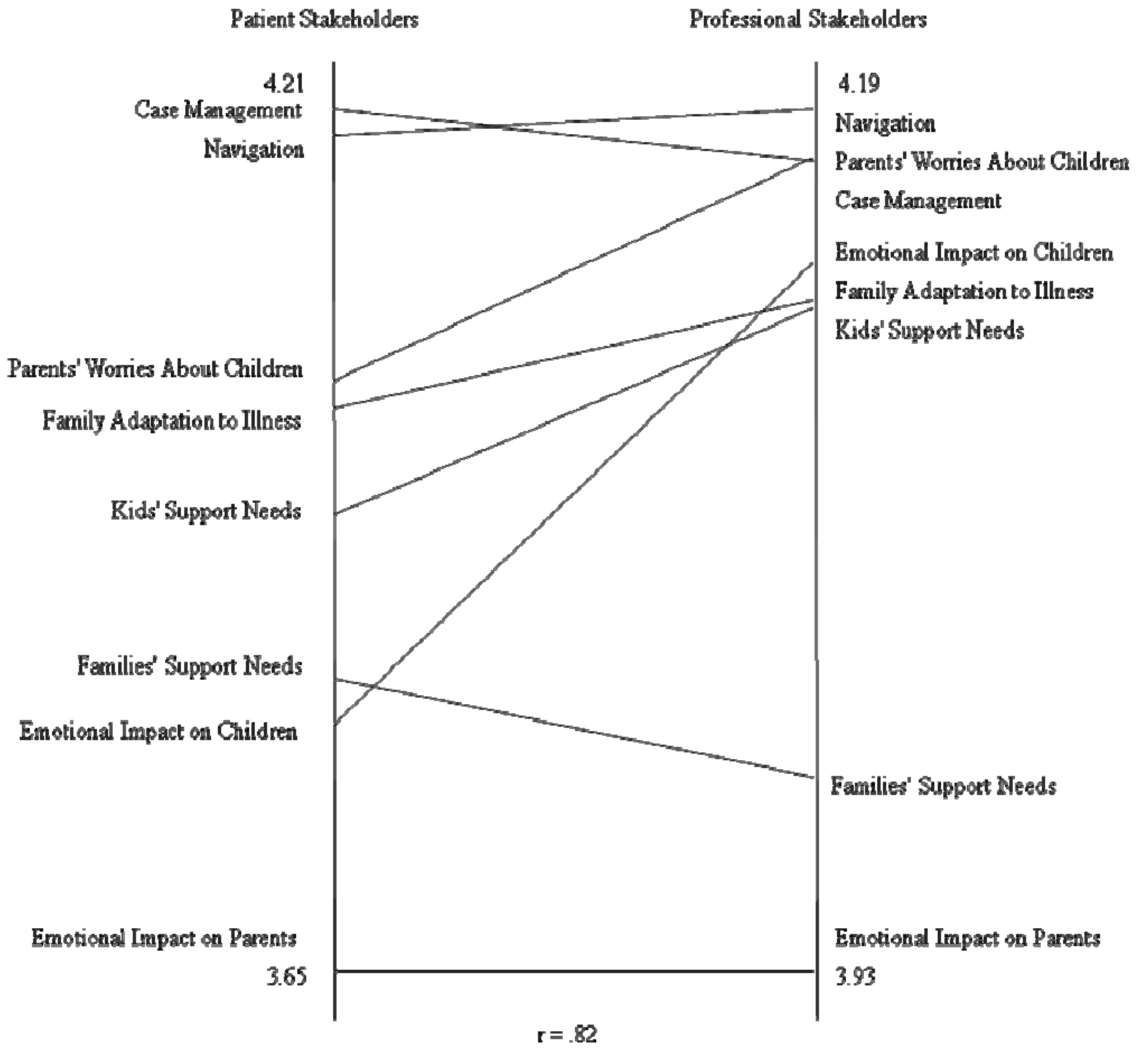
important to the *somewhat important* range.

Appendix E lists the individual clusters and descriptive statistics for each clusters' level of importance (Table E1), level of utilization (Table E2), and level of satisfaction (Table E3) as rated by all stakeholders. Examination of Table E1 confirms that the *Case Management* and *Navigation* clusters are tied for level of importance with mean average cluster ratings of 4.19. These are followed by *Parents' Worries About Children* and *Family Adaptation to Illness* with average cluster ratings of 4.11 and 4.08, respectively. Next in level of importance are *Kids' Support Needs* and *Emotional Impact on Children* with mean cluster ratings of 4.05 and 4.00. Finally, the clusters with the lowest rated importance are *Families' Support Needs* and *Emotional Impact on Parents* and with average ratings of 3.92 and 3.81

Level of importance pattern match. The differences in how each stakeholder group rated each cluster on level of importance is required data for answering one of the major research hypotheses put forward in this study. These differences can be examined more holistically by reviewing the pattern match for level of importance in Figure 9. A review of Figure 9 reveals that the patient and professional stakeholder groups rated each of the eight clusters similarly, evidenced by a strong correlation coefficient of .82.

The greatest difference in ratings on level of importance occurred for the cluster *Emotional Impact on Children*, while the most similar ratings occurred for the cluster *Emotional Impact on Parents*. The strong correlation on this pattern match is evidence that there is much agreement between the patient and professional stakeholder groups on what support needs are important to young families experiencing a parental diagnosis of cancer. It is also apparent that the patient stakeholder group ranks the *Case Management* cluster as the most important with *Navigation* closely behind.

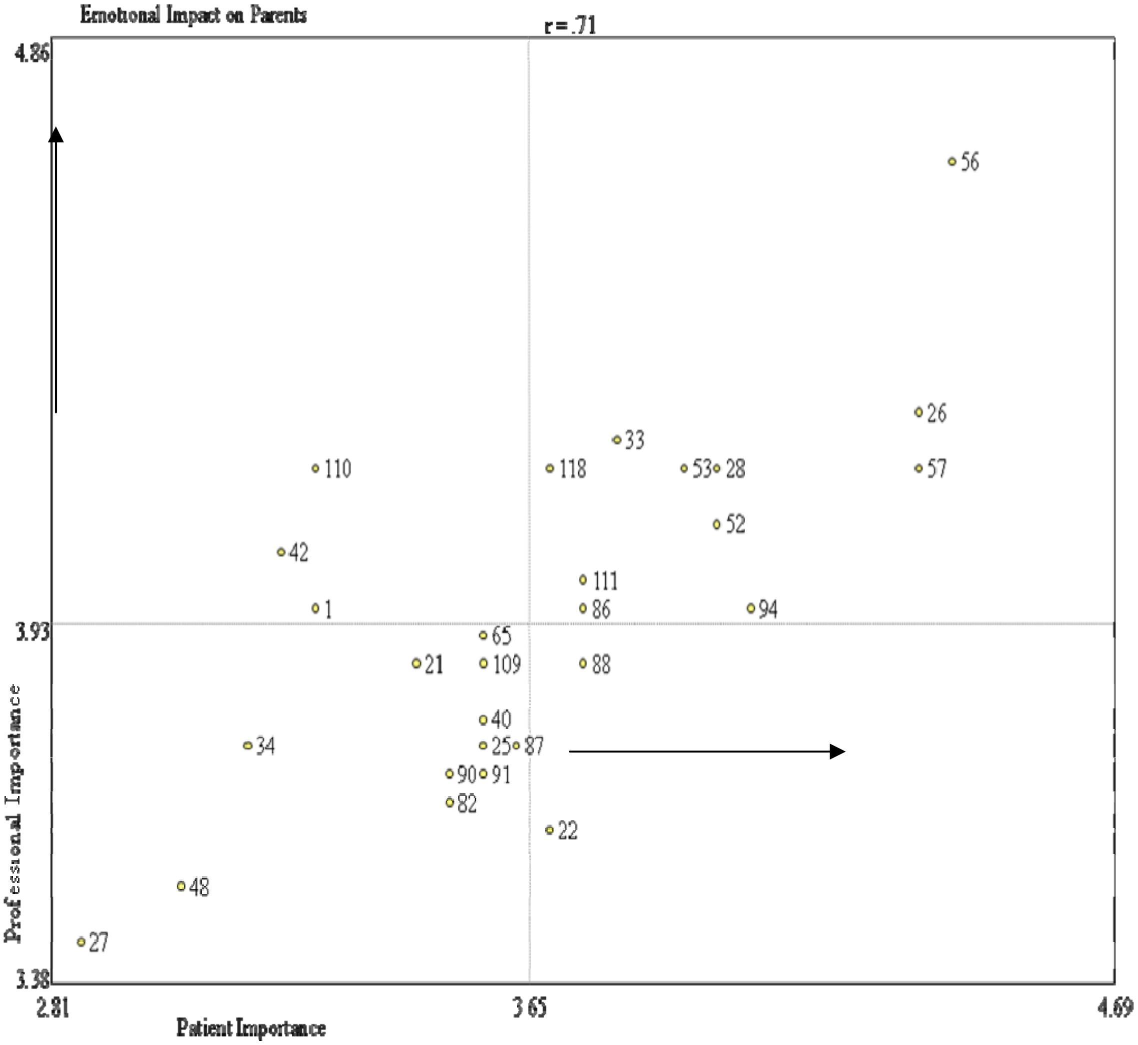
Figure 9. Pattern Match for Level of Importance Patients vs. Professionals



Level of Importance bivariate plot analyses. The bivariate plot for each of the clusters on level of importance shows the rating averages for each statement in a cluster, depicted in an X-Y graph that is divided in quadrants above and below the mean value within the cluster of each rating variable. The Y axis represents the ratings of professional stakeholders and the X axis the ratings of the patient stakeholders. This is the most effective way to evaluate within cluster rating differences between both stakeholder groups.

Figure 10 shows a Pearson correlation coefficient of .71 for the *Emotional Impact on Parents* cluster, indicative of a strong correlation between the perceptions of the two groups about how important the statements in this cluster are.

Figure 10. Bivariate Plot for Level of Importance – Emotional Impact on Parents



The upper-right quadrant shows statements in the cluster that were rated above the mean by both groups, thus indicating the patient and professional stakeholders agree these statements are more important than the others in the cluster. The lower-left quadrant shows statements rated below the mean by both groups, indicating their agreement that these statements are less important than the others in the cluster. The upper-left and lower-right quadrants are the most relevant to this study because statements occurring in these quadrants are those that are disagreed upon by the patient and professional stakeholders. Statements rated low by patient stakeholders and high by the professional stakeholders are seen in the upper-left quadrant. Statements rated high by patient stakeholders and low by professional stakeholders are seen in the lower-right quadrant.

The statements appearing in the upper-left quadrant include number 1 (*Ill parents may isolate themselves from their family*), 42 (*All family members [including ill parent] have problems adjusting to ill parents' body image changes*), and 110 (*There is not enough support for the husbands/fathers of the women with diagnosis*). These statements are not considered to be as important to the patient stakeholders as they are to the professional stakeholders.

The statements located in the lower right quadrant include 88 (*Parents are concerned about fertility and reproductive issues)* and 22 (*The ill parent may feel alone because the spouse cannot go to appointments due to home and work responsibilities).* These statements are considered more important to the patient stakeholders than the professional stakeholders.

While reviewing the remainder of the bivariate plots for level of importance it is important to remember that the statements appearing in the upper-left and lower-right quadrants represent differences between the two groups' understanding of what is important to patients, thus creating potential programmatic bottlenecks which pose as barriers for developing programs that address those statements.

Figure 11 shows a correlation coefficient of .61, indicative of a moderately strong relationship between how both groups rated statements in the *Parents' Worries About Children* cluster. The statements appearing in the upper-left quadrant include number 19 (*Some parents shield children from diagnosis making it hard for the child to understand*) and 119 (*Parents want* *to know how kids feel, but it can be hard for them to actually hear about how their illness is impacting them*). These statements are not considered to be as important to the patient stakeholders as they are to the professional stakeholders. The only statement that appears in the lower-right quadrant is number 4 (*Parents have to be aware of what they say to each other when kids are around*). This statement is considered more important to the patient stakeholders than the professional stakeholders.

Figure 11. Bivariate Plot for Level of Importance – Parents' Worries About Children

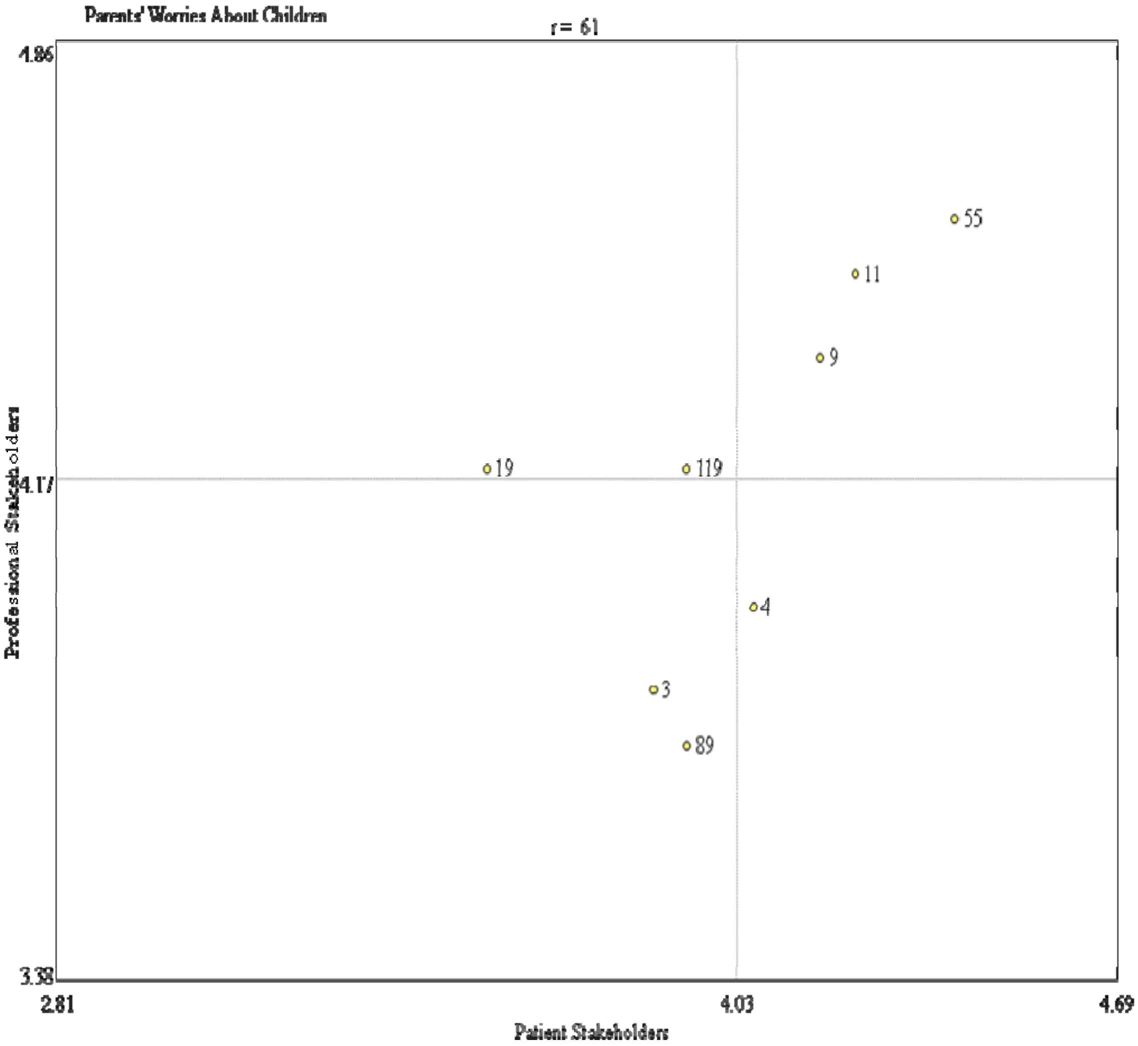
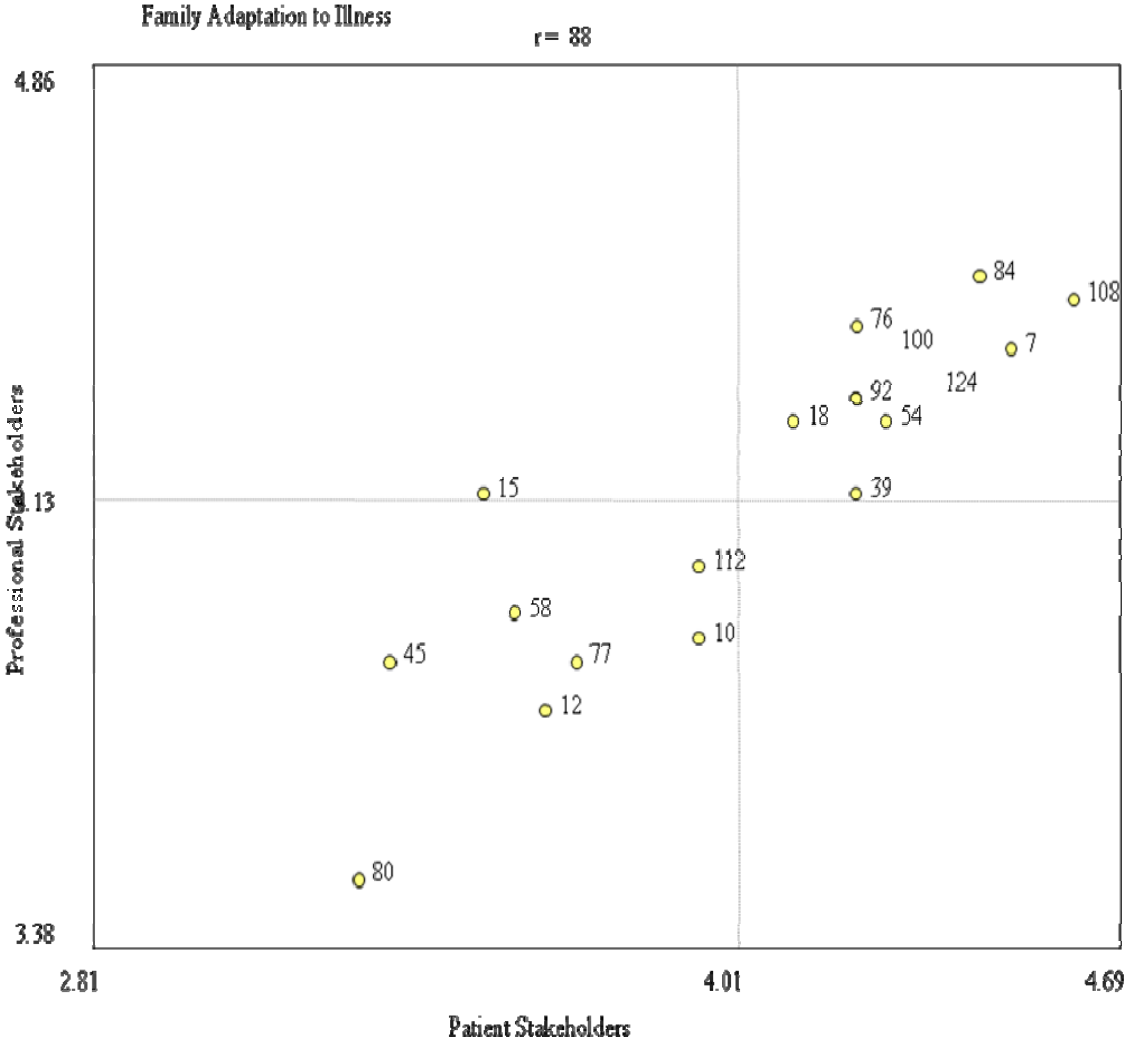


Figure 12 indicates a strong correlation (r = .88) between both groups' with no statements in the lower-right quadrant and only one statement in the upper-left quadrant, number

15 (*Family members need to be a part of planning for the future, regarding the patient's personal health choices).* This is the only statement the professional stakeholders rated higher than the patient stakeholders. There is much cohesion in how both groups rated statements regarding the importance of *Family Adaptation to Illness*. This is a good result for this cluster as it is one of the clusters central to the 8 cluster concept map, and makes up the central super dimension, *Family Functioning* (see Figure 4).

Figure 12. Bivariate Plot for Level of Importance – Family Adaptation to Illness



In Figure 13 a moderately strong correlation (r = .67) is observed for the statements in the *Navigation* cluster. Only one statement appears in the lower-right quadrant, number 74 (*Family* *could use a patient navigator to help them understand and make sense of all different sources of information*). This statement is more important to patients than it is to professionals. No statements appear in the upper-left quadrant. Overall, Navigation cluster is rated as one of the most important by both stakeholder groups.

Figure 13. Bivariate Plot for Level of Importance – Navigation

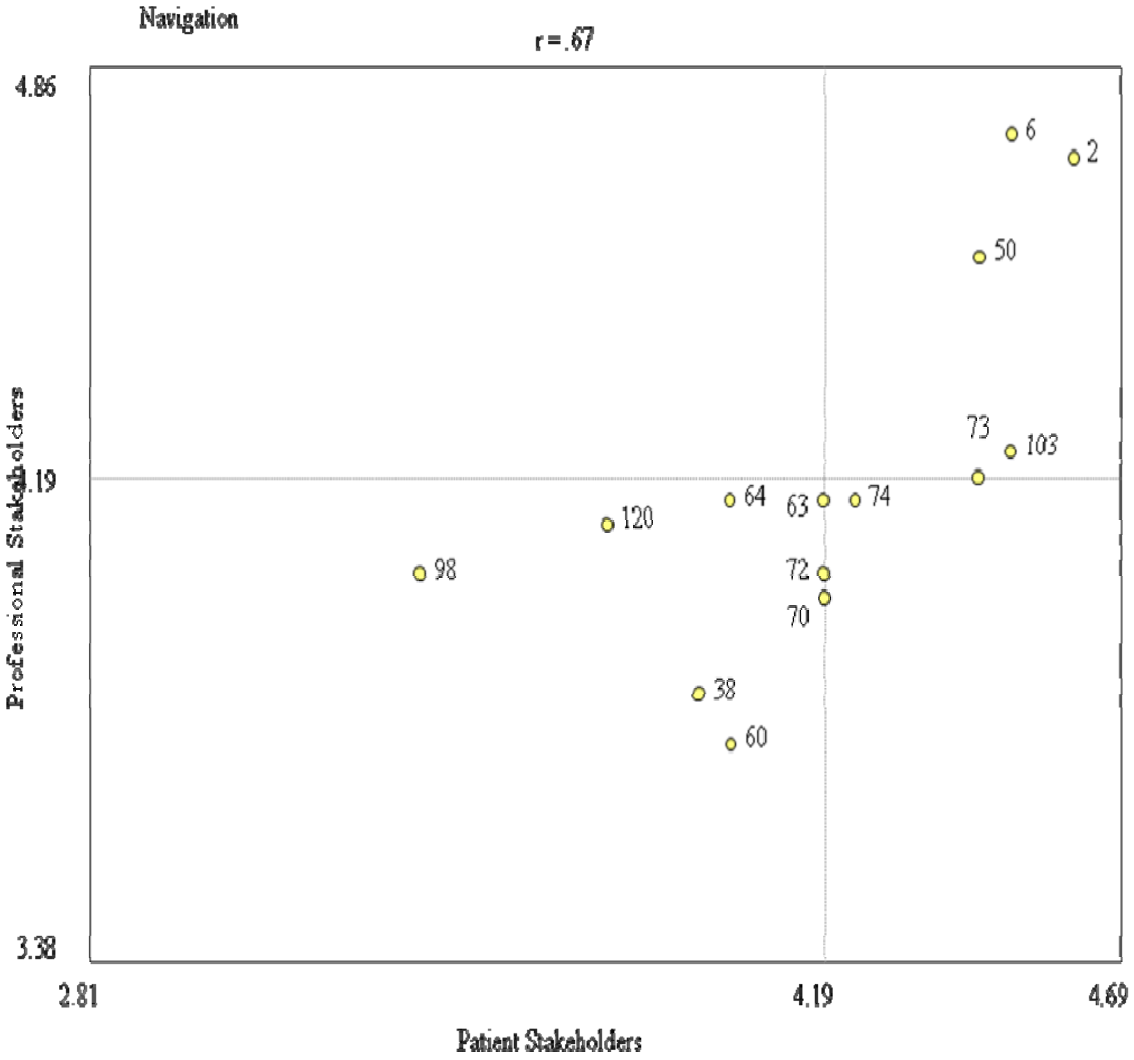
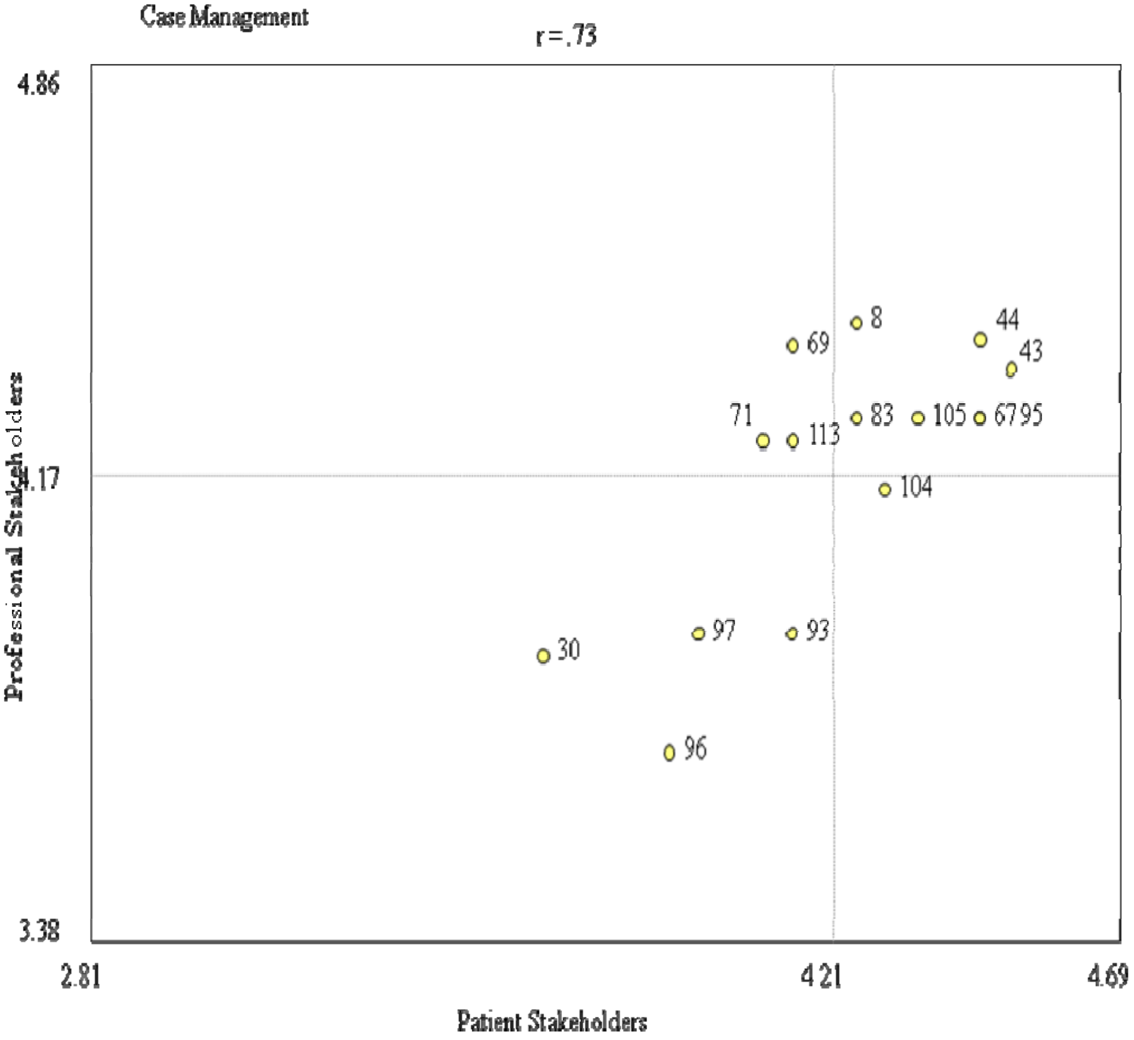


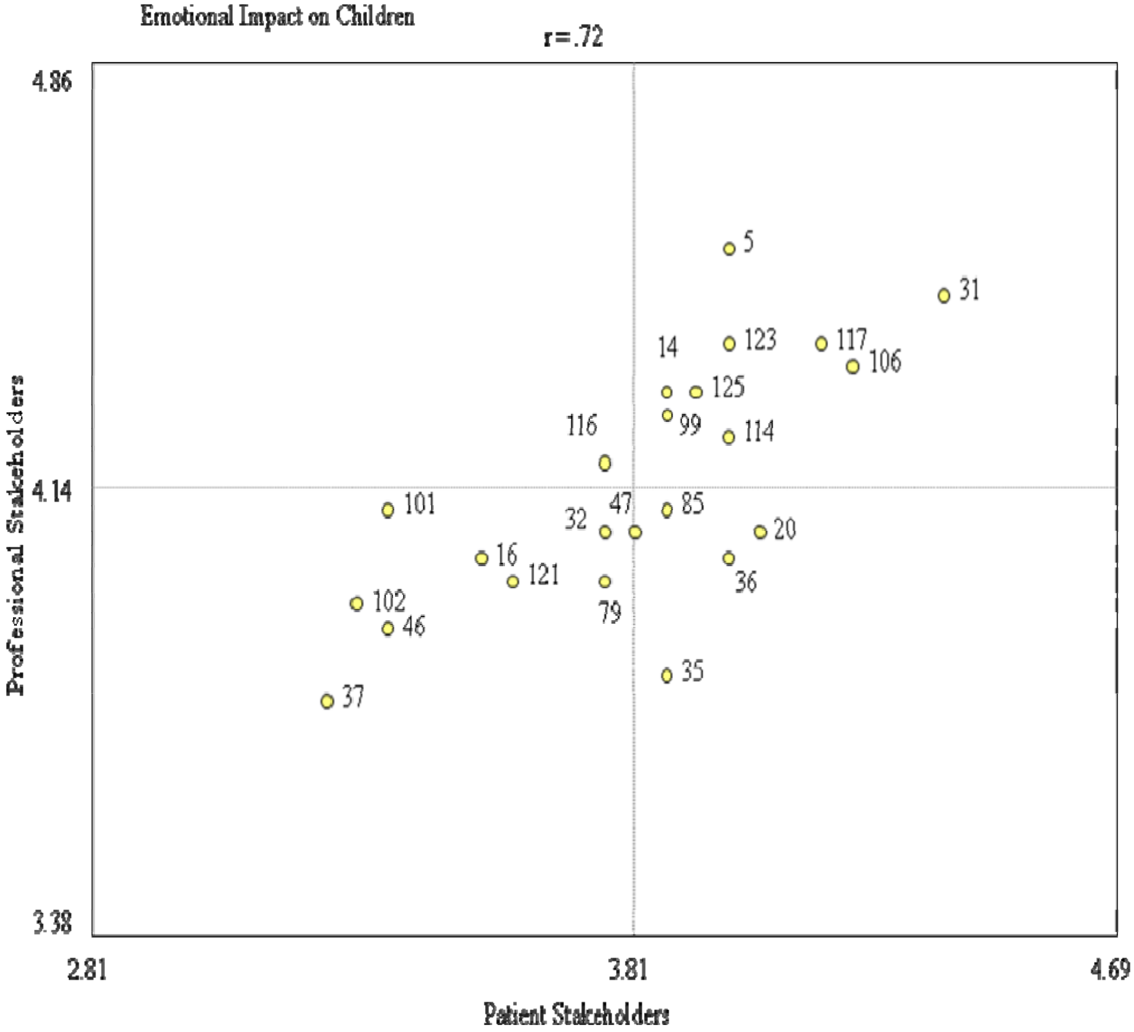
Figure 14 is the bivariate plot for the *Case Management* cluster. The Pearson correlation coefficient for this cluster is strong (.73) with only one statement appearing in the lower-right quadrant, 104 (*Transportation assistance for the multiple family household needs*). Three statements appear in the upper-left quadrant, 69 (*Personal patient liaison who understands the diagnosis and treatment, as well as the realities of parenting*); 71 (*Financial advocate to help manage family finances)*; and 113 (*Traveling to far places for treatment for treatment or consultations causes many child care problems for parents*). This cluster is rated as one of the most important by both stakeholder groups, along with *Navigation*.

Figure 14. Bivariate Plot for Level of Importance – Case Management



The *Emotional Impact on Children* cluster (*r* = .72) contains several statements in the lower-right quadrant. Review of Figure 15 reveals that statements 85 (*Kids worry they will get cancer*), 35 (*Children miss their family life before cancer*), 20 (*Children unable to articulate* *what they feel so they act out*), and 36 (*Children will act out their behavior with other caregivers and appear to be ill behaved children*), are all rated with a higher level of importance by the patients than they are by the professionals. One statement appears in the upper-left quadrant, number 116 (*Kids can have academic problems when parents are sick*), indicating the professionals rated this statement higher than the patients.

Figure 15. Bivariate Plot for Level of Importance – Emotional Impact on Children



The Pearson correlation coefficient for the *Kids' Support Needs* cluster is .74. Examination of Figure 16 reveals no statements in the lower-right or upper-left quadrants, indicating no significant differences between the two groups in how they rated the statements for this cluster on level of importance.

Figure 16. Bivariate Plot for Level of Importance – Kids' Support Needs

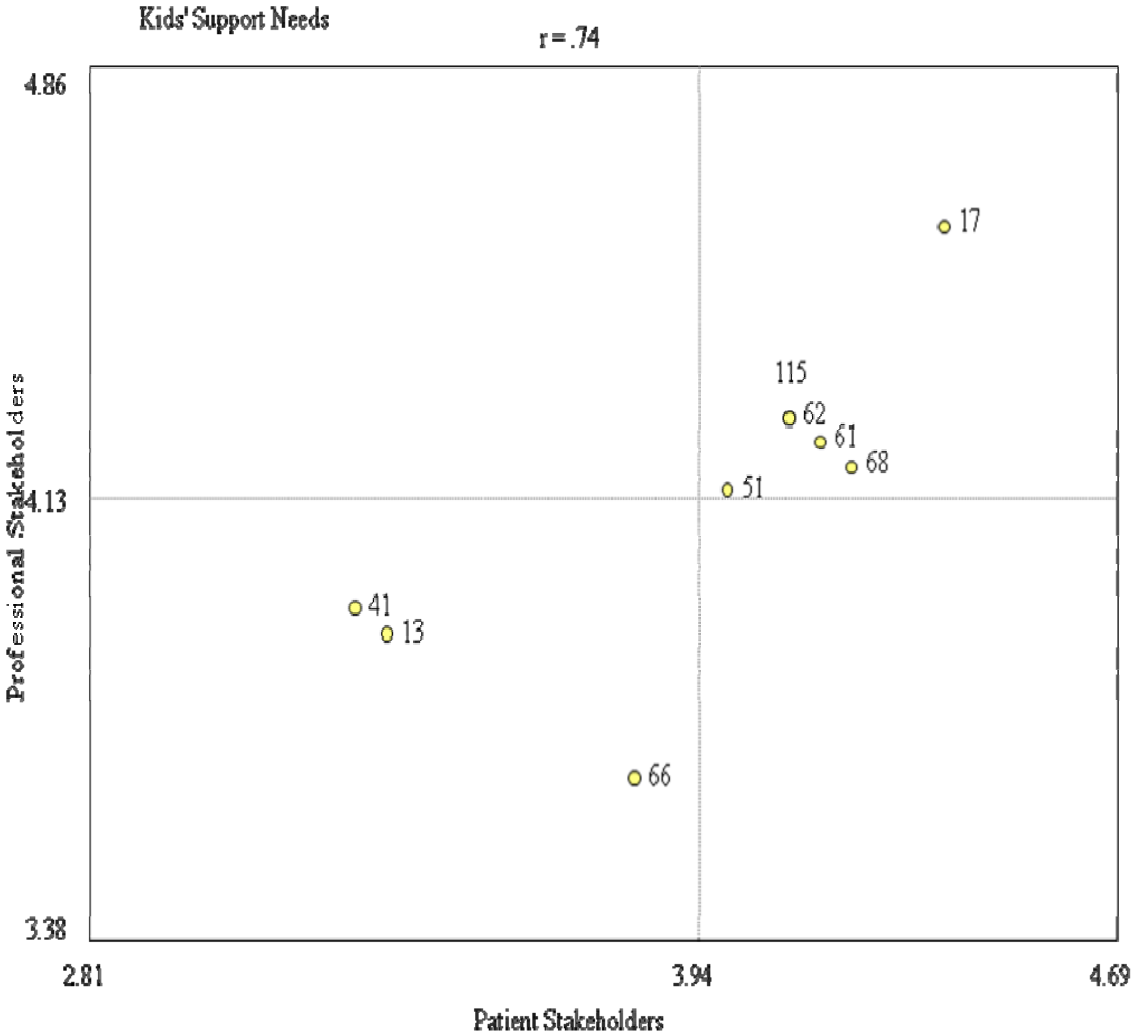
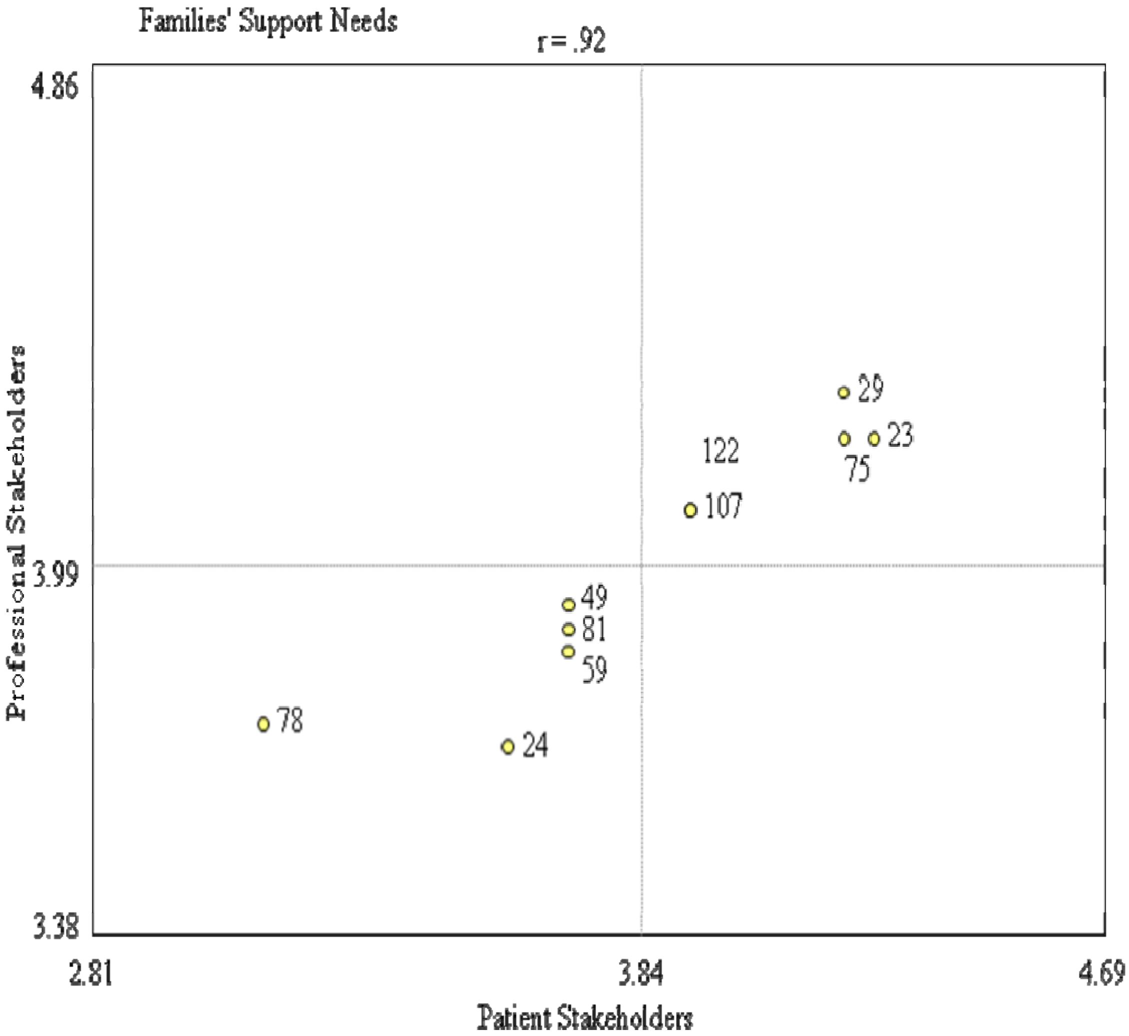


Figure 17 is the bivariate plot for the *Families' Support Needs* cluster. This cluster has the most highly correlated statement ratings with a Pearson correlation coefficient of .92. There are no statements in the lower-right or upper-left quadrants. Therefore, all statements rated below and above the mean are agreed upon by both stakeholder groups. This cluster is also central to the 8 cluster map, and is part of the *Family Functioning* super dimension (see Figure 4).

Figure 17. Bivariate Plot for Level of Importance – Families' Support Needs



To summarize, there are nine statements across five clusters that the patient stakeholders rate above the mean on level of importance, while the professional stakeholders rate those same statements below the mean on level of importance. In addition, there are seven statements across four clusters that the professional stakeholders rate above the mean on level of importance, while the professional stakeholders rate those same statements below the mean on level of importance. These discrepancies in level of importance ratings could present as a barrier for effective education and support program development. However, in spite of these differences, the highest correlations in ratings on importance occur for the *Family Adaptation to Illness* (*r* = .88) and

Families' Support Needs clusters (r = .92). Both of these clusters are central to the 8 cluster map and comprise the *Family Functioning* super dimension. Next, level of utilization is examined across all clusters via a cluster rating map, pattern match, and bivariate plots.

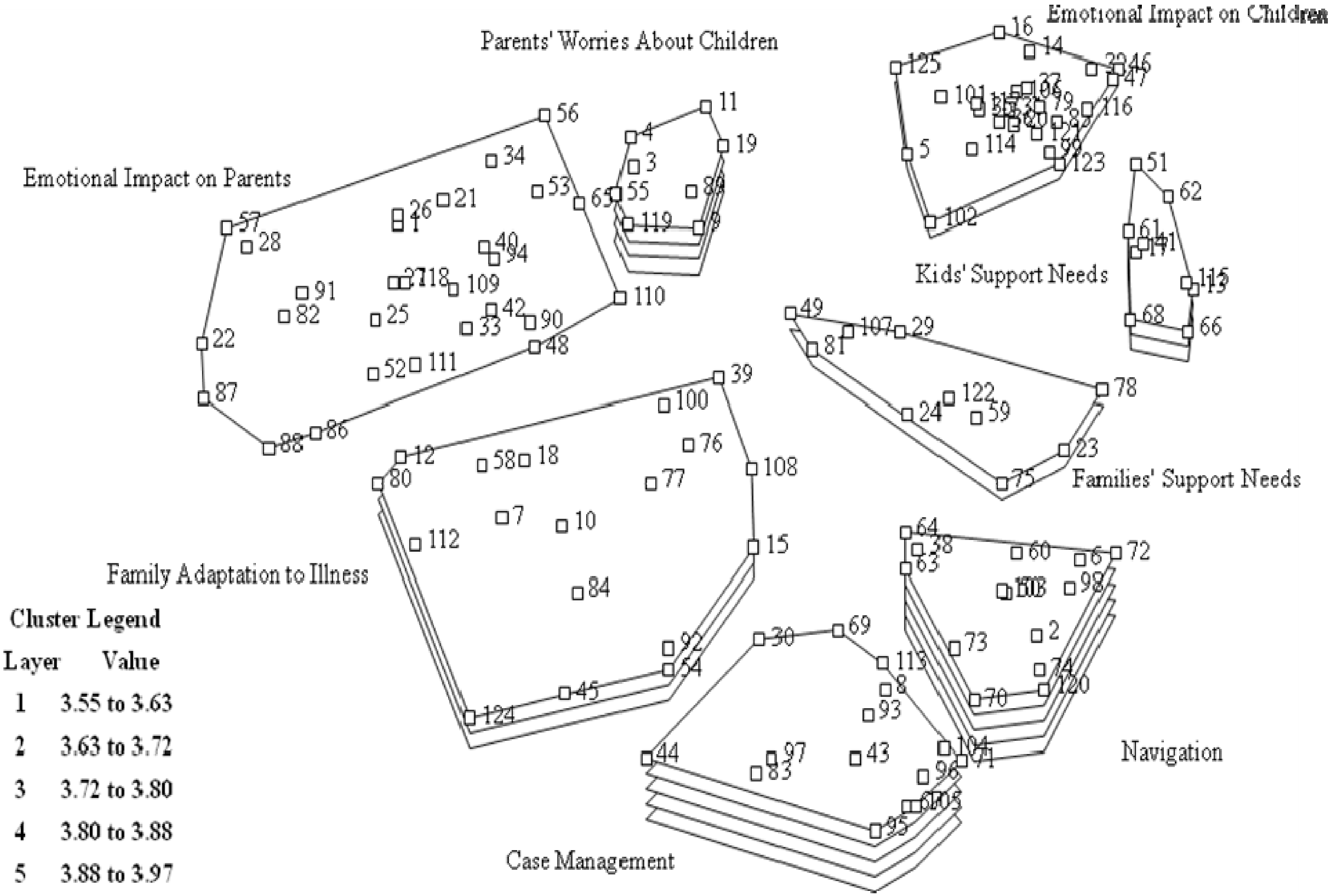
Cluster Level of Utilization

Figure 18 is the cluster rating map that illustrates how both stakeholder groups rated the 8 clusters on level of utilization. As with Figure 8, each cluster of points is stacked in layers from one to five. However, on this cluster rating map the layer of any single cluster is dependent upon how participants rated what they anticipate the level of utilization would be for a service that addressed the statement being rated.

As per the cluster legend, single layer clusters have an average utilization rating ranging from 3.55 to 3.63. Clusters with two layers have an average utilization rating raging from 3.63 to 3.72. Clusters with three layers have an average utilization rating ranging from 3.72 to 3.80. Clusters with four layers have an average utilization rating ranging from 3.80 to 3.88 and clusters with five layers have an average utilization rating ranging from 3.88 to 3.97.

Based on this legend, no single cluster was rated below *moderate utilization* by participants. The clusters rated most utilized by participants (5 levels) were *Case Management* and *Navigation*. These were the two highest rated clusters for level of importance as well. The statements within these clusters were rated on average as *significantly* to *extremely utilized* by participants. The next highest rated cluster for utilization is *Parents' Worries About Children*, with four layers. The statements within these clusters were rated on the average as *moderately* to *significantly utilized*. The *Family Adaptation to Illness* cluster has three layers, an indication the

Figure 18. Level of Utilization Cluster Rating Map – All Stakeholders



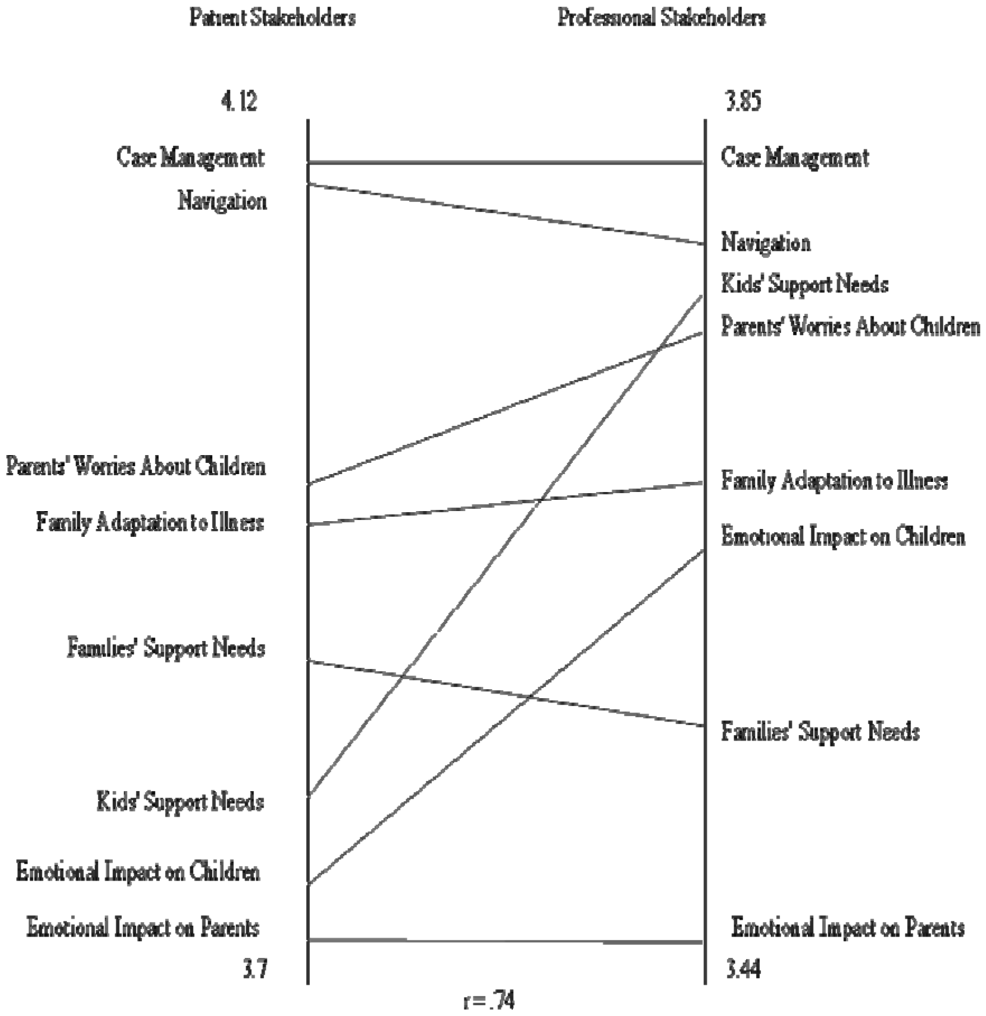
statements within this cluster were rated in the *moderately to significantly utilized* range. The *Emotional Impact on Children*, *Kids' Support Needs*, and *Families' Support Needs* clusters all have two layers, indicative of statements rated in the *moderately utilized* range. Finally, the *Emotional Impact on Parents* cluster has 1 layer, which indicates the statements in this cluster were rated on the *moderately utilized* range as well, only lower than the two layers by a fraction of a point.

Examination of Table E2 in Appendix E confirms that the *Case Management* and *Navigation* clusters were rated similarly for level of utilization with average cluster ratings of 3.97 and 3.94 respectively. These are followed by *Parents' Worries About Children* (3.84), *Family Adaptation to Illness* (3.79), *Kids' Support Needs* (3.78), *Emotional Impact on Children* (3.68), *Families' Support Needs* (3.68), and *Emotional Impact on Parents* (3.55).

Level of utilization pattern match. Knowledge of the differences in how each stakeholder group rated each cluster on level of utilization is also imperative to one of the major research hypotheses put forward in this study. As with level of importance, these differences can be examined more holistically by reviewing the pattern match for level of utilization in Figure 19. Examination of Figure 19 reveals that the patient and professional stakeholder groups closely agree about the level services addressing needs in the *Case Management, Family Adaptation to Illness, Navigation, Families' Support Needs*, and *Emotional Impact on Parents* clusters would be utilized. However, the professional stakeholders rated utilization higher on the clusters *Kids' Support Needs, Parents' Worries About Children,* and *Emotional Impact on Children* than the patient stakeholders did.

The strong agreement across five of the clusters is evidenced by a correlation coefficient of .74. Overall, the patient stakeholders rated a higher level of utilization than the professional stakeholders with a beginning rating average of 3.70 vs. 3.44 and an ending average of 4.12 vs. 3.85. In addition, as with level of importance, the patient stakeholders rated *Case Management* and *Navigation* as the top-two rated clusters for level of utilization, indicating that services addressing the identified needs within each cluster would be *Significantly Utilized* by them.

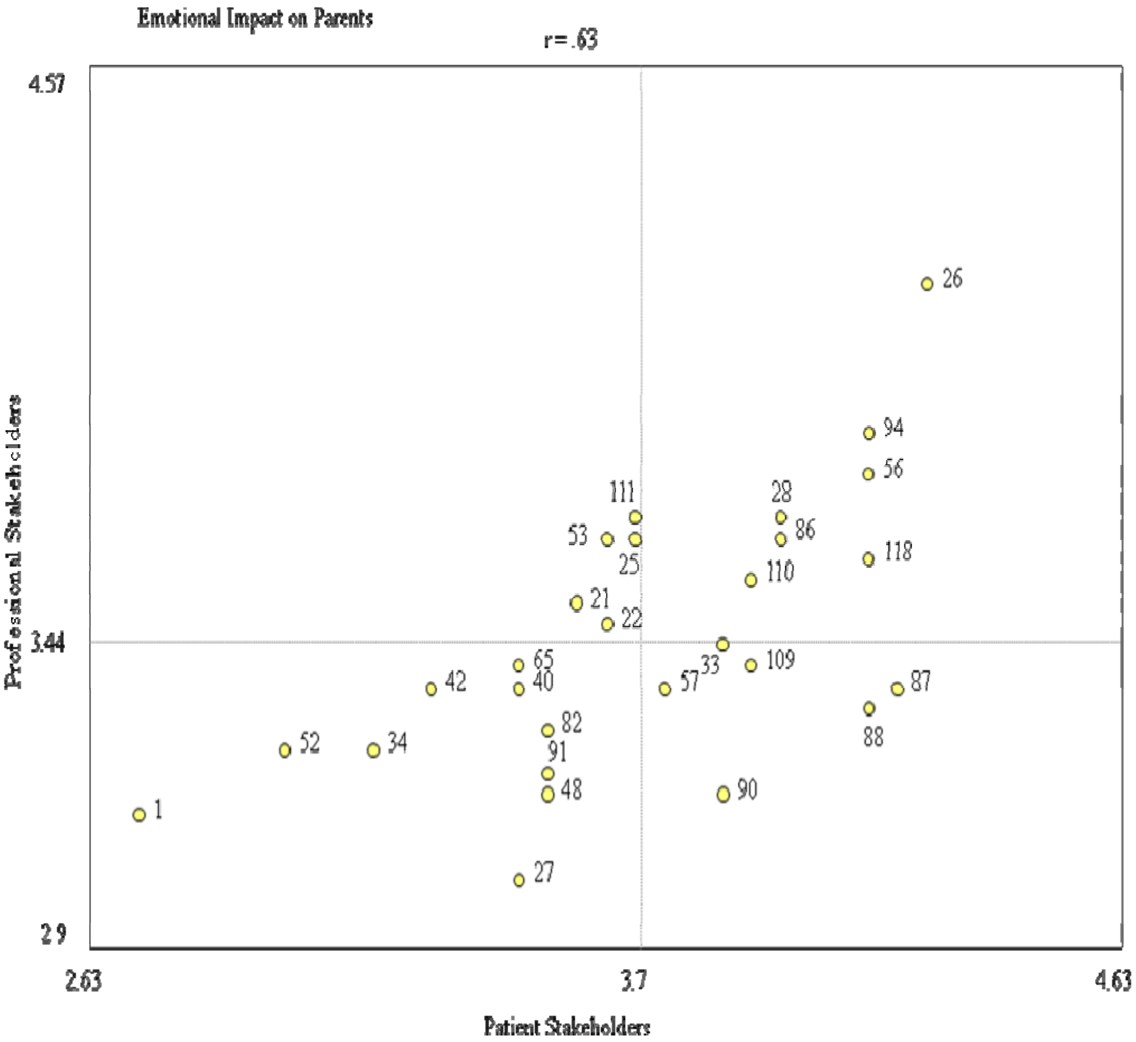
Figure 19. Pattern Match for Level of Utilization Patients vs. Professionals



Level of utilization bivariate plot analyses. As with level of importance, the bivariate plot for each of the clusters on level of utilization shows the averages for each statement in a cluster, depicted in an X-Y graph that is divided in quadrants above and below the mean value within the cluster of each rating variable. The Y axis represents the ratings of professional stakeholders and the X axis the ratings of the patient stakeholders.

Figure 20 shows a Pearson correlation coefficient of .63 for the *Emotional Impact on Parents* cluster, indicative of a moderately strong correlation between the perceptions of the two groups about how likely services would be utilized that addressed each statement in the cluster. As with level of importance, the lower-right and upper-left quadrants are the most relevant to this study because statements appearing in these clusters demarcate the differences between these groups in how they rated the statements on level of utilization. Statements that are rated high by patients (above their group mean) and low by professionals (below their group mean) appear in the lower-right quadrant and statements rated high by professionals and low by patients appear in the upper-left quadrant. Such differences in ratings on level of utilization for these statements could pose as barriers to program development because they can result in under-emphasis on developing programs that will be utilized by patients, or an over-emphasis on development of programs with the chance of under-utilization by patients.

Figure 20. Bivariate Plot for Level of Utilization – Emotional Impact on Parents



The statements appearing in the lower-right quadrant of Figure 20 (*r* = .85) include 33 (*Parents have difficulty admitting they need help*), 109 (*Parents may feel guilty for the disruption of their family's life*), 57 (*Parents feel they have to protect each other from their own distress so get more isolated and distant from each other*), 87 (*Illness disrupts normal sex life of the parent–partner couple*), 88 (*Parents are concerned about fertility*), *and 90 (Parents have difficulty letting go of control of how things are done in their home and family*). These statements are rated higher on utilization by the patient stakeholders than they are the professional stakeholders.

The statements appearing in the upper-left quadrant are rated higher on utilization by the professional stakeholders than the patient stakeholders. These statements include 21 (*The ill parent worries about their children more than they do themselves*), 22 (*The ill parent may feel alone because the spouse cannot go to appointments due to home and work responsibilities*), 25 (*Ill parent has to comfort spouse and children because of their difficulties in accepting illness*), 53 (*Parents can have many overwhelming emotions that impact their ability to be involved with their children*), and 111 (*Ill parents struggle with how to stay active in kids' lives when they are tired and weakened by illness and treatment*).

Figure 21. Bivariate Plot for Level of Utilization – Parents' Worries About Children

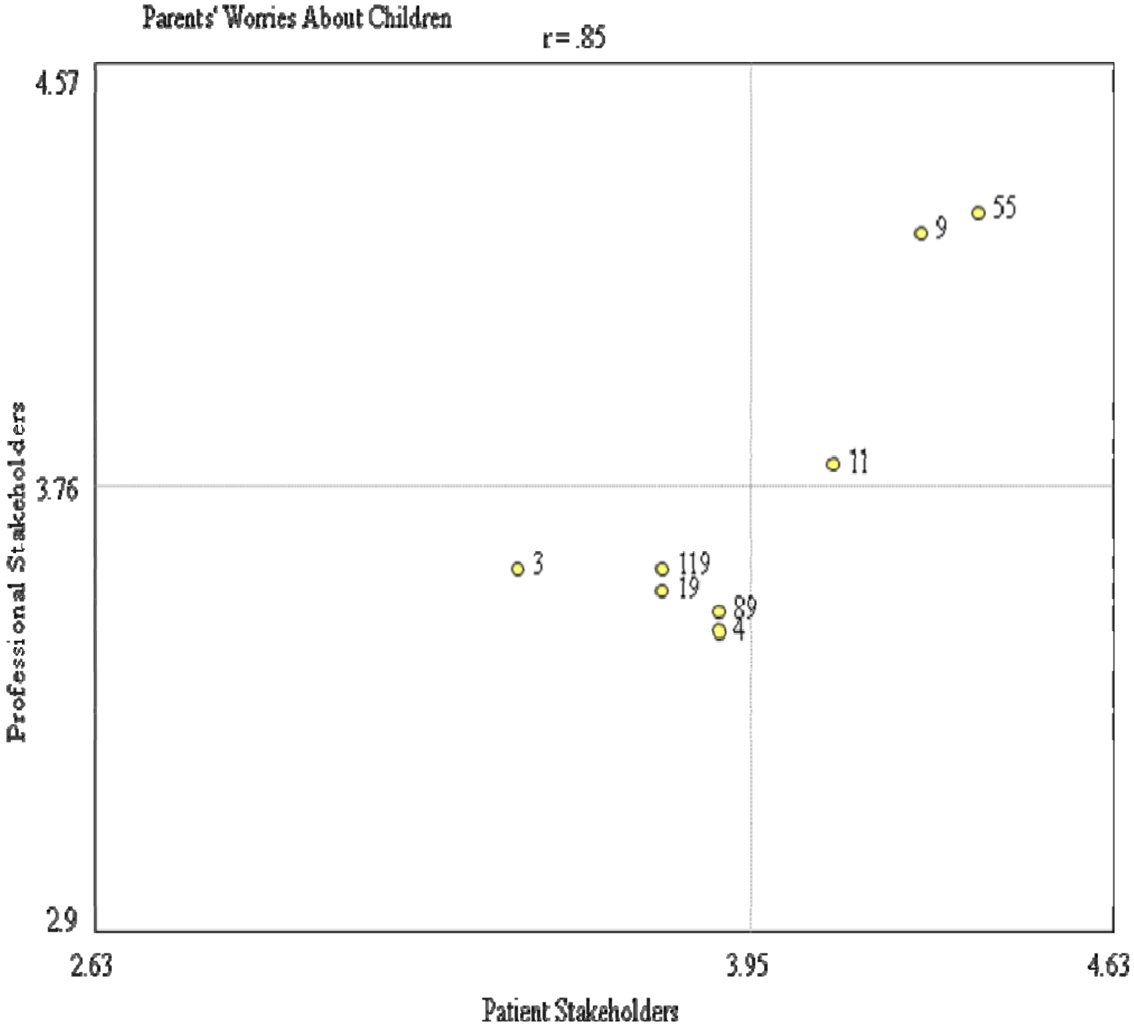
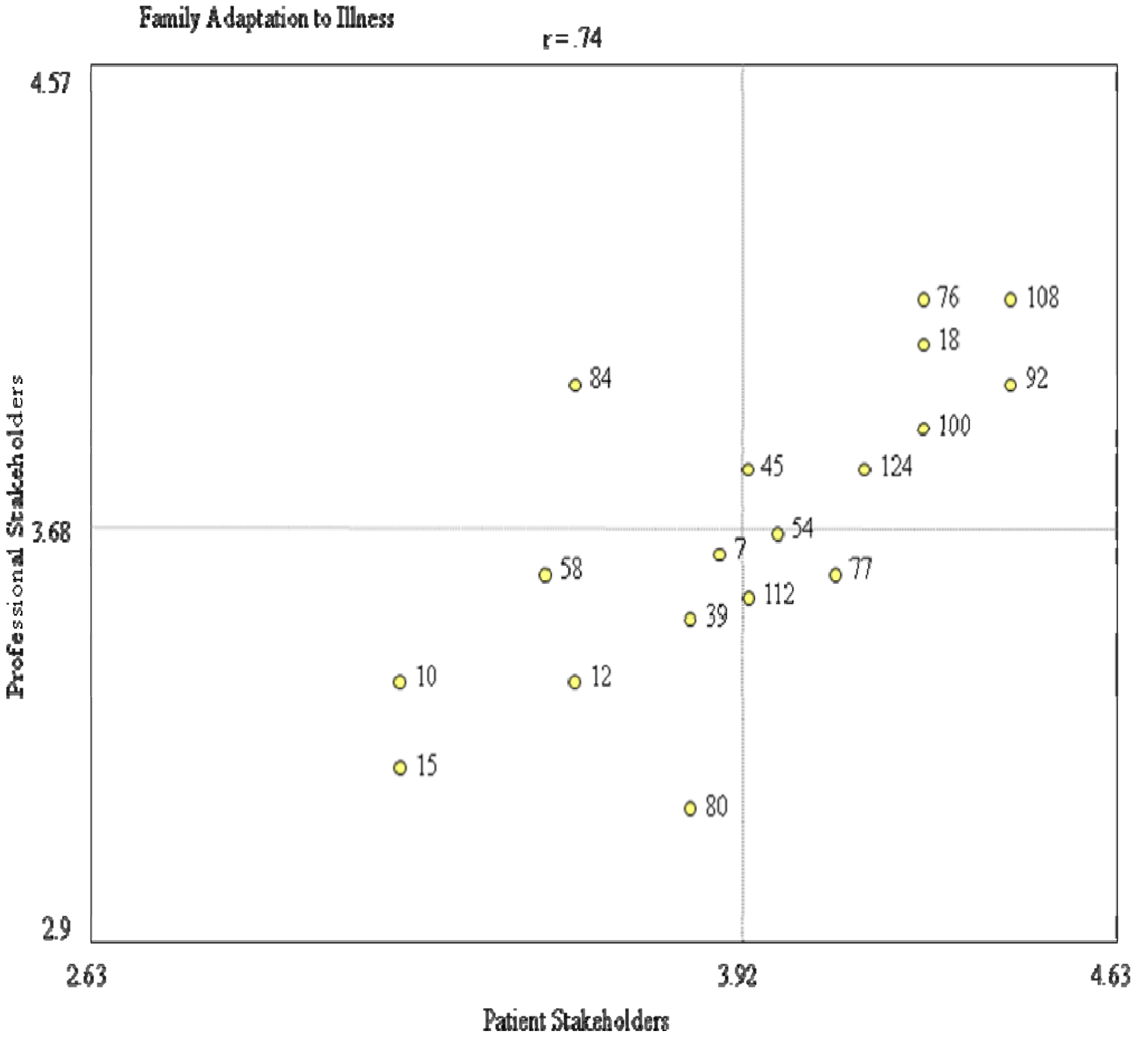


Figure 21 shows a strong correlation (*r* = .85) between how the two stakeholder groups rated statements for the *Parents' Worries About Children* cluster. There appears to be a good level of agreement in all statements rated below and above the mean for each group.

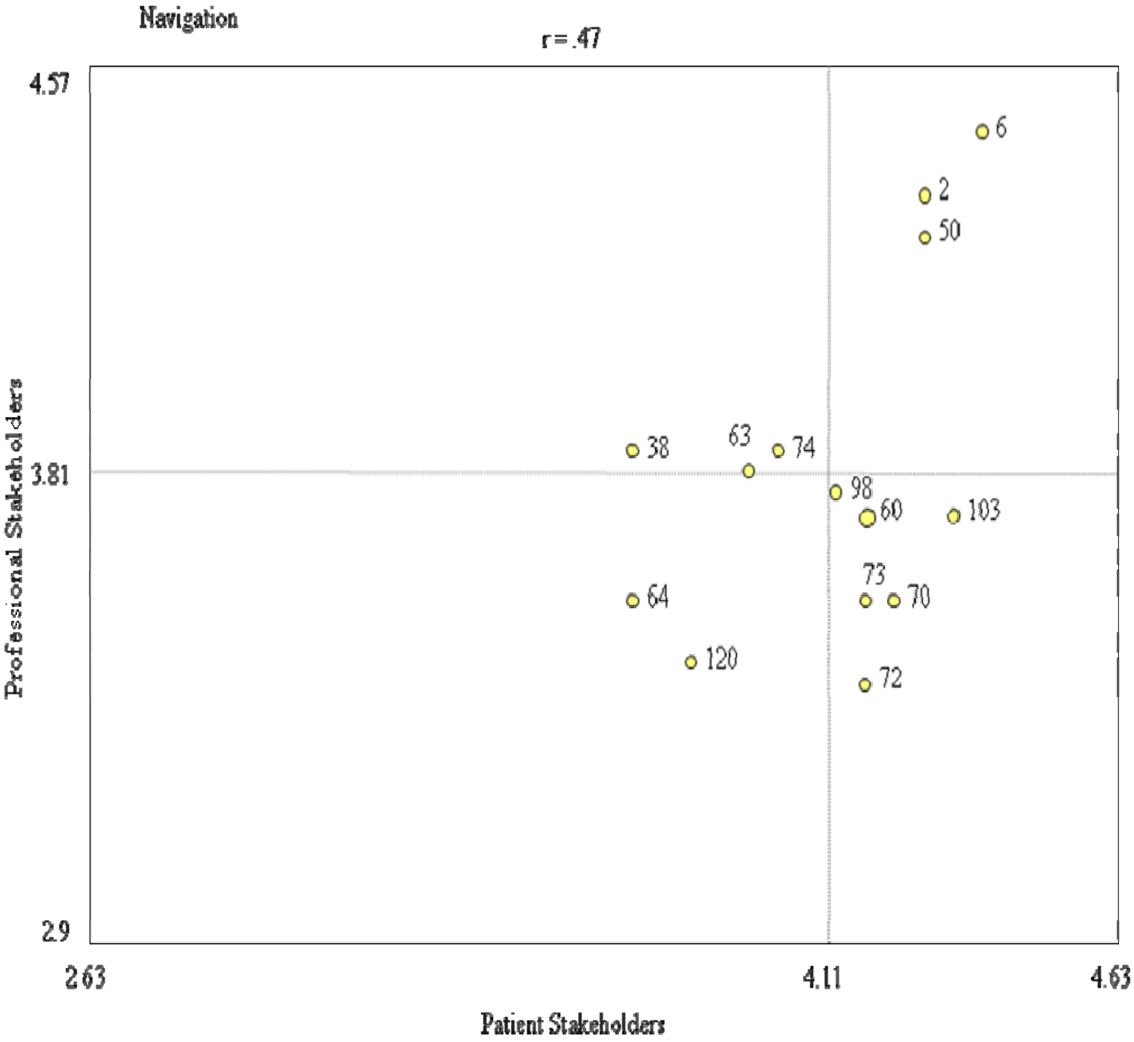
There is a weaker relationship (*r* = .74) on statement ratings for the *Family Adaptation to Illness* cluster (see Figure 22). A total of three statements appear in the lower-right quadrant. Those statements include 54 (*Families have little or no experience with the healthcare system, which can make this very difficult for them*), 77 (*Families need support in adapting / coping when fertility cannot be preserved*), and 112 (*Cognitive effects of treatment [chemo-brain] interferes with managing busy household and family).* There is one statement appearing in the upper-left quadrant, number 84 (*Parents may have to give up parental rights or plan for custody after death, due to their illness*).

Figure 22. Bivariate Plot for Level of Utilization – Family Adaptation to Illness



The bivariate plot for the *Navigation* cluster (Figure 23) has a Pearson correlation coefficient of .47, indicating a weak relationship between stakeholder group ratings in this cluster. The lower right quadrant contains statements 98 (*Families are so busy that they often*

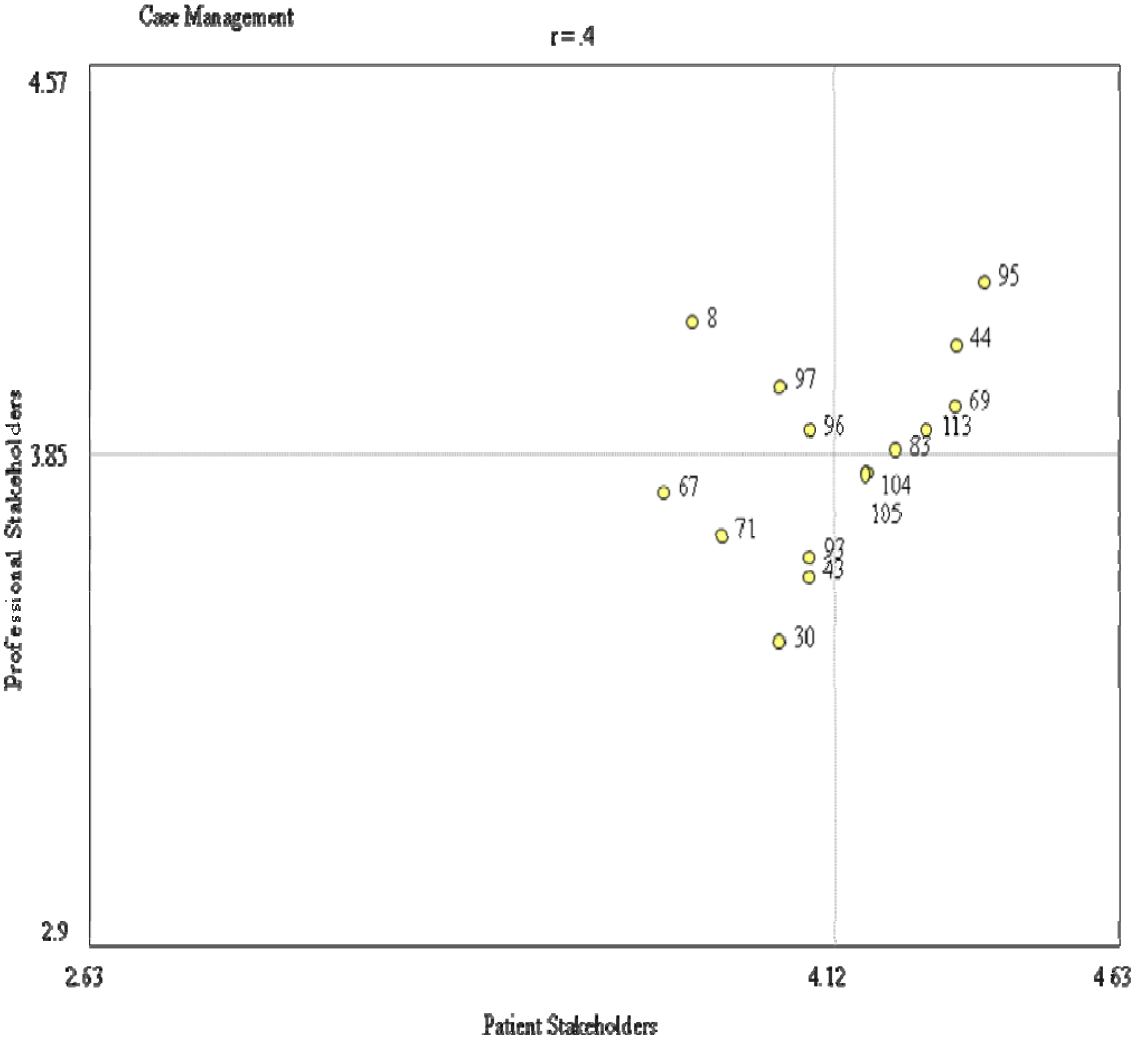
Figure 23. Bivariate Plot for Level of Utilization – Navigation



need support delivered in places that are convenient for them), 60 (*Hard for families to coordinate all the family, school, treatment, and supportive activities and resources*), 103 (*Child care assistance during treatment when coming into clinic, and at home after treatment recovery*), 73 (*Respite is needed for care giving parent / partner*), 70 (*Help with household management*), and 72 (*Families need organized extended family support*).

The statements appearing in the upper-left quadrant include 38 (*Families are faced with so much information overload that they don't know what is right for them*), 63 (*Families need follow-up after an initial supportive contact because their needs and readiness change* *frequently*), and 74 (*Family could use patient navigator to help them understand and make sense of all different sources of information).*

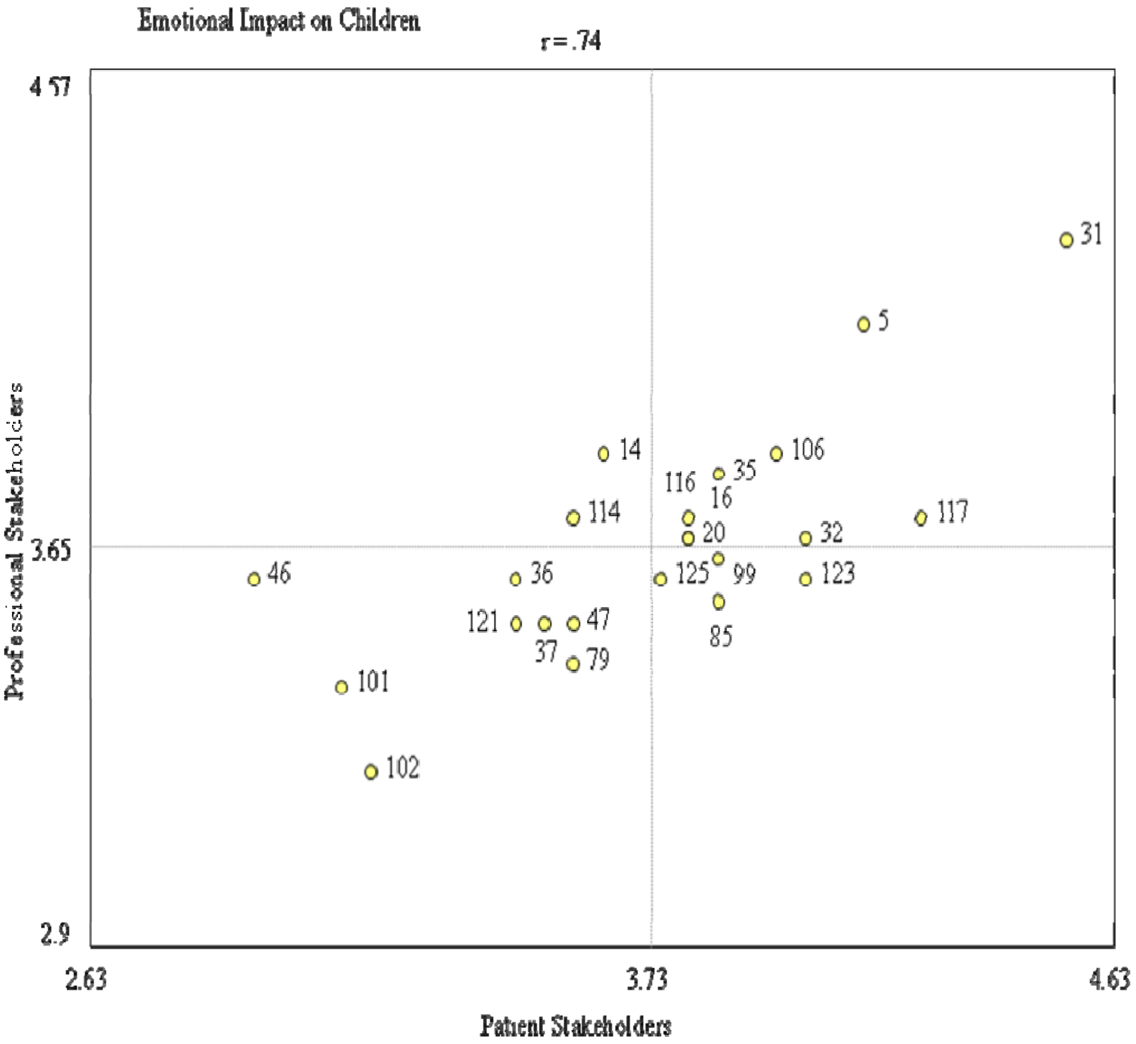
Figure 24. Bivariate Plot for Level of Utilization – Case Management



The correlation coefficient for the utilization ratings of the *Case Management* cluster is significantly weak (*r* = .4). There are two statements in the lower-right quadrant of Figure 24. Those statements are 104 (*Transportation assistance for the multiple family household needs*), and 105 (*Financial assistance to help family keep up with normal activities and secure necessary things like school supplies*). The statements appearing in the upper-left quadrant include 8 (*Lack of knowledge about services available for patient*), 96 (*Help with making home handicap* *accessible*), and 97 (*Patient-parents need access to medical equipment when doing things with family*).

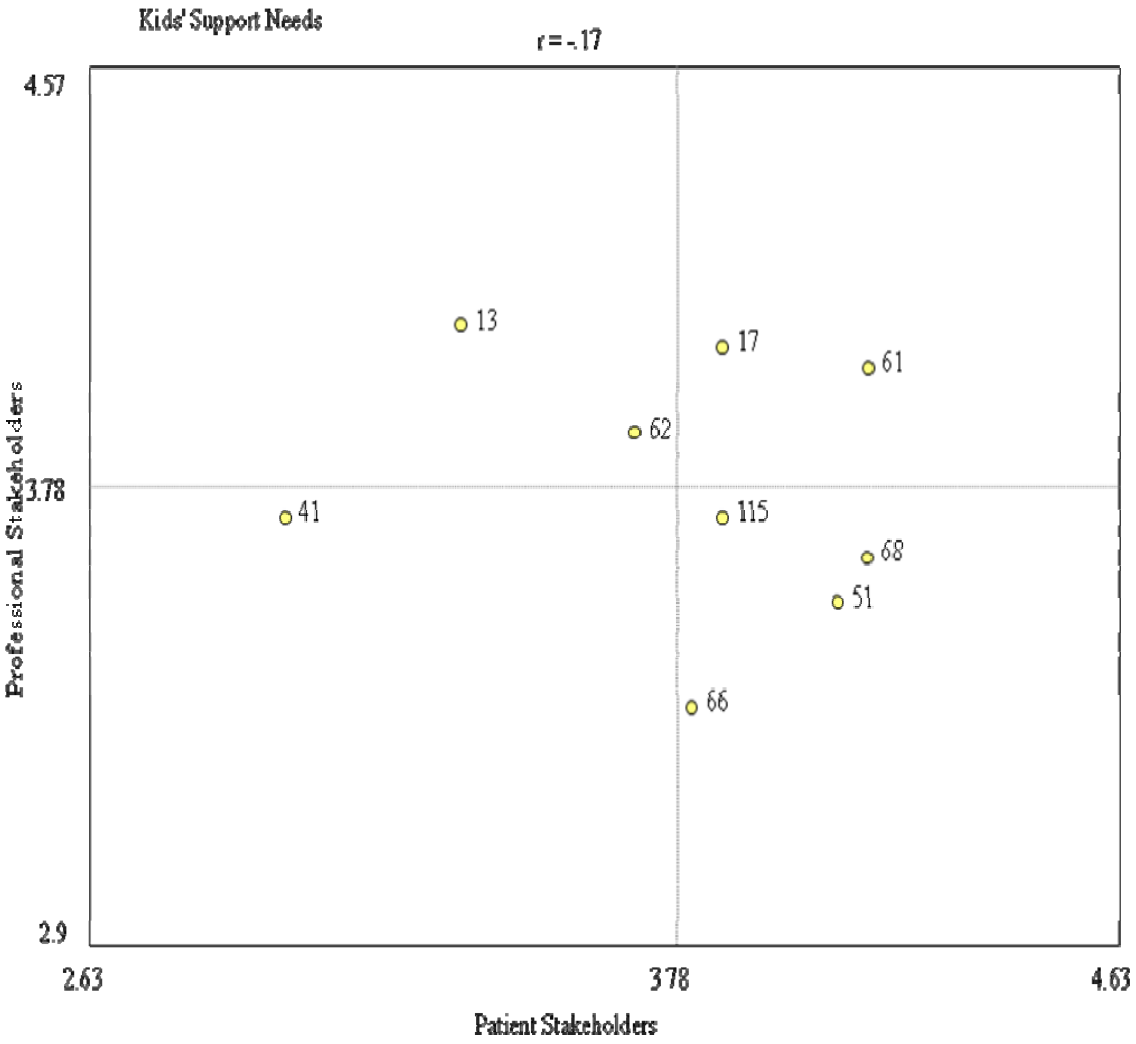
There is a fairly strong relationship between how both stakeholder groups rated the *Emotional Impact on Children* cluster (Figure 25) evidenced by a correlation coefficient of .74. A total of four statements appear in the lower right quadrant which means the patient stakeholders rated them higher on possible utilization if they were services, than the professional stakeholders. The four statements are 99 (*Kids don't know how to express needs and concerns about how the family will move forward*), 125 (*Adolescents may conceal their thoughts, fears and feelings to protect parents and not cause tension in the relationship*), 123 (*Children have a hard time understanding a very complex and scary illness*), and 85 (*Kids worry they will get cancer*). The statements appearing in the upper-left quadrant include 14 (*Teenage caregivers burn-out with too many responsibilities*) and 114 (*Illness needs can detract from attention kids should get for their developmental needs*).

Figure 25. Bivariate Plot for Level of Utilization – Emotional Impact on Children



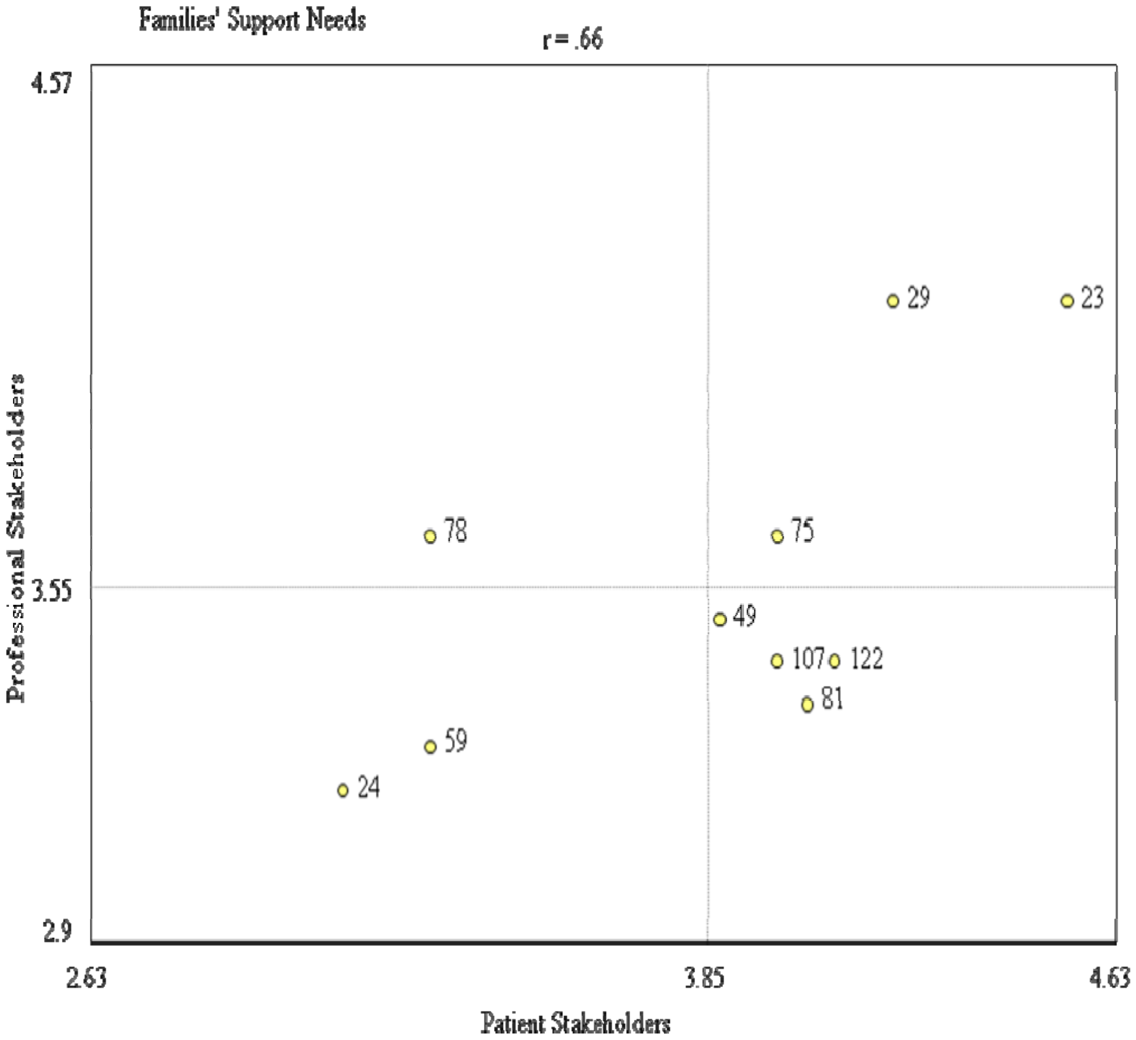
The Pearson correlation coefficient for the *Kids' Support Needs* cluster is -.17, indicating a negative relationship between how statements were rated by both stakeholder groups. Four out of the nine statements in this cluster appear in the lower right quadrant. Those statements include 115 (*Kids may not know how to access help or how to ask for it*), 68 (*Someone for kids to talk to outside of family*), 51 (*Kids lack peer support*), and 66 (*Normal play group for kids*). The statements appearing in the upper-left quadrant include numbers 13 (*Internet support groups for teenagers to share their feelings and concerns without judgment are needed*) and 62 (*Kids are not sure who they can talk to*).

Figure 26. Bivariate Plot for Level of Utilization – Kids' Support Needs



The *Families' Support Needs* cluster has a correlation coefficient of .66, indicating a moderately strong relationship. There are a total of four statements in the lower-right quadrant of the bivariate plot (see Figure 27) for this cluster. Those four statements are 49 (*Family members often experience anger and don't know how to deal with that*), 81 (*Family members don't always know how to talk about the situation*), 107 (*Treatment and illness disrupts normal routines and activities of kids and families*), and 122 (*Logistical realities of treatment disrupts* *care and schedule of children*). There is one statement appearing in the upper-left quadrant, number 78 (*Not enough utilization of technology to help connect kids*).

Figure 27. Bivariate Plot for Level of Utilization – Families' Support Needs



To summarize, there are twenty-nine statements across seven clusters that the patient stakeholders rate above the mean for level of utilization, while the professional stakeholders rate those same statements below the mean on level of utilization. In addition, there are seventeen statements across seven clusters that the professional stakeholders rate above the mean on level of utilization, while the patient stakeholders rate those same statements below the mean on level of utilization. There also seems to be more disagreement on utilization than on importance for the two central clusters that make up the *Family Functioning* super dimension (Family Adaptation Illness and Families' Support Needs). Overall, the discrepancies in level of utilization ratings could present as a barrier for effective support program development. Next, level of satisfaction is examined across all clusters via a cluster rating map, pattern match, and bivariate plots, to determine if patients' emergent needs are adequately addressed by current programming.

Cluster Level of Satisfaction

Figure 28 is the cluster rating map that illustrates how both stakeholder groups rated the 8 clusters on level of satisfaction. As with Figures 8 and 18, each cluster of points is stacked in layers from one to five. However, on this cluster rating map the layer of any single cluster is dependent upon how participants rated their level of satisfaction with having the issue or need addressed by current programming.

As per the cluster legend, single layer clusters have an average satisfaction rating ranging from 2.59 to 2.64. Clusters with two layers have an average satisfaction rating ranging from 2.64 to 2.69. Clusters with three layers have an average satisfaction rating ranging from 2.69 to 2.74. Clusters with four layers have an average satisfaction rating ranging from 2.74 to 2.80 and clusters with five layers have an average satisfaction rating ranging from 2.80 to 2.85.

Based on this legend, every cluster was rated on average in a range from *somewhat satisfied* to *moderately satisfied.* Therefore, all eight clusters were rated lower on satisfaction than they were for level of importance and level of utilization, by all stakeholders. The clusters rated with the most satisfaction by both stakeholder groups include *Emotional Impact on Parents*, *Family Adaptation to Illness*, and *Navigation*. These clusters each have five layers and mean average cluster ratings of 2.85, 2.83, and 2.80, respectively. The clusters with the next highest ratings for satisfaction include Parents' *Worries About Children*, *Emotional Impact on Children*, *Kids' Support Needs*, and *Families' Support Needs*. These clusters each have four layers and have average cluster ratings of 2.79, 2.78, 2.77, and 2.80 respectively. The lowest rated cluster, which has only one layer, is *Case Management*. It has an average cluster rating of 2.59 Patients rated this cluster the highest on level of importance and level of utilization, and the lowest for satisfaction. These aggregate ratings make the *Case Management* cluster, and the statements within it, a primary target for program development.

Figure 28. Cluster Rating Map for Level of Satisfaction

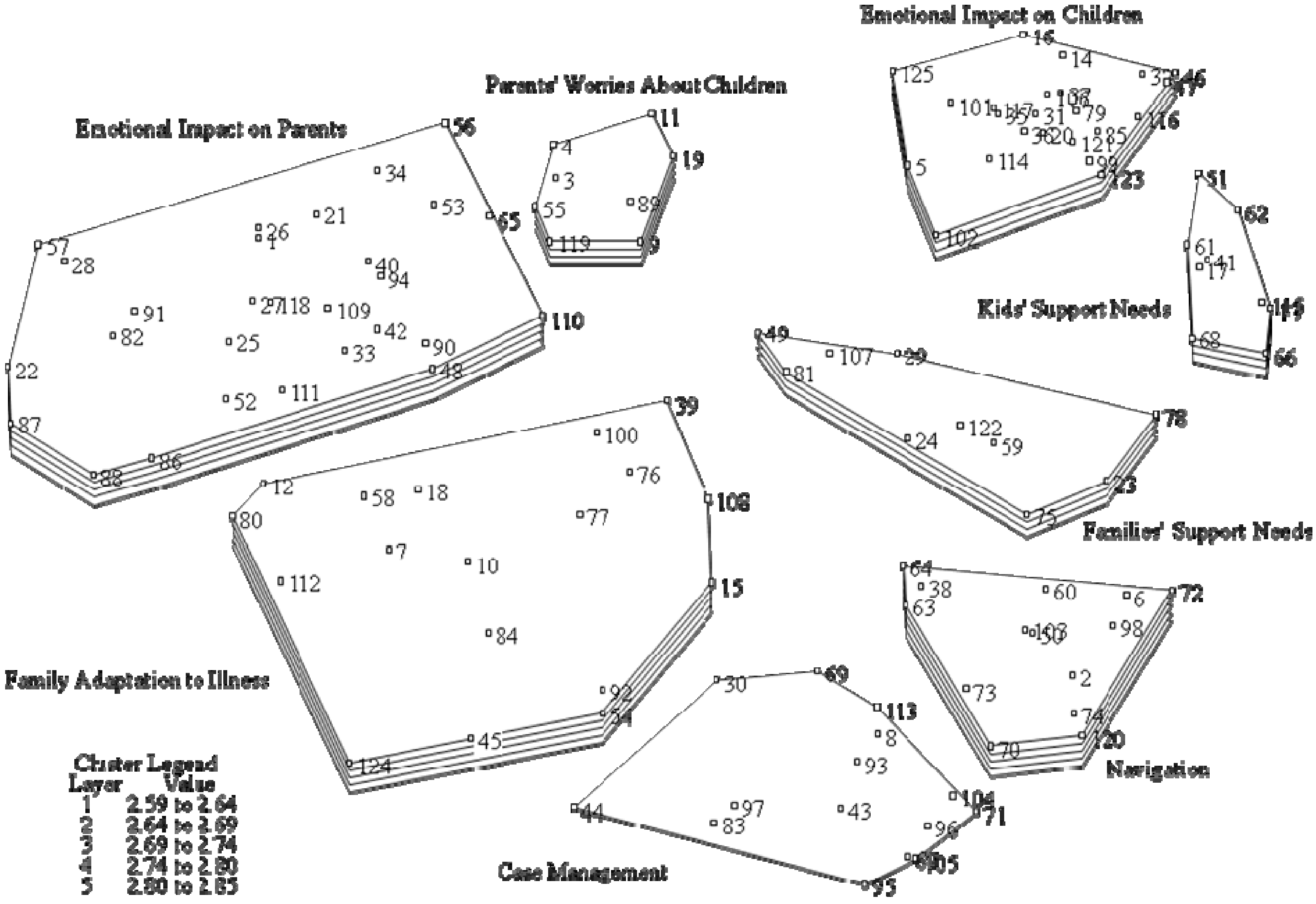
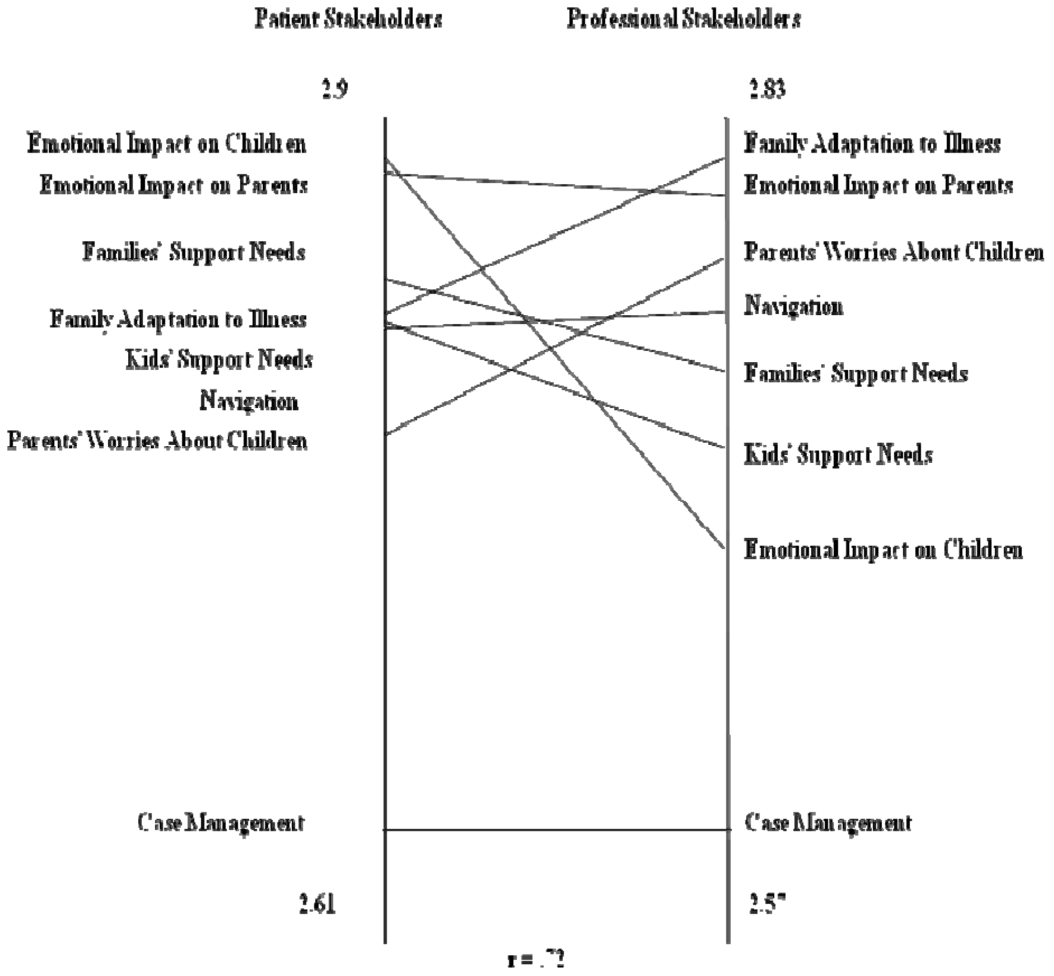


Figure 29. Pattern Match for Level of Satisfaction – Patients vs. Professionals



Level of satisfaction pattern match. How stakeholders rated each cluster on level of satisfaction is required data for answering one of the major research hypotheses put forward in this study. These ratings can be examined more holistically by reviewing the pattern match for level of satisfaction in Figure 29. Figure 29 reveals that the patient and professional stakeholder groups rated each of the eight clusters similarly, evidenced by a strong correlation coefficient of .72. The greatest difference in ratings on level of satisfaction occurred for the clusters *Emotional Impact on Children, Parents' Worries About Children*, and *Family Adaptation to Illness*. The clusters Emotional *Impact on Parents, Families' Support Needs, Kids' Support Needs,* and

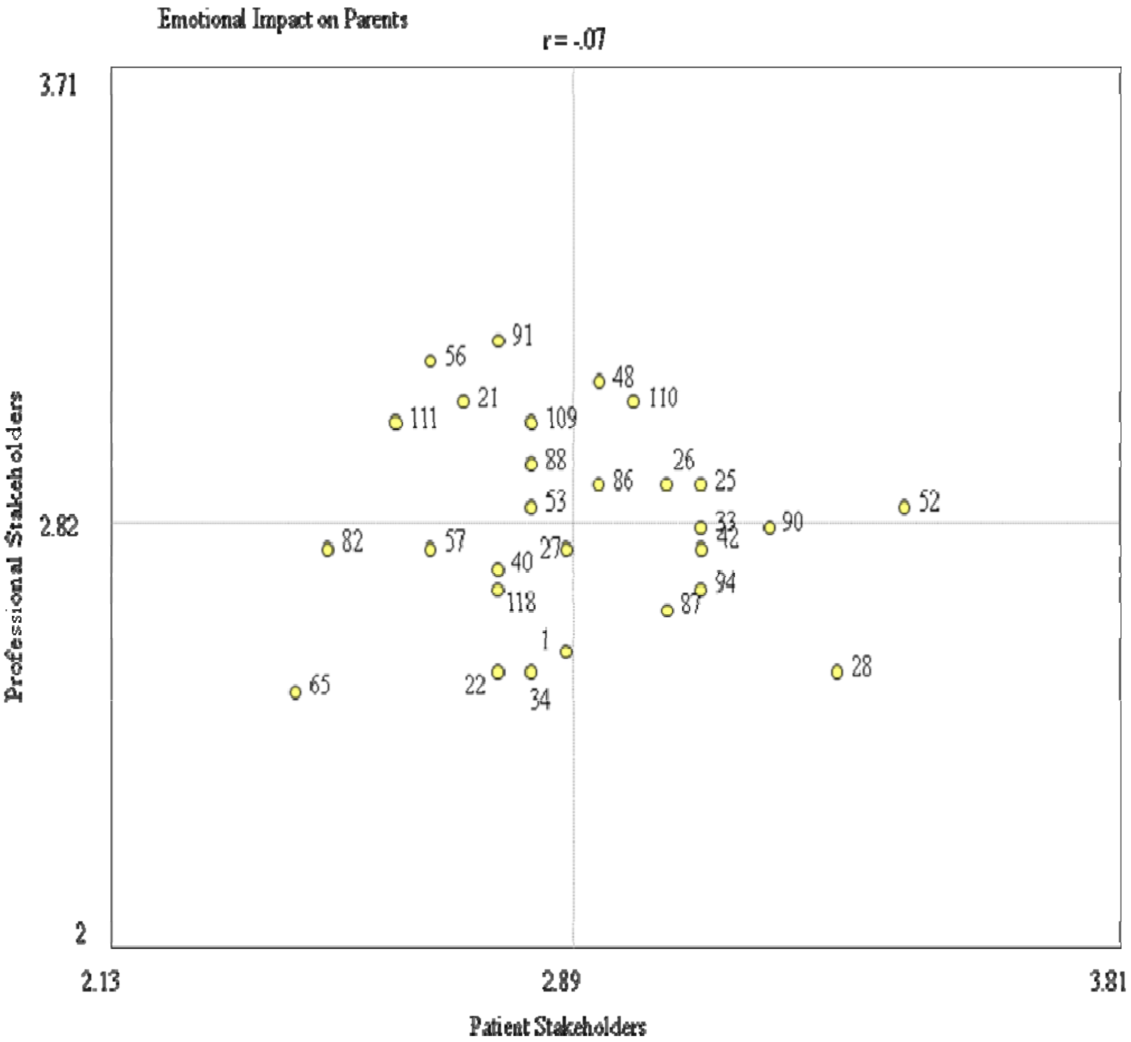
Navigation were rated more similarly. The most similarly rated cluster on level of satisfaction is *Case Management*.

Level of satisfaction bivariate plot analyses. As with level of importance and level of utilization, the bivariate plot for each of the clusters on level of satisfaction shows the averages for each statement in a cluster, depicted in an X-Y graph that is divided in quadrants above and below the mean value within the cluster of each rating variable. The Y axis represents the ratings of professional stakeholders and the X axis the ratings of the patient stakeholders.

Unlike analyses of the bivariate plots for level of importance and level of utilization, analyses of the plots for level of satisfaction requires examination of the upper and lower left quadrants. These quadrants contain the statements for each cluster which the patient stakeholder group rated below their group means for level of satisfaction. Those in the upper quadrant are statements that were disagreed upon by the patient and professional groups on level of satisfaction (professionals rated above their group mean, patients rate below their group mean) and those in the lower quadrant are those that were agreed upon by the two groups (both rated below their group means). This analysis begins to answer the research question pertaining to the satisfaction level of patients in having their emergent needs met.

Figure 30 reveals a Pearson correlation coefficient of -.07 indicating a negative relationship between the two groups' ratings on the *Emotional Impact on Parents* cluster. There are nine statements in the lower left quadrant and seven in the upper left quadrant. This amounts to sixteen statements rated below the group mean for satisfaction by patient stakeholders in this cluster. On average, the lowest rated statement in this cluster on level of satisfaction is number 65 (*If non-custodial parent is ill, it can increase isolation for parents and kids*) with a rating of 2.41, in the *somewhat satisfied* range.

Figure 30. Bivariate Plot for Level of Satisfaction – Emotional Impact on Parents



Overall, this cluster is also the highest rated cluster on level of satisfaction (see Figure 28) and contains more total statements than any other cluster, with a total of twenty-eight.

The *Parents' Worries About Children* cluster (Figure 31) has a correlation of .04, indicating a weak relationship between how the patient and professional stakeholders rated the statements on level of satisfaction. Two statements appear in the upper-left quadrant and three statements appear in the lower-left quadrant. This amounts to five statements rated below the group mean for satisfaction by patient stakeholders in this cluster. On average, the lowest rated statement in this cluster on level of satisfaction is number 3 (*Parents need to maintain* *boundaries with [not parentify] their kids even in times of extreme stress or grief*). It has a rating of 2.54, in the *somewhat satisfied* range.

Figure 31. Bivariate Plot for Level of Satisfaction – Parents' Worries About Children

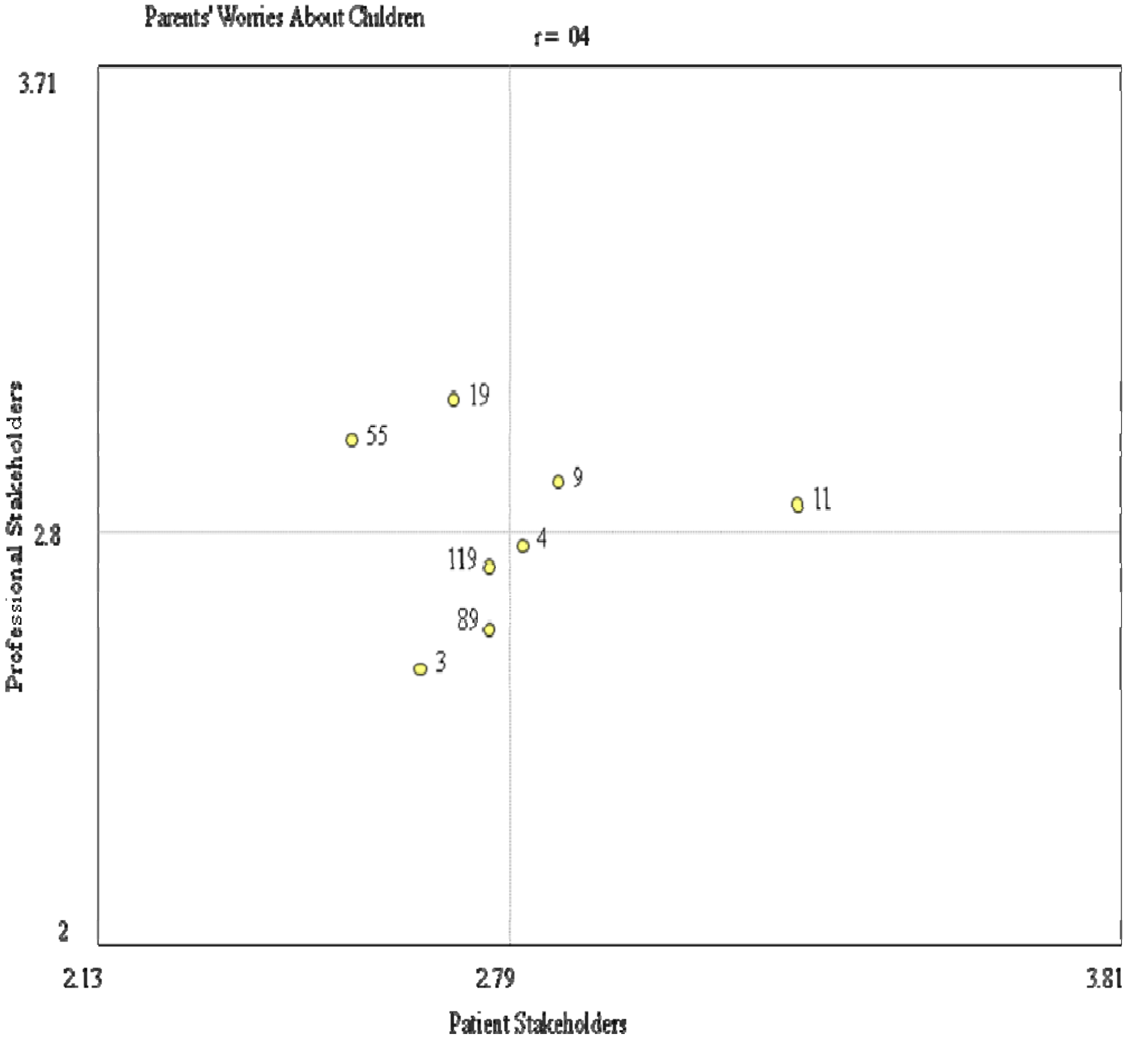
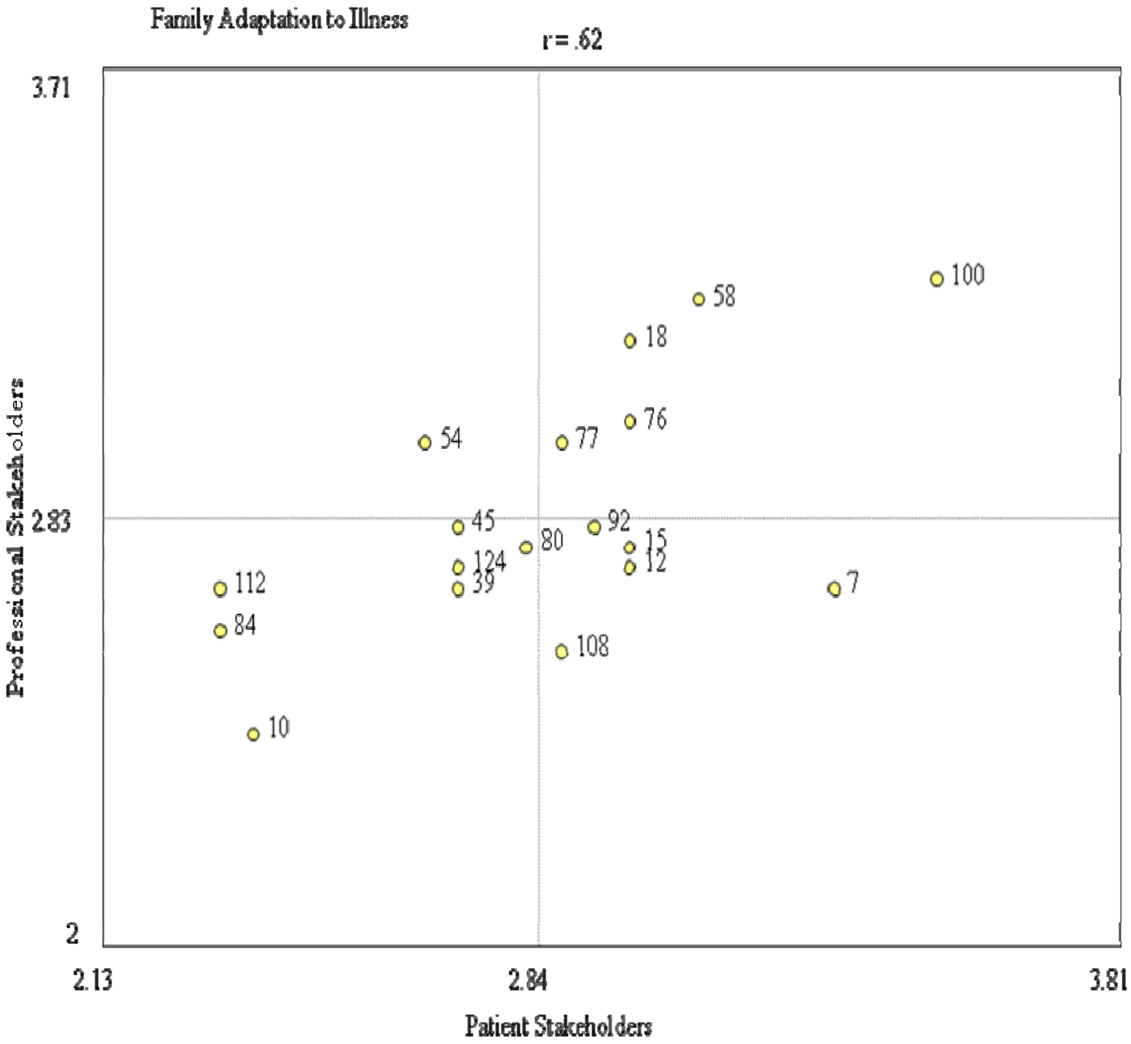


Figure 32 indicates a moderately strong correlation (r = .62) for the *Family Adaptation to Illness* cluster. One statement appears in the upper-left quadrant and seven appear in the lower-left quadrant. This amounts to eight statements rated below the group mean for satisfaction by patient stakeholders in this cluster. On average, the lowest rated statement in this cluster on level of satisfaction is number 10 (*There is not enough support for the husbands/fathers of the women with the diagnosis*). It has a rating of 2.32, in the *somewhat satisfied* range.

Figure 32. Bivariate Plot for Level of Satisfaction – Family Adaptation to Illness



In the *Navigation* cluster (see Figure 33) there is a strong correlation (r = .83) between how both groups rated the statements. However, two statements appear in the upper-left quadrant and eight statements appear in the lower-left quadrant. This amounts to ten statements rated below the group mean for satisfaction by patient stakeholders in this cluster. On average, the lowest rated statement in this cluster on level of satisfaction is number 70, (*Help with household management*). It has a rating of 2.22, in the *somewhat satisfied* range.

Figure 33. Bivariate Plot for Level of Satisfaction – Navigation

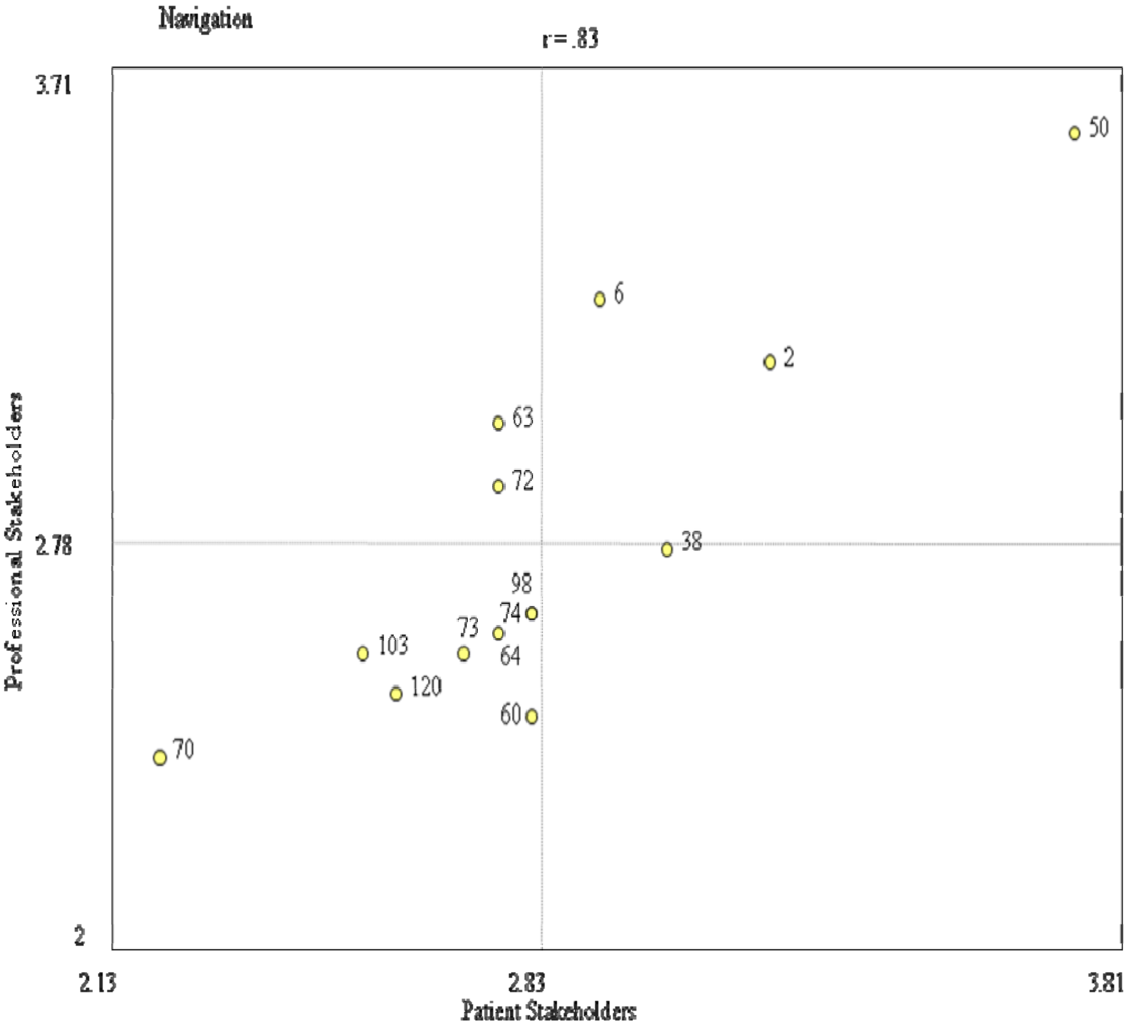
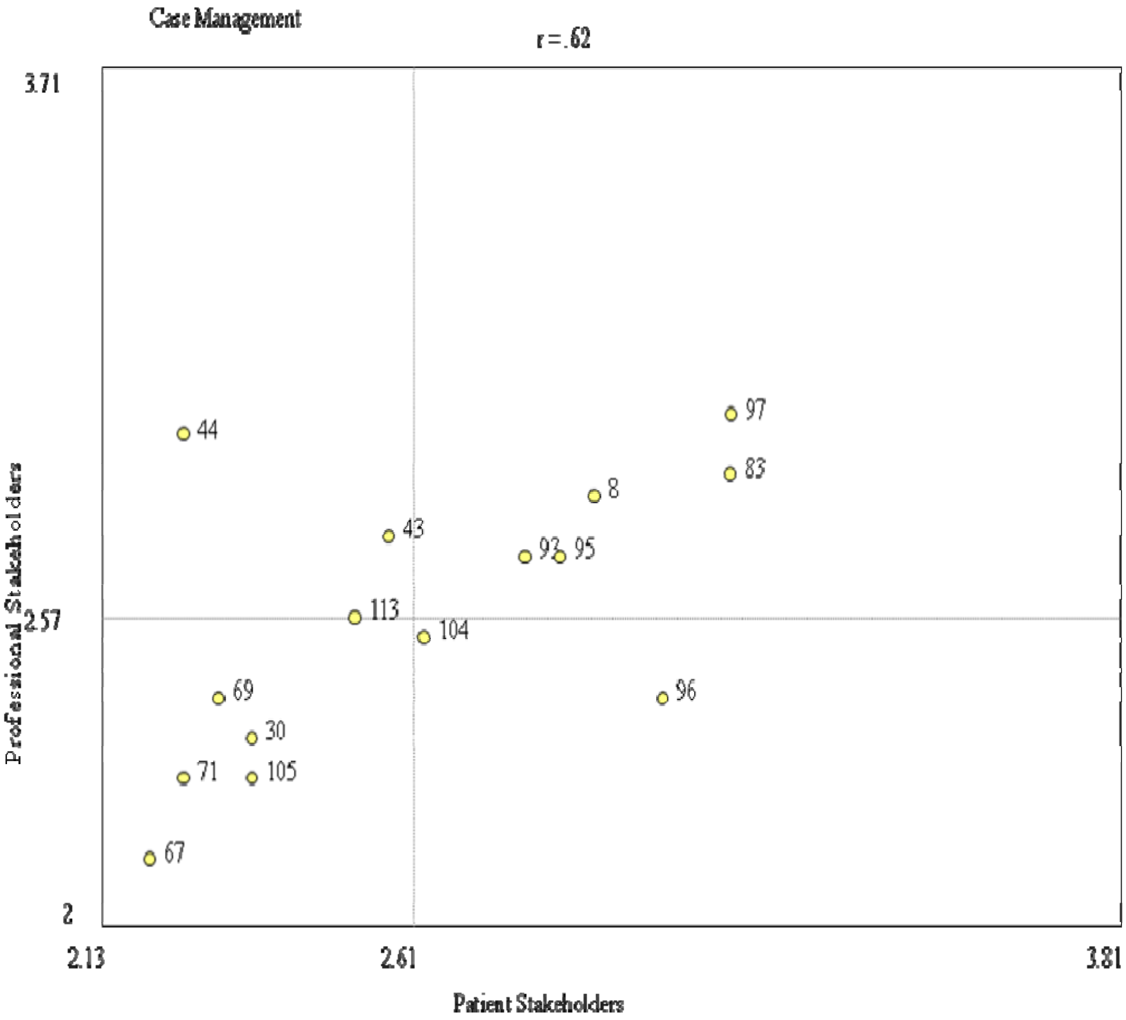


Figure 34 has a correlation of .62, indicative of a moderately strong relationship between how both stakeholder groups rated the statements in the *Case Management* cluster. There are three statements in the upper-left quadrant and five in the lower-left quadrant. This amounts to eight statements rated below the group mean for satisfaction by patient stakeholders in this cluster. On average, the lowest rated statement in this cluster on level of satisfaction is number 67 (*An emergency financial fund or account*). It has a rating of 2.05, in the *somewhat satisfied* range, and is the lowest rated statement on level of satisfaction. Remember, the *Case Management* cluster is also rated the lowest for level of satisfaction by both stakeholder groups.

Figure 34. Bivariate Plot for Level of Satisfaction – Case Management



The *Emotional Impact on Children* cluster (Figure 35) has a correlation coefficient of .31, indicating a weak relationship between how both groups rated statements on level of satisfaction. There are five statements in the upper-left quadrant and five statements in the lower-left quadrant. This amounts to ten statements rated below the group mean for satisfaction by patient stakeholders in this cluster. On average, the lowest rated statement in this cluster on level of satisfaction is number 14 (*Teenage caregivers burn-out with too many responsibilities*). It has a rating of 2.30, in the *somewhat satisfied* range.

Figure 35. Bivariate Plot for Level of Satisfaction – Emotional Impact on Children

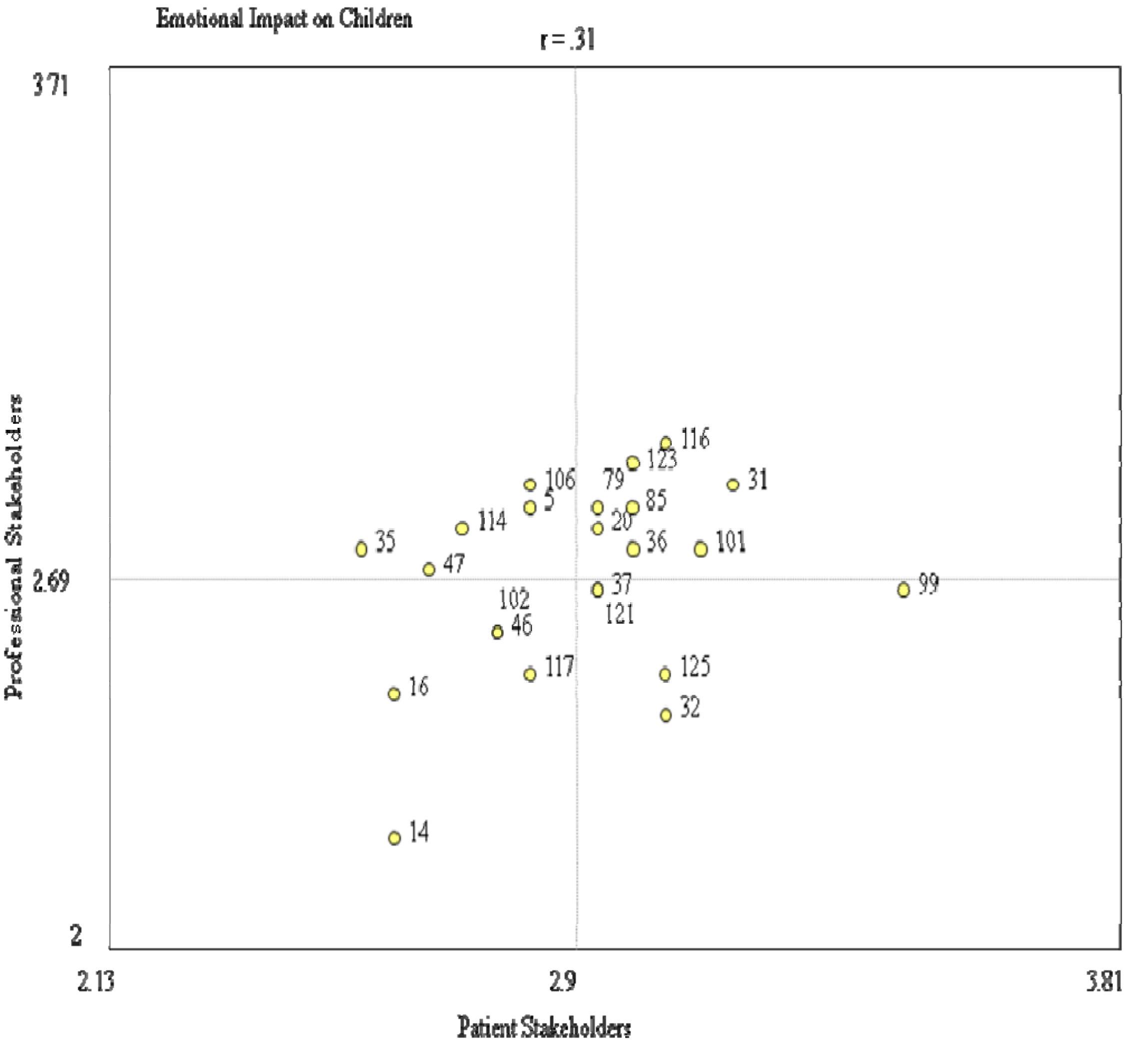


Figure 36 reveals a correlation of .34 indicative of a weak relationship between how the two groups rated statements in this cluster. One statement appears in the upper-left quadrant and two appear in the lower-left quadrant. This amounts to three statements rated below the mean for satisfaction by patient stakeholders in this cluster. On average, the lowest rated statement in this cluster on level of satisfaction is number 13 (*Internet support groups for teenagers to share their feelings and concerns without judgment are needed*). It has a rating of 2.35, in the *somewhat satisfied* range.

Figure 36. Bivariate Plot for Level of Satisfaction – Kids' Support Needs

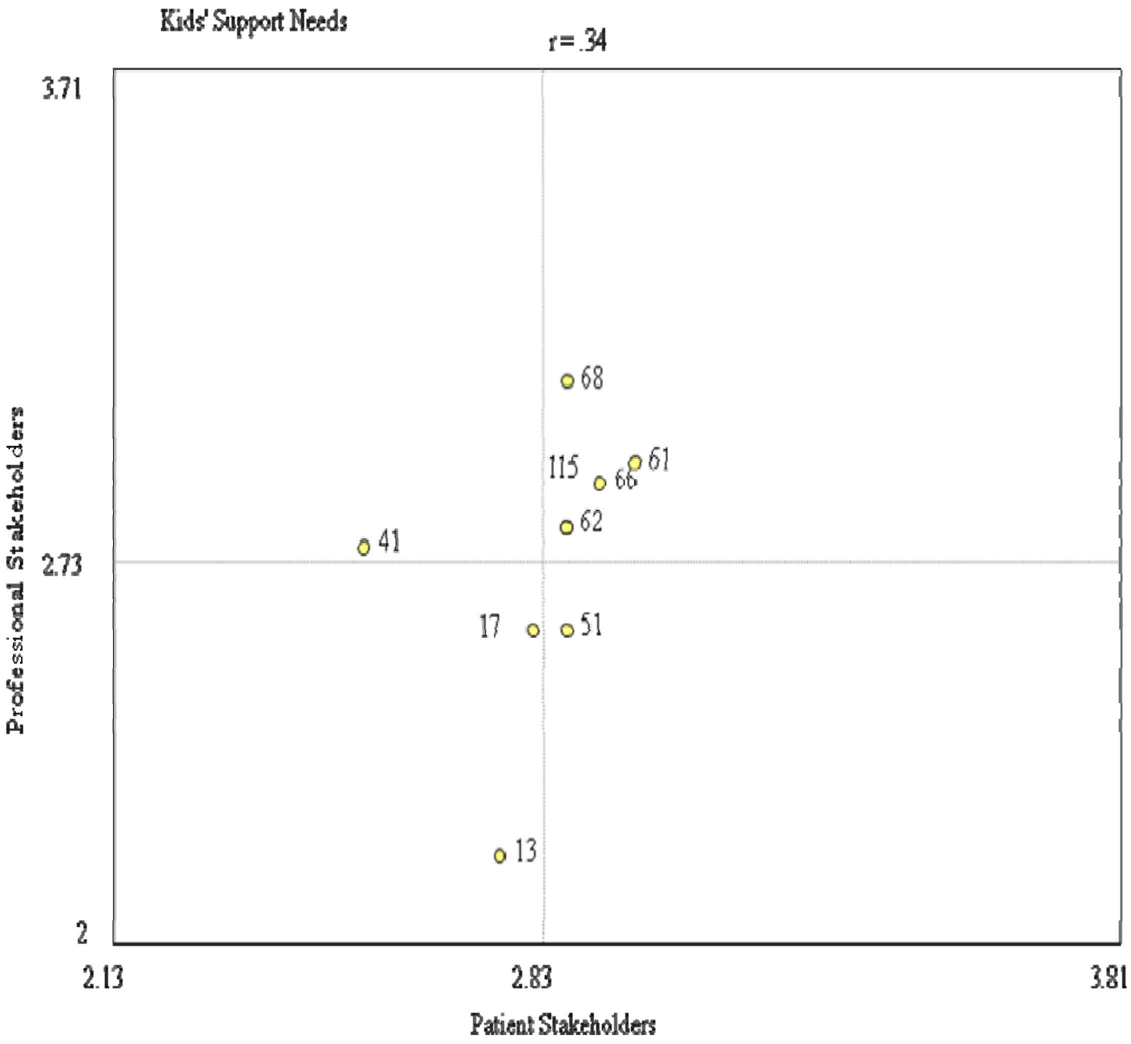
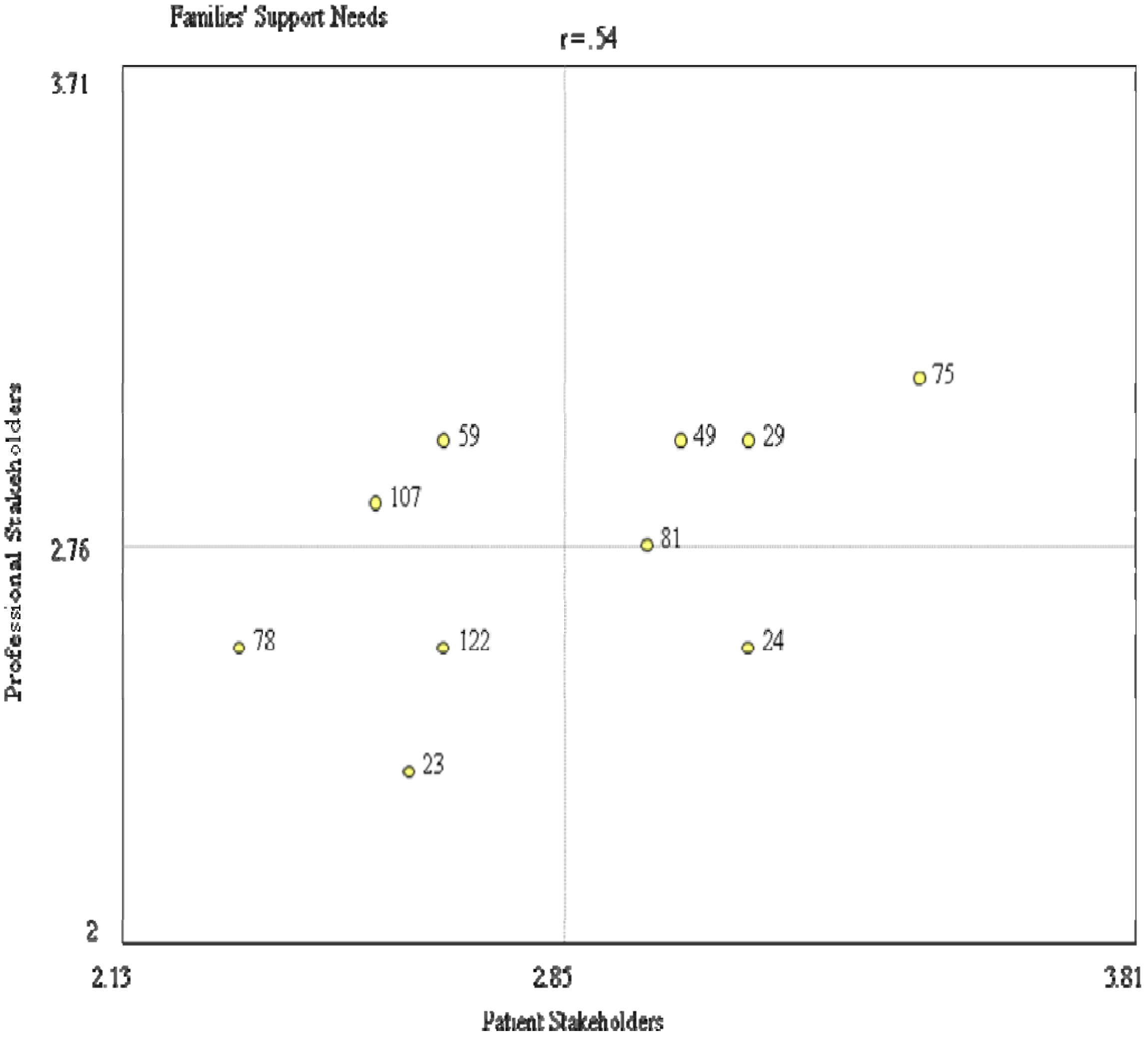


Figure 37 (r = .54) contains two statements in the upper-left quadrant and three statements in the lower-right quadrant. This amounts to five statements rated below the mean for satisfaction by patient stakeholders in the *Families' Support Needs* cluster. On average, the lowest rated statement in this cluster on level of satisfaction is number 23, (*Need assistance with childcare*). It has a rating of 2.38, in the *somewhat satisfied* range.

Figure 37. Bivariate Plot for Level of Satisfaction – Families' Support Needs



In sum, the patient stakeholder group rated sixty-six statements below their group mean on level of satisfaction. The *Emotional Impact on Parents* cluster contained the most statements rated below the mean. Yet, the *Case Management* cluster was rated the lowest of all the clusters and contained the statement with the lowest rating, statement 67, "An emergency financial fund, or account". The lowest rated 10 statements on level of satisfaction are presented in Table 4 along with the respective clusters in which they belong.

Out of the sixty-six statements rated below the mean on level of satisfaction, 43 are emergent need statements. Appendix E (Table E3) summarizes all of the statements rated on level of satisfaction, categorized by cluster, by both stakeholder groups. Table 5 summarizes the 43 emergent need statements that are rated below the group mean on level of satisfaction by patient stakeholders. Examination of Table 5 reveals that 14 of the 28 statements in the *Emotional Impact on Parents* cluster were identified as emergent needs and rated below the group mean by patient participants. This cluster has the highest percentage of these statements contained within it when compared to the other clusters. From there *Navigation* has 6 of 14, *Kids' Support Needs* has 3 of 9, *Emotional Impact on Children* has 7 of 23, *Families' Support Needs* has 3 of 10, *Parents' Worries About Children* has 2 of 8, and *Case Management* has 2 of 15 statements identified and rated this way.

Table 4

Lowest 10 Rated Statements – Level of Satisfaction with Cluster Names

#	*Statement*	*Rating*	*Cluster*
67	An emergency financial fund or account.	2.05	Case Management
71	Financial advocate to help family manage finances.	2.19	Case Management
70	Help with household management	2.22	Navigation
105	Financial assistance to help family keep up with normal activities and secure necessary things like school supplies.	2.24	Case Management
14	Teenage caregivers burn-out with too many responsibilities.	2.30	Emotional Impact on Children
30	Need for a mentor who can work with patient during and after treatment	2.30	Case Management
10	There is not enough support for the husbands/fathers of the women with the diagnosis.	2.32	Family Adaptation to Illness
69	Personal patient liaison who understands the diagnosis and treatment, as well as the realities of parenting.	2.32	Case Management
13	Internet support groups for teenagers to share their feelings and concerns without judgment are needed.	2.35	Kids’ Support Needs
23	Need assistance with childcare.	2.38	Families’ Support Needs

Table 5

Summary of Emergent Needs Rated Below Patient Group Means on Satisfaction

#	Statement	Average Rating
Cluster 1: Emotional Impact on Parents		
91	Parents need permission to be sick.	3.03
56	Family members are afraid parent / patient will die.	2.95
109	Parents may feel guilty for the disruption in their family's life.	2.95
21	The ill parent worries about their children more than they do themselves.	2.92
53	Parents can have many overwhelming emotions that impact their ability to be involved with their children.	2.84
111	Ill parents struggle with how to stay active in kid's lives when they are weakened by illness and treatment.	2.84
27	Friends don't always react to your cancer diagnosis in a way you expected.	2.81
118	Young parents have few peers who have had to deal with like concerns and can feel isolated.	2.70
57	Parents feel they have to protect each other from their own distress get more isolated & distant from each other.	2.70
1	Ill parents may alienate themselves from their family.	2.68
34	Families can start to isolate themselves from other families who are not dealing with cancer	2.62
82	After treatment the parent's relationship needs change so they don't always have their social needs met.	2.62
22	The ill parent may feel alone because the spouse cannot go to appointments due to home and work responsibilities.	2.59
65	If non-custodial parent is ill, it can increase isolation for parents and kids.	2.41

table continues

#	Statement	Average Rating
Cluster 2: Parents' Worries About Children		
119	Parents want to know how kids feel, but it can be hard for them to hear about how their illness is impacting them.	2.73
3	Parents need to maintain boundaries with (not parentify) their kids even in times of extreme stress or grief.	2.54
Cluster 3: Family Adaptation to Illness		
54	Families have little or no experience with the health care system, which can make this very difficult for them.	2.84
45	Parents are uncertain of how much health status information to give to their employers.	2.76
124	Illness can change or jeopardize the parents' job status.	2.70
39	Pre-existing family issues become exacerbated with the stress of cancer, making family life more difficult.	2.68
112	Cognitive effects of treatment (chemo-brain) interferes with managing busy household and family.	2.49
Cluster 4: Navigation		
63	Families need follow-up after an initial supportive contact because their needs and readiness change frequently.	2.92
72	Families need organized extended family support.	2.84
98	Families are so busy that they often need support delivered in places that are convenient and comfortable for them.	2.70
74	Family needs a patient navigator to help them understand and make sense of all different sources of information.	2.70
64	Families can be reluctant or find it difficult to ask for help.	2.65
60	Hard for families to coordinate all the family, school, treatment, and supportive activities and resources.	2.57
120	Families need coordinator to help manage all concerns, appointments, and demands.	2.49

table continues

#	Statement	Average Rating
Cluster 5: Case Management		
69	Personal patient liaison who understands the diagnosis and treatment, as well as the realities of parenting.	2.32
71	Financial advocate to help family manage finances.	2.19
Cluster 6: Emotional Impact on Children		
47	Kids experience role changes and are often expected to do more than they are capable of doing.	2.68
102	Family norms, rules, values, may not allow children to express themselves.	2.65
46	Kids may have increased absences from school.	2.65
35	Children miss their family life before cancer	2.65
117	Having an ill parent makes kids feel alone or isolated.	2.62
16	College aged children worry about leaving for school not knowing what the future holds for their ill parent.	2.49
14	Teenage caregivers burn-out with too many responsibilities.	2.30
Cluster 7: Kids' Support Needs		
17	Teenagers need someone to turn to for help with coping healthfully.	2.68
41	Kids may need or want an opportunity to talk with their parent's doctor or member of the health care team.	2.65
13	Internet support groups for teenagers to share their feelings and concerns without judgment are needed.	2.35

table continues

#	Statement	Average Rating
Cluster 8: Families' Support Needs		
59	Difficulties adjusting family priorities.	2.84
78	Not enough utilization of technology to help connect kids.	2.41
23	Need assistance with childcare.	2.38

Priorities for Program Development

Figure 38 is a pattern match representing the differences between patient stakeholder cluster ratings on level of importance and level of satisfaction. The Pearson correlation coefficient for this comparison is - .73, indicative of a very strong negative relationship between how the patient stakeholders rated all clusters on level of importance and level of satisfaction. Review of this figure reveals that patients rated all clusters ranging from the *moderately* to *significantly* range on importance, and rated all clusters in the *somewhat* range on satisfaction. This is a strong indication that the patients view all clusters as important, yet, are only somewhat satisfied with the services available to address the needs contained within them. The cluster rated highest in importance and lowest in satisfaction is Case Management.

Figure 38. Patient Pattern Match – Importance vs. Satisfaction

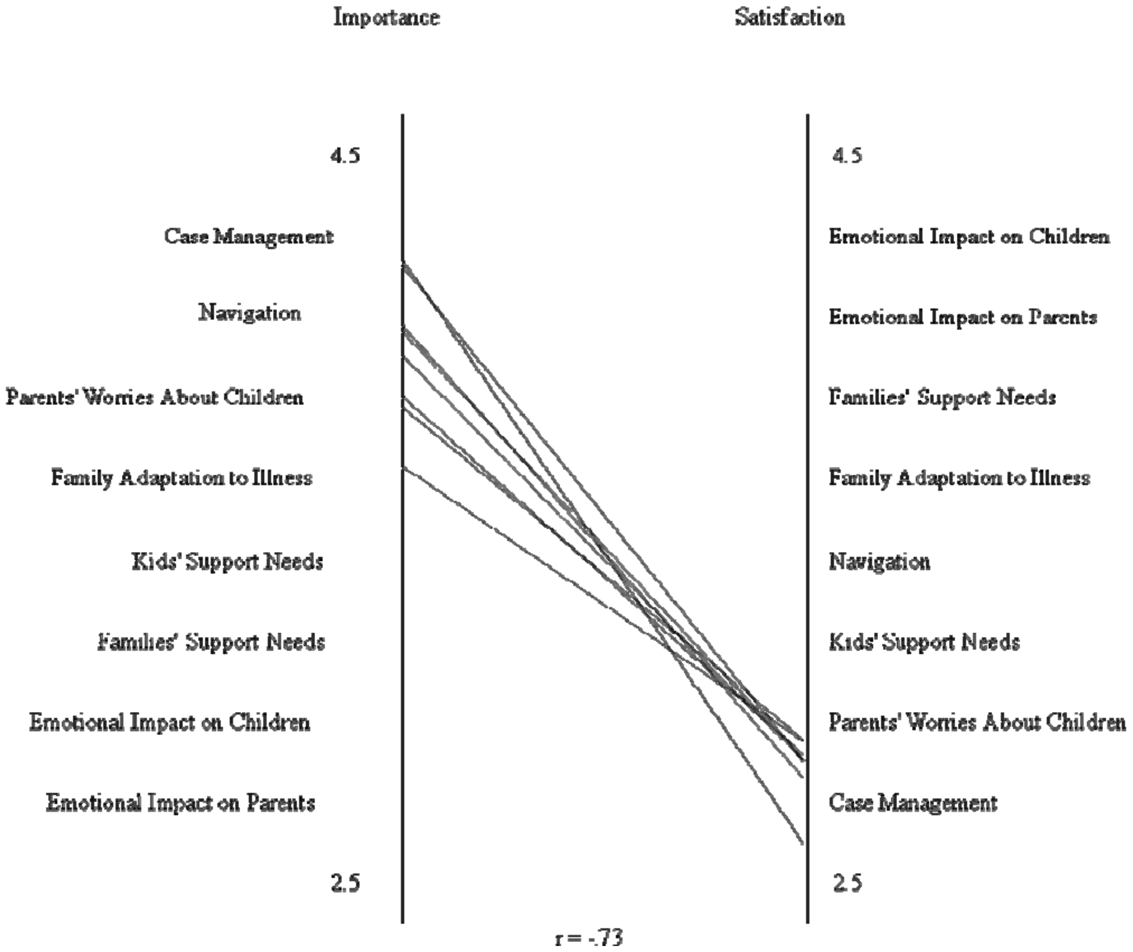
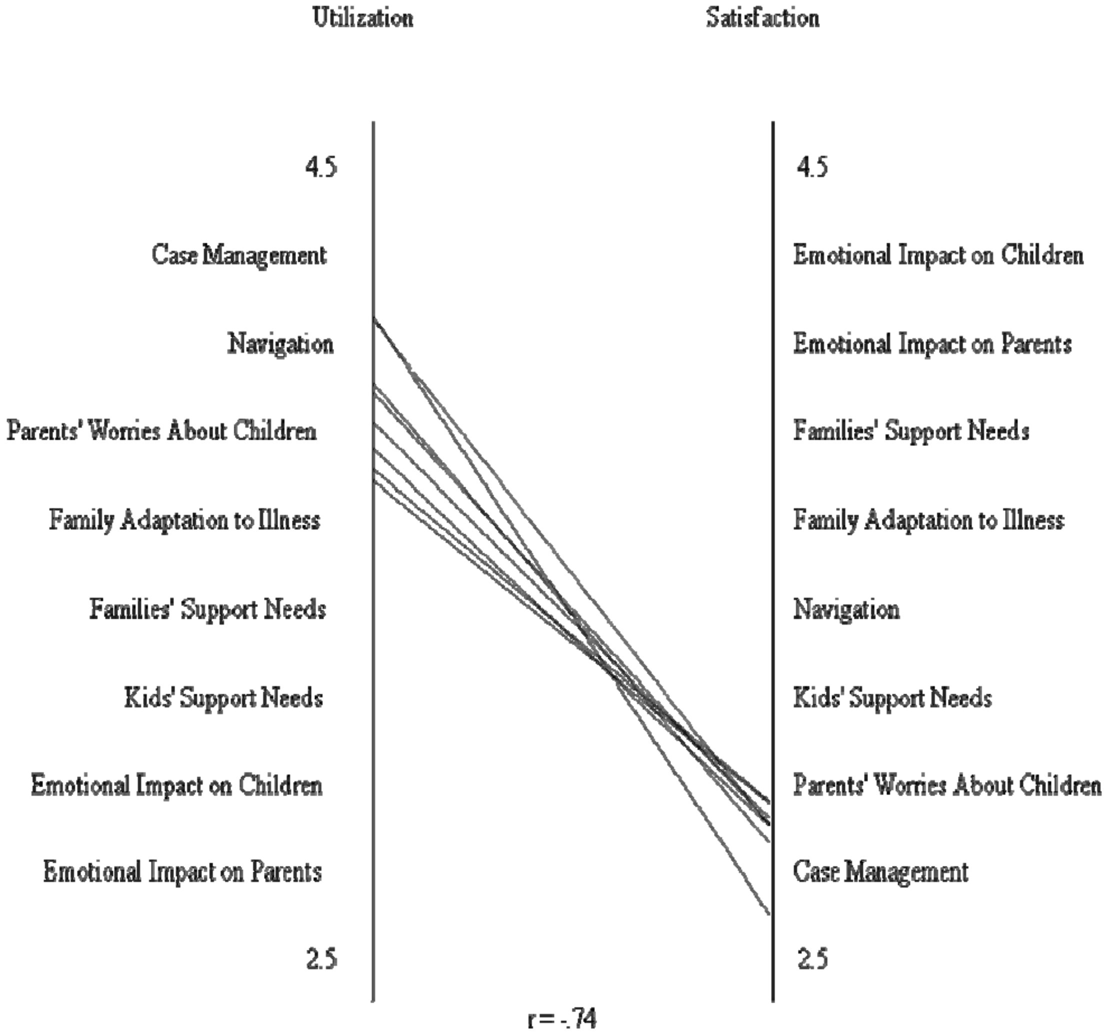


Figure 39 is a pattern match representing the differences between patient stakeholder cluster ratings on level of utilization and level of satisfaction. The Pearson correlation coefficient for this comparison is - .74, again indicative of a very strong negative relationship between how the patient stakeholders rated all clusters on level of utilization and level of satisfaction. Review of this figure reveals that patients rated all clusters ranging from the *moderate* to *significant utilization* range, and rated all clusters in the *somewhat satisfied* range. This is a strong indication they would utilize services and program components that address the needs that currently have a rating of *somewhat satisfied*. As with Figure 38, the cluster rated highest in utilization and lowest in satisfaction is Case Management.

Figure 39. Patient Pattern Match – Utilization vs. Satisfaction



In sum, Figure 38 and 39 are nearly identical and reveal that patients rated all clusters higher on importance and utilization than they did on satisfaction. Case Management was the most significantly rated cluster for low satisfaction, and high importance / utilization.

Analysis of the all-cluster bivariate plots (Figures 40 and 41) in conjunction with Figures 38 and 39, tells a more precise story as it pertains to the individual items. Analysis of Figures 40 and 41 is comprised of reviewing patient-rated statements in the lower-right quadrant of the bivariate plots for ratings on level of importance versus level of satisfaction (see Figure 40) and level of utilization versus level of satisfaction (see Figure 41). By comparing the statements that appear in the lower-right quadrants of these two bivariate plots, a list was generated of statements that patients rated high on level of importance and utilization, and low on satisfaction.

Figure 40. Bivariate Plot Level of Importance vs. Level of Satisfaction

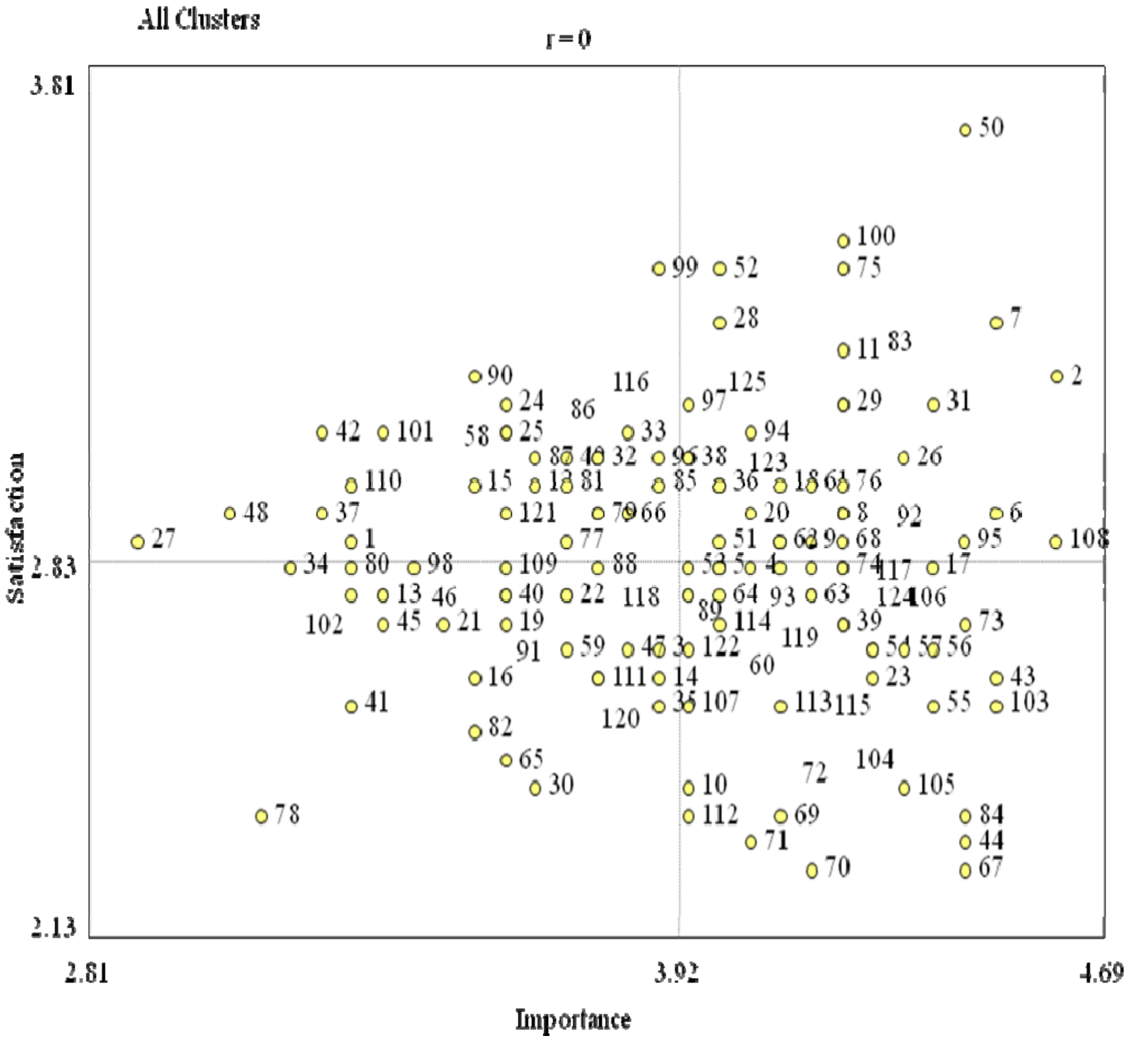


Figure 41. Bivariate Plot Level of Utilization vs. Level of Satisfaction

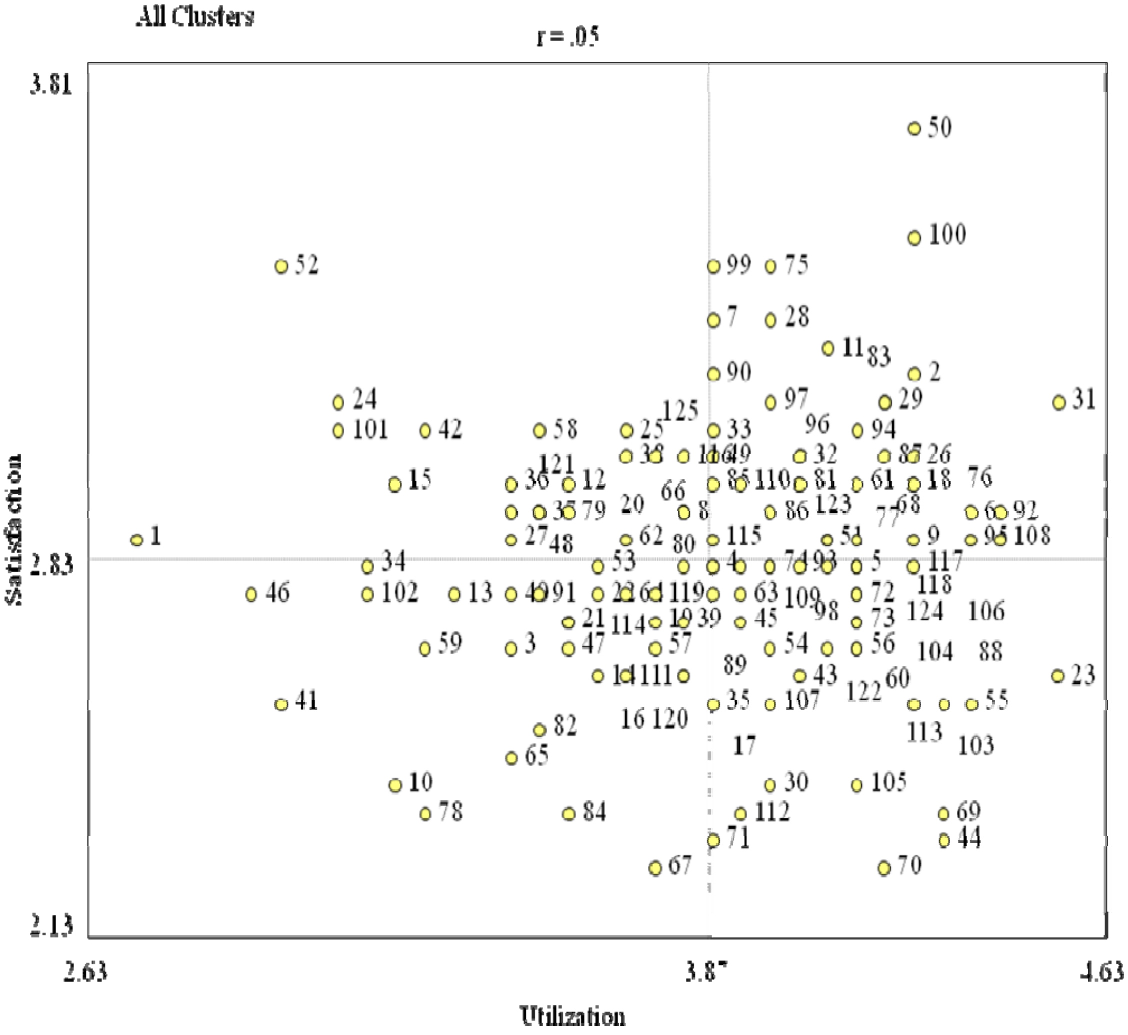


Table 6 is a summary of those statements with their corresponding clusters. There are a total of nineteen statements across all eight clusters. These statements represent the most actionable areas for oncology support program development at the CR Wood Cancer Center because the patient stakeholders rated them above their group mean on level of importance and utilization, and below their group mean on level of satisfaction.

Table 6

Priorities for Program Development

#	*Cluster and Statement*
Emotional Impact on Parents	
56	Family members are afraid parent / patient will die.
57	Spouses / partners who feel they have to protect each other from their own distress are isolated and distant from each other
88	Parents are concerned about fertility and reproductive issues.
118	Young parents have few peers who have had to deal with like concerns and can feel isolated.
Parents' Worries About Children	
55	Parents are afraid to tell kids about negative prognosis or dying.
Family Adaptation to Illness	
54	Parents and families have little or no experience with the healthcare system, which can make this very difficult for them.
124	Illness can change or jeopardize the parents' job status.
Navigation	
73	Respite is needed for care giving parent / partner.
103	Child care assistance during treatment, when coming into clinic and at home after treatment recovering.
Case Management	
44	Parents worry about ability to get or keep health insurance for their family for the future.
105	Financial assistance to help keep family up with normal activities and secure necessary things like school supplies.
Emotional Impact on Children	
5	Age appropriate information needs to be shared with the kids at all times to keep them in the loop.
35	Children miss their family life before cancer.
106	Kids experience emotions that can be tough to deal with.

table continues

117 Having an ill parent makes kids feel alone or isolated.

Kids’ Support Needs

17 Teenagers need someone to turn to for help with coping healthfully.

Families’ Support Needs

23 Need assistance with childcare.

107 Treatment and illness disrupts normal routines and activities of kids and families.

122 Logistical realities of treatment disrupts care and schedule of children.

Chapter 5: Discussion

Overview

This study set out to uncover the support needs of young families who are living with and beyond a parent diagnosed with cancer. The researcher hoped this multi-perspective study would uncover areas in need of program development. There were three research hypotheses for this study. The first was that several previously unknown needs would emerge. This research question was answered by performing a content analysis of the statements generated by the pilot study and current study to determine which statements were similar and dissimilar. The second hypothesis was that participant satisfaction ratings would indicate the Center's current programming would not adequately address the emergent needs of the sample population under study. This research question was answered by reviewing the patient stakeholder level of satisfaction and level of importance ratings for those statements identified as emergent needs. The third hypothesis was that statement ratings on level of importance and level of utilization of new services to address the statements would be discrepant between the patient and professional stakeholders, uncovering the existence of potential barriers in program development. This research question was addressed by comparing the patient and professional stakeholders' cluster level of importance and utilization ratings by way of cluster rating maps, pattern matches, and bivariate plots. While not a formal research hypothesis, it was anticipated various barriers to program development would be encountered within the organizational, practitioner, researcher, and community domains put forward by Petosa (2001).

The results regarding the three research hypotheses are discussed in their respective sections below. The researcher confirms the experience of barriers to program development and discusses the process of this investigation while considering Petosa's *Ecology of Health*

Behavior Programs theory (see Figure 1). The recommendations section contains recommended next steps for program development and for overcoming potential program development barriers. The limitations of this study are also included, as well as future directions, which focuses on exploring the super dimensions that emerged from this study. Finally, the Researcher Reflection contains a summary of lessons learned regarding research in a naturalistic setting and an account of the personal events leading to this study.

Emergent Needs and Satisfaction

It was determined a total of 94 *previously undocumented* needs did emerge from this study. The description of previously unknown refers to needs not identified in the prior pilot study. Out of these 94 emergent needs, patient stakeholders consider 43 of them to be below their group mean on levels of satisfaction ratings. The ratings on these statements average in the *somewhat satisfied* range, indicating that patients are somewhat satisfied with having these emergent needs addressed at the present time. A closer look at the 43 statements reveals they are spread out through all of the clusters with the *Emotional Impact on Parents* cluster containing the largest percentage within one cluster (50%). From these results it can be concluded that there are many emergent needs that are not currently adequately addressed by existing services.

The majority of these needs exist in the *Emotional Impact on Parents* cluster, even though this is one of the highest rated clusters on overall level of satisfaction, with five layers (see Figure 28). New needs, with a low level of satisfaction, also emerged from the *Navigation*, *Emotional Impact on Children*, *Kids' Support Needs*, *Families' Support Needs*, and *Parents' Worries About Children* clusters. It is also apparent the *Case Management* cluster is the one with the lowest overall level of satisfaction ratings, with one layer (see Figure 28).

Table 7
Comparison of Institute of Medicine Needs vs. Eight Cluster Map of Oncology Support Needs

IOM Categories	*Cluster*
Information about illness, treatments, health, and services	Case Management, Navigation
Help in coping with emotions accompanying illness and treatment.	Emotional Impact on Parents, Parents' Worries About Children, Emotional Impact on Children, Kids' Support Needs, Families' Support Needs, Family Adaptation to Illness
Help in managing illness. (emphasizes self-management / selfcare)	N/A
Assistance in changing behaviors to minimize impact on disease.	N/A
Material and logistical resources, such as transportation.	Case Management
Help in managing disruptions in work, school, and family life.	Family Adaptation to Illness, Families' Support Needs
Financial advice and / or assistance.	Case Management

While the IOM (2008) study did not focus specifically on the needs of young families experiencing the parental diagnosis of cancer, the clusters of statements developed in this study are in line with those uncovered by the IOM. This suggests there is some generalizability in the needs of cancer patients and their families. Table 7 summarizes the need categories identified by the IOM with the corresponding clusters discovered in this study.

The Center's current programming includes services that address the emotional need category areas put forth by the IOM and this study. These services include the Young Survivors' Group, Family Connections, Outpatient Psychotherapy, and Spiritual Care. There are also services in place that address needs in the *Emotional Impact on Children, Kids' Support Needs, Families' Support Needs* and *Parents' Worries About Children* clusters. These services again include Family Connections, Spiritual Care, and Outpatient Psychotherapy, in addition to

Cindy's Comfort Camp. The Oncology Resource Education service addresses some needs found in the *Navigation* cluster, but not all. This service also addresses the *help in managing illness* category put forth by the IOM. In addition, there is a Case Management service at the Center which is described as dedicated to coordinating medical care, accessing resources including financial assistance, transportation for appointments, and referrals for additional community services, covering all relevant categories from the IOM and this study.

The question remains as to why satisfaction levels remain low at the Center across all identified education and support clusters in spite of the availability of services that address many of the identified needs. The IOM (2008) suggests the first area to examine is case management, which was the cluster found to have the lowest level of satisfaction and highest level of importance and utilization ratings from patients. In no way should this be interpreted as an indication of lack of ability of case management staff to perform their work. Instead, it is a testament to the intense, complex, and all-encompassing nature of the needs of young families with a parental diagnosis of cancer. Patients that fall into this sub-group simply have more complex, far-reaching needs than those who do not. In case management language this means they require linkages and referrals for services not required by the more proto-typical cancer patient, such as child care, fertility issues, and assistance with understanding and managing an impacted child's behavior, to name just a few.

Discrepant Ratings

As the results section indicates, there are dozens of discrepant statement ratings on level of importance and utilization between the patient and professional stakeholders that could lead to potential barriers for effective program development. These discrepancies could pose as barriers to program development because they may lead to programs being developed that are not important to the patients and are therefore under-utilized. At the same time these discrepancies could inhibit the development of highly important, highly utilized programs that the patients desire and would benefit from. It is also noteworthy the *help in managing illness* and *assistance in changing behaviors to minimize the impact on disease* categories put forth by IOM (see Table 6) are the only categories not represented by statements or clusters generated in this study. This may be an example of needs over-valued by professionals and under-valued by patients when assessing the needs of young families with a parental diagnosis of cancer.

Again, this speaks to the importance of a thorough needs assessment before developing education and support programming to avoid developing programming that is underutilized and not considered important by patients. However, according to the IOM (2008), payment and reimbursement is often a barrier for a thorough needs assessment. In 2006, the Current Procedural Terminology (CPT) coding manual (Beebe et al., 2006) defined health and behavior (H/B) assessment procedures as a way for clinical staff to assess the needs of patients with physical health problems. Two H/B CPT codes were specifically created for this assessment, 91650 (initial assessment) and 96151 (re-assessment). Yet, the IOM (2008) states that “in early 2007 an American Psychological Association list serve contained anecdotal reports of denial of reimbursement for these services by Medicaid, and coverage by private-sector health plans is not yet uniform” (p. 252). The risk of lack of reimbursement has resulted in no use of these codes at the Center (G. Florio, personal communication, May 12th, 2009).

In addition to the H/B codes, case management services and assessment procedures are billable under the physician evaluation and management (E/M) CPT codes. According to the IOM (2008) these codes:

> Provide for physicians' need to take a patients' social history and relevant social factors into account in evaluating and managing their symptom(s), condition, or illness; provide for clinicians' review of mental health status; and include coordination of care with other providers or agencies…consistent with the nature of the problem and the patient's and or family's needs. (p. 253)

In order to bill for services under these codes, the Center needs the licensed professional personnel in place required to do so. These include physicians, nurses, case managers, and social workers. These staff exist at the Center, making the E/M CPT codes the most likely successful CPT codes for reimbursement for needs assessment services, when compared to the risks involved with the H/B CPT codes.

To avoid the potential pitfalls of not being reimbursed for ongoing needs assessment, the Cancer Center has a final option. The information contained within the Eight Cluster Oncology Education and Support Needs Concept Map can be used to develop a questionnaire or interview. According to Kane and Trochim (2007):

> The statements within clusters can be considered 'draft items' for an instrument. The researcher may then construct a short paper-and-pencil or electronic instrument to ask respondents to rate each statement relative to its desirability for some potential activity or program component, or to rate the degree to which each issue or problem is salient to them. (p. 138)

Rating information pertaining to desirability for potential program activity or content has already been collected and will prove useful. However, each patient has varying needs throughout their cancer experience making the latter rating (degree of saliency of issue or problem), very important. With this information case managers can immediately link and refer the patients and their families to the services they identified as important. Program developers can also access the aggregate information from instruments completed at the Center over a period of time to get a better understanding of the trends of patient needs, before developing collocated programming.

Barriers to Program Development

As discussed in the Introduction, the four categories of barriers to health-behavior program development put forth by Petosa (2001) are organizational factors, community factors, practitioner factors, and research factors. The researcher encountered several barriers to program development throughout the process of this needs assessment study, in each of these categories.

Organizational factors. The initial approval and planning stages of this study required successful navigation within two organizations; Glens Falls Hospital and Antioch University New England. Each of these organizations has their own goals and values and resources for achieving them (Petosa, 2001). While attending to the Institutional Review Board requirements of each organization, it became clear that the values and goals for each of these organizations were different. Both organizations shared concern for protection of the safety and rights of each participant. However, Glens Falls Hospital had required guidelines for the format of the Informed Consent, which delayed the process of gaining approval from both organizations.

In addition to the delay, the Hospital’s required language on the Informed Consent turned a handful of patients away from this study. The patients were concerned that the Food and Drug Administration (FDA) would access their medical records, as the Hospital’s Informed Consent required this clause. After explaining this dilemma to members of the Hospital’s research committee, there was no reconciliation, it is just simply hospital policy that all Informed Consents have to include the permission clause allowing the FDA to access participants’ health information, regardless of the impact it has on participant recruitment. This barrier directly impacted the sample size of this study.

This experienced barrier is similar to the one described by Petosa as a “disruption of established decision-making processes” (Petosa, 2001, p. 56). It is understandable the hospital has a process for organizing and implementing research and has regulatory agencies they need to answer to. While I understand organizations can have policies and protocols with flexibility, it was apparent these organizational constraints were static, regardless of the implications for evidence-based research. As a result, this researcher felt thrust into the decision-making process in a way that disrupted the natural and accepted flow of an already existing process (Petosa, 2001).

In addition to barriers in the IRB process, the advertising requested did not come to fruition. A public service announcement (PSA) was developed to play on local radio stations with the goal of recruiting participants. The proper procedures were followed for gaining approval of this PSA. However, approval was never obtained from the Hospital. It is understood this request likely did not receive the staff focus and time required for approval due to the primary purpose of the Hospital, to treat patients. Radio advertisements regarding this study are understandably secondary when compared to this primary purpose (Petosa, 2001). While the researcher understands the importance of the primary purpose over the secondary purpose, this experience is recognized as a barrier because it also inhibited the potential sample size for this study.

Community factors. Petosa (2001) defines a community as “a collection of people identified by mutually held concerns for the development and well-being of their group (e.g. neighborhood, a geographic region, or a collection of people who share a common identity)” (p.

57). The groups Petosa was referring to include citizens, special interest groups, and the target population. He also indicated that members of these communities ultimately have to impose limits on the time, money, and other resources they channel to programs or program development.

The researcher reached out to several citizen and special interest groups for financial support and for help recruiting participants for this study. A few community groups responded and were able to assist with finances and some participant recruitment. However, many of the community groups did not respond to the researcher's request at all. These experiences were barriers for this study because they inhibited the potential sample size by limiting the participant pool and limiting the amount of incentive available to pay each participant.

Another community factor barrier presented itself at the beginning of the data collection phase. Originally, a series of focus groups and follow up activity meetings were going to be conducted as the method for data collection. These focus groups did begin, but required a lot of time for participants to attend. After having several unsuccessful attempts, this method was scrapped and replaced by Internet data collection. This method was more convenient for both the patient and professional stakeholder groups, but increased the cost of the study significantly, as there is an increase in the project license fee when you switch from the faceto-face method to the Internet method.

A final community factor barrier presented itself at the time of data analysis. In the original plan for this study the researcher proposed to recruit a group of stakeholders from the participant sample to participate on an advisory board. The advisory board would then assist the researcher with various aspects of data analysis. Of the 30 participants who were asked to participate on the advisory board only 10 responded. All 10 participants who responded could not participate due to personal or professional responsibilities and constraints. These experiences are considered barriers because they impacted the cost of the research, and potentially impacted the idea synthesis process that is highly valued in the concept mapping process (Kane & Trcohim, 2007).

Practitioner factors. According to Petosa (2001) practitioner factors exist within groups of associated program service providers. In this study, the practitioners were members of the professional stakeholder group. The researcher experienced a few barriers when working with this group in the form of resistance, as evidenced by practitioners not completing the tasks required for the study. In addition, several practitioners did not follow the directions given to them for the rating procedure and did not use the full range of the scales. In fact, there were a few practitioners who rated all statements with a single number on all levels (importance, utilization, satisfaction). These experiences are considered barriers because they resulted in several participant datasets that needed purging before final data analysis, thus reducing the sample size of the study.

Researcher factors. Within the researcher factor domain, Petosa (2001) put forward that a researcher's limited exposure to practitioners and target populations can often develop into a barrier for program development. Such a barrier is often evidenced by a dampening of "researchers' willingness to commit the time necessary for extended collaboration in the context of a team of health professionals" (Petosa, 2001, p. 60). I identify this was an ongoing factor throughout this study, as I often was unsure of what I could do to facilitate more collaboration within the hospital and community. I recognize this was in part due to my lack of experience in conducting research in a clinical setting with medical patients and practitioners. I was also unable to commit more time than the hours I allotted per week to complete this study.

An additional researcher factor that was obvious in this study refers to Petosa's (2001) idea that barriers develop when researchers focus their energies on summative evaluations. I experienced this early in the study when a need to change the method of data collection from face-to-face and more structured, to Internet based with less-structure, was imminent. This was a challenging experience for me because switching gears to make the study more convenient and feasible for participants could potentially sacrifice the more rigorous face-to-face method of data collection, thus compromising the research and my rather young reputation as a researcher. Petosa identifies these as common concerns for researchers.

Recommendations for Overcoming Barriers

The barriers in the organizational domain were a challenge because they directly impacted the planned schedule and samples size of the study, in addition to the generalizability of results. The barriers in the community domain also negatively impacted the sample size in addition to the data collection and analyses processes, also posing a threat to the generalizability of results. The barriers in the practitioner domain impacted the quality of the data collected in this study resulting in the purging of this data and a decrease in sample size. The barriers in the researcher domain impacted the researcher's ability to develop more collaboration with the participants. In addition, the researcher was hesitant to choose participant convenience over a more rigorous methodology when the time came to switch the method of data collection from face-to-face to Internet-based.

The researcher reviewed the literature in search of ways to overcome organizational, community, practitioner, and researcher factors that inhibit program development. While no universally accepted guidelines are evident, Petosa (2001) has noteworthy recommendations resulting from *diffusion of innovations* research by Rogers (1983) and program development research by Goodman and Steckler (1989). Petosa put forward several characteristics of innovations that tend to have a stronger influence on whether or not the innovation (in this case program development research) will be adopted and supported. Those characteristics include relative advantage, compatibility, complexity, trialability, observability, and program champions.

Petosa (2001) indicated “relative advantage is the degree to which an innovation is perceived as better than current approaches” (p. 62). Therefore, it should be the goal of future program developers at the C.R. Wood Cancer Center to facilitate the organization, practitioners, and community to acknowledge the relative advantage of empirically-based program development over the currently accepted methods. This can be achieved by educating stakeholders about the methods and overall advantages of empirical program development.

Compatibility “is the degree to which an innovation is perceived as being consistent with existing values, past experiences, and needs of potential adopters” (Petosa, 2001, p. 63). Compatibility does not come easy, as program development endeavors are met with significant levels of anxiety within the organization and among practitioners. This is because they associate evaluation and development activities with their program or service being examined too closely. To overcome these barriers at the Center, it is important for future program developers to engage in a shared decision making process regarding the purpose of the research and the methods to be used. The goal would be for practitioners and administrators to feel empowered in the process and want to meaningfully participate.

Petosa (2001) described complexity as “the degree to which the innovation is perceived as difficult to understand and use” (p. 64). Therefore, the goal for future program developers should be to facilitate change in the organization’s and practitioners’ perceptions that the research methods may be intrusive to their practice or judgmental of their measured abilities. In addition to this, Petosa indicated it is significantly important that “clear limits need to be set on the uses of evaluation results. The purpose of formative evaluation is to refine and improve programs, not determine careers or pass final judgment on a program” (p. 65). In retrospect, I paid no attention to the potential anxieties this may cause practitioners. I urge future program developers at the Center to be sensitive to this issue by immediately reducing staff fears and increasing their trust through on-going education about the process as it unfolds.

“Trialability is the degree to which an innovation may be implemented on a limited basis” (Petosa, 2001, p. 65). If program developers get to the point of piloting actual program components, it is important for them to take small, well-planned steps. In doing so, they will increase the likelihood of organizational, practitioner, and community buy-in. In addition, Petosa recommends developers have a “keen sensitivity as to how empirical program development can be conducted without disrupting day-to-day operations of health agencies” (p. 65). This sensitivity will be important for developing programs at the Center, it is a busy place, and the practitioners are whole-heartedly focused on patient care.

Petosa (2001) indicated that “observability is the degree to which the results of the innovation are visible to others” (p. 66). The responsibility of maintaining observable results falls on the program developer and administration. The program developers at the Center will have to disseminate findings regularly to all stakeholders. The Center’s administrators will need to commit to recognizing the efficacy of the methods being used and to support program development efforts by declaring them “as quality product-building processes” (Petosa, 2001, p. 66).

Finally, program champions are paramount “in establishing and institutionalizing programs within an agency. These individuals possess credibility and can influence the decision making of both superiors and subordinates in an organization" (Petosa, 2001, p. 66). I was fortunate to have a supportive and effective program champion in this study. Without his involvement in coalition building within and outside the Center, this research would have likely stagnated. It will be important for future program developers at the Center to recruit a program champion that is "a key member…. [who is] adequately trained to support the proposed innovation knowledgeably and enthusiastically" (Petosa, 2001, p. 66), as mine was.

Recommended Next Steps for Program Development

By examining the content of the identified needs in this study and the priorities for program development in Table 6; program developers can seek out services in the community and or create interventions to integrate with current services that address these specific needs. Ideally, program developers should develop interventions and programs that address the emergent needs more directly or develop community partnerships that would facilitate them to do so. Either way, individual patients' and families' needs must be precisely and continuously assessed so the appropriate referral or linkage to services can be made. This exemplifies the importance of effective case management services.

The IOM (2008) indicated an effective model for referral services that includes "structured referral arrangements and formal agreements with external providers, case management, and collocation and clinical integration of services" (p. 190). The IOM (2008) also emphasizes the significance of ongoing accurate needs assessment of individual patients' needs in the earliest phases of the patient–provider relationship and throughout their cancer care experience. The results of this study lead me to concur.

A significant barrier to ongoing needs assessment identified by the Center and the IOM is the lack of insurance reimbursement for this activity. The Center can potentially overcome the barrier of getting reimbursed for the assessment by utilizing the H/B CPT codes, which pose some risk for reimbursement, or the E/M CPT codes which pose less risk for reimbursement. Either way, reimbursement for ongoing needs assessment services will ensure more effective program development in the future, as it will allow program developers to understand the needs of patients before acting on professional or clinical intuition, which appears to be misaligned with the realities of the patients' needs in this particular study.

A final consideration for continued needs assessment would be for the Center to take the data provided in Table 6 and develop a self-report inventory that patients can fill out in their initial visit and on follow-up visits to the Center. Table 6 contains the individual statements and clusters the patient stakeholders identified as actionable areas for program development. Ongoing patient needs assessment for this special population may solidify these actionable areas, which in turn should create the impetus for program development.

If the momentum for program development evolves and stakeholder cooperation is achieved, there are several key steps recommended by Sussman and Wills (2001) to continue the process via an empirically-based method. As discussed in the Literature Review, Sussman and Wills propose a six-step program development chain model. The first step, which has been completed in this research, is needs assessment. The remaining five steps are *systematic pooling and warehousing*, *systemization of perceived efficacy studies*, *systemization of immediate-impact studies*, *systemization of program construction and pilot testing*, and *refinement*. Next, these steps and how program developers can apply them to the results of this research are summarized.

Systematic pooling and warehousing. This step is comprised of searching for promising, empirically-based activities or interventions to consider for inclusion in the program. It involves locating and surveying resources and systematically pooling and warehousing information pertaining to the subject(s) under study (Sussman & Wills, 2001). This process is an important step for program development because “collecting and analyzing information about other interventions related to the program you are developing enables you to benefit from the critical thinking and creativity that others have invested in planned efforts to improve health status” (D'Onofrio, 2001, p. 159).

In addition, taking this step in program development significantly contributes to the process in six more significant ways. First, it strengthens the rationale of the program to be developed. Second, it facilitates the development of a detailed intervention plan. Third, it facilitates the identification of programmatic issues that may need to be addressed before implementing the proposed programming effectively. Fourth, engaging in this step gives the researcher and stakeholders the opportunity to estimate the time and resources needed for program development. Fifth, it cultivates and builds support for the program. Sixth, by engaging in the systematic pooling and warehousing step, the planning of a meaningful evaluation is initiated (D’Onofrio, 2001).

D’Onofrio (2001) recommends an extensive list of clear strategies for systematically pooling and warehousing activities and interventions. This researcher recommends program developers utilize these strategies to search for interventions that focus on case management, in addition to those that address the individual items in Table 6. The strategies include the following:

1. Researching reports of specific interventions regarding the population studied
2. Reading overviews of existing programs at other cancer centers
3. Searching for and utilizing meta-analyses of applicable psychosocial oncology programs and program components

4. Reading critical reviews of current psychosocial interventions and activities in use
5. Reviewing articles about cancer case management the program will address
6. Reading books from the psychosocial oncology field
7. Reviewing technical reports
8. Reviewing papers from conferences and professional meetings,
9. Reviewing government and association guidelines and recommendations, such as the National Institutes of Health and the IOM
10. Reviewing resource books and program manuals
11. Searching clearing houses and resource centers
12. Contacting grant funding agencies

These strategies can be implemented by way of the World Wide Web and or direct contact with program developers or organization staff dedicated to public relations and information (D’Onofrio, 2001).

Systemization of perceived efficacy studies. According to (Nezami, Davison, & Hoffman, 2001) “perceived efficacy studies involve a shorthand presentation of components or ideas regarding a potential program that is provided (e.g., a one paragraph description of program activities is read to subjects), which quickly describes or summarizes program components’ contents” (p. 287). This step should involve a program developer and a stakeholder advisory board screening among promising activity and intervention ideas gathered in the pooling and warehousing step, in an effort to narrow down the pool to acceptable, relatively time-and-cost effective program components (Sussman & Wills, 2001). In this process, “subjects generally receive summary information about a program or program activity and make judgments regarding how successful the program or activity is likely to be if it were to be implemented" (Ayala & Elder, 2001, p. 240).

There are several methods of perceived efficacy study that fall within the categories of verbal and non-verbal (Ayala & Elder, 2001; Nezami et al., 2001). The description of each is beyond the depth of this manuscript; however, this researcher prefers the *Delphi technique* (Ayala & Elder, 2001). This is a verbal method used to generate a collection of ideas within a small group through either written or verbal communication. The "qualifications for a traditional Delphi are anonymity, iteration with feedback, and both qualitative and quantitative responses. The technique is most commonly used when it is not convenient or desirable for a group of individuals to come together face-to-face" (Ayala & Elder, 2001, p. 255). Another defining feature of this technique is its ability to assist the participants "to think creatively about a problem and then interact with others via written judgments and suggestions, generally in the form of qualitative and quantitative responses to a questionnaire" (Ayala & Elder, 2001, p. 255).

The rationale of using the Delphi technique exists in its identified advantages. According to Ayala and Elder (2001) some of those advantages include the anonymity in participation, the cost-effectiveness of administration, the guidance of the group toward a final decision, and that there are minimal social pressures on participants to influence responses. In addition, the participants are afforded the opportunity to think creatively. This process puts a premium on the members' perceived influence of the process which achieves a perceived sense of satisfaction for participants (Ayala & Elder, 2001).

These advantages are relevant to this study for several reasons. First, it is important to recognize that the advisory board should be comprised of individuals that represent the patient and professional stakeholder groups. The researcher understands there are power dynamics that exist between patient and practitioner, community and family members, and researchers and all of the above. These power dynamics could potentially serve as a catalyst for socially desirable or biased response sets. The anonymity of this method controls for such dynamics. Cost-effectiveness is also an important factor for choosing this method. By administering an online survey and follow up process, the program developer will not be faced with organizing for a meeting space, paying for refreshments, or paying for incentives to compensate board members for participation. The guiding approach to resolution is another important factor because this approach has been a salient theme throughout this program development process, beginning with needs assessment. It is important to continue this trend, as it results in buy-in and continued participation from the stakeholders (Kane & Trochim, 2007).

Systemization of immediate-impact studies. In this step the workability of individual program components is evaluated. In this process, the researcher and advisory board should evaluate how well or ineffective components are together which will narrow the margin of error in program implementation (Sussman, 2001). Simon, Bosworth, and Unger (2001) suggest *component studies* are a good method of determining immediate impact. Using this research project as a template, let’s assume that all the data have been collected from the perceived efficacy study and ten different interventions were identified as efficacious to address the case management cluster or one of the need areas identified on Table 6. The interventions identified as effective may include hypothetical interventions 1, 2, 4, 6, 9, 13, 16, 18, 25, and 34. These different interventions can be considered, according to Simon et al., as a component to a program. A component study is an investigation of the immediate impact of one or two of these interventions without investigation of a fully functioning program.

The assumption is that by testing these individual components, a program developer can achieve several important goals (Simon et al., 2001). First, those components that represent redundancy in what needs them address can be identified and removed from further consideration. Second, *building blocks* (Simon et al. 2001) can be identified and utilized in the later pilot testing of a complete program (step 5). Building blocks in this example, are evident when "two or more program components may be related to each other sequentially in that Component A is necessary for the effectiveness of Component B….the building-blocks relationship is often found in skills building curricula" (Simon et al., 2001, p. 324). This relationship is sequential, so the sequential design of the larger program is often dependent upon effectively testing program components for complimentary qualities. Using this study as an example, a program developer may find that in order for a spouse to do well in a hands-on training for care-giving (component B), he or she may first need didactic training on how to competently and confidently provide care (component A).

Third, testing individual components facilitates the program developer in identifying those components that are complimentary. In this example, "two or more components present different types of material, and these components enhance the effects of each other. By enhancing each other's effects, they may achieve greater impact than either might when provided alone (i.e., a synergistic effect pattern results)" (Simon et al., 2001, p. 324). Complimentary components are different from building block components in that they do not require the other to be effective. Instead, the effectiveness is enhanced by combining the components in whatever way is complimentary. For example, if it is found that a respite service for child care enhances the ability of the spouse and diagnosed parent to attend psychosocial or education support programming, then child respite care would be a complimentary component to the support services offered to parents.

The fourth benefit of engaging in immediate-impact studies is that they assist developers in selecting the appropriate *constellations* of components. Constellations are made up many program components that address the varying needs of the population under study (Simon et al. 2001). In this study, the needs of patients, caregivers, and children have been assessed. Each of these participant demographics has different needs and different interventions or activities will be identified to address those needs. As the immediate-impact study persists, constellations of program components are identified that address the various needs of the different stakeholders. These constellations become an effective structure and implementation plan as they identify larger potential programmatic sequences and the overall feasibility of program implementation (Simon et al., 2001).

Simon et al. (2001) suggests using one of three methods for immediate-impact studies. Those methods include *substantive component studies, order-base studies,* and *group comparison evaluations.* In a *substantive component study* the various components of the potential program are evaluated for effectiveness by how they compare to each other (if they address the same identified needs) or by how they compare in effectiveness to some standard already in place or external from the components under study (Simon et al., 2001). For example, if two of the potential program components address the need of respite child care, these two components would be tested and compared to one another for effectiveness. Or, if there is an existing respite child care service in place, the two components would be tested and compared to that existing external service.

According to Simon et al. (2001) *order-based studies* involve “testing different sequences of two or more components to determine the most effective building-block sequence. Only small segments of a program are compared” (p. 325) in this process. The participants of these studies are exposed to varied sequences of the same component content and method of delivery with the ultimate goal of purging needless program content (Simon et al., 2001). For example, if the perceived efficacy studies reveal family caregiver education and problem-solving education as two viable interventions for the spouse of a person with cancer; small segments of each of these interventions should then be administered in different sequences to participants. Depending on the outcome, this process will then determine if it is more efficacious to order one before the other when program piloting is implemented.

Finally, in a *group comparison evaluation*, “the immediate impact of the components is compared across different target groups or across different subgroups within a target group to identify components that are relevant and feasible across different audiences, giving health researchers and practitioners a sense of generalizability of program effects” (Simon et al., 2001, p. 326). In our most recent example, the interventions of care giver education and problem-solving education were deemed viable. In this method of evaluation the two components may be tested on the actual parent diagnosed with cancer or the children within the family to determine if their effectiveness is generalizable across these sub-groups.

Systemization of program construction and pilot testing. This step allows program developers the opportunity to consider program content and process sequencing, along with the pragmatics of testing a complete program (Sussman, 2001). Pilot studies involve applying a fully drafted program to a relatively small sample size. There are a number of benefits to engaging in a pilot program test. According to Lynskey and Sussman (2001) those benefits include:

> First the pilot program provides an opportunity to examine and test the eases of implementing the program. Second, such programs give an opportunity to assess the acceptability of the program participants. Third, pilot programs provide a vehicle for the preliminary testing of a program's likely effectiveness. Fourth, in a pilot study, one can manipulate potential mediators of change of the complete program. Finally, and most important, pilot programs provide an empirical basis for making program changes and refinements before large-scale implementation of a program. (p. 391)

Pilot studies utilize several types of research designs. They include *single-group designs*, *experimental designs*, and *quasi-experimental designs* (Kazdin, 2003). The designs used by future program developers will depend greatly upon the resources available to the Center and the aims and time constraints that exist within the larger hospital organization (Lynskey & Sussman, 2001).

Refinement. Refinement involves improving and enhancing the program and its components based on what is learned from the pilot study. It is also a process of analyzing *mediating* and *moderating* variables to be considered for program evaluation. According to Donaldson, Street, Sussman, and Tobler (2001) mediators are variables that are "affected by the program, which in turn affects the outcome of interest. In contrast, a moderator variable affects the direction or strength of the relationships between the program and a mediator or a mediator and an outcome" (p. 471).

Program evaluation measures are developed after a program is piloted and data is collected. From this pilot outcome data, the conceptual framework is refined (Donaldson et al., 2001). This process is repeated until the program developer decides the program is ready for full implementation. This refinement process produces long-term outcome measures to be used for full program evaluation (Donaldson et al., 2001). In future program implementation of discovered interventions the long-term outcome measures will depend on this refinement process as well as review of outcome measures created by the concept mapping process. Such outcome measures may include post-test measures of importance, satisfaction, or utilization of services developed or broader measures such as perception changes within and between groups over time (Kane & Trochim, 2007).

Limitations

A significant limitation of this study is the small sample size. While the results contain some very important and fascinating information, a sample size of 56 is not generalizable to all young families experiencing a parental diagnosis of cancer. A *stratified purposive* method of sampling, as recommended by Kane and Trochim (2007), was originally proposed for this study. Such sampling strengthens the external validity of the study (Kazdin, 2003). However, the participant pool was so sparse it was not possible to stratify the sampling of participants. In addition, the participants were primarily geographically located in Warren, Washington, and Saratoga counties of northeastern New York, which also constrains external validity and the generalizability of results.

The methodology used to decide upon the final cluster solution is another limitation in this study. While this process did rely on the consideration of statistical data in the form of cluster bridging values to make a final determination, it also relied on the judgments of the researcher and project champion. It is possible other researchers would have chosen a different cluster solution, resulting in different findings and recommendations altogether (Florio et. al, 1998).

The exclusion of child and adolescent family members in this study is another limitation. Including this demographic in this study posed quite a challenge as the researcher could not develop or implement a strategy to protect these participants from the adult content contained within the statements generated. Therefore, the statements and clusters pertaining to children's experience of a parental diagnosis of cancer were not generated by children, and instead by adults who do not have first-hand knowledge of their children's experience. This is a significant limitation and if children were included it would change the content of statements, the structure of the map and clusters, and how each cluster was rated.

Finally, this study did not implement "a one-shot concept mapping process" (G. Florio, personal communication, January 10th, 2011). For concept mapping projects, the synergistic qualities of a one-time group format is beneficial in obtaining rich, meaningful data (Kane & Trochim, 2007). According to Florio it is also a less involved process over time which is a more convenient involvement for participants, potentially resulting in a larger sample size.

Future Directions

Based on the limitations discussed above it is imperative a larger sample size is recruited for future research that investigates the education and support needs of this population. Perhaps a more representative sample could be recruited by partnering with a large national cancer organization such as the American Cancer Society or the Lance Armstrong Foundation. It would be advantageous to include child and adolescent family members in the study, as this would contribute to a more valid set of statements describing their experience of parental diagnosis of cancer.

This leads us to the final discussion pertaining to the serendipitous discovery of the central location of the *Family Functioning* super region. This particular region merges with all quadrants of the eight cluster map and therefore illuminates the significance of family adaptation to illness and addressing family support needs in the overall parental cancer experience. In support of this interpretation, Huizinga et al. (2003) found that if a family demonstrated chaotic adaptation at the time of parental cancer it was associated with higher levels of internalizing problems, externalizing problems, and total problems in children of the family, as well as lower family cohesion and overall family functioning.

In addition, the Family Adjustment and Adaptation Response (FAAR) Model (McCubbin & Patterson, 1983) supports the importance of family adaptation in times of significant stress. I briefly elaborate on this model here to demonstrate its' relevance. In the FAAR model, family adaptation to family stress and strain is paramount in overcoming the event and maintaining healthy family functioning. When McCubbin and Patterson (1988) applied the FAAR model to illness within the family they proposed a bidirectional relationship exists between the factors impacting the family's ability to adapt to illness. These factors included community, individual, and family meaning systems and methods for coping, as well as resources available to the family.

By again reviewing the titles and content of each of the eight clusters listed in Appendix C, one can see the similarities between the content and titles of each cluster and the dynamically interacting factors proposed in the FAAR model. In addition, the patient and professional stakeholders similarly rated the two clusters that make up the Family Functioning super dimension, on level of importance. This is important as this super dimension may represent a bridge between less agreed upon dimensions, in other words, a common ground. These interpretations and conclusions could possibly be the beginnings of developing a theory or model that gets to the core of family adaptation issues within this population. Such a discovery would contribute greatly to developing and implementing services that support family adaptation to illness when a young family experiences a parental diagnosis of cancer, thus decreasing the experience of distress for all family members involved.

Researcher Reflection

Lessons Learned

The experience of conducting research in this naturalistic environment brings to mind some common themes best described in metaphor. At first, I set out on a hero’s journey. The evidence of this can be perused in the seventy-five page first-draft dissertation proposal I submitted in January of 2009. In the beginning, I had in my mind a progressive and linear way of overcoming the large but seemingly surmountable problem of assessing and addressing the needs of young families with a parental diagnosis of cancer.

Not far into the project, this hero’s quest changed to a life-story journey; a journey that consisted of one or more people carrying and preserving whatever was valued in the process, and for the future. On this journey the characters supported each others' efforts. They cooperated and the process was more web-like than linear. There was no hero but there was self-sacrifice. This story contained all of the dilemmas, bends, and revelations inevitable in any great story or action research project. It involved a process of growing and thriving with what emerged and with what was discovered. This was certainly my experience.

Not only did my role in research change metaphorically from hero to supporting character, it frequently changed back-and-forth from observer, to reflector, to planner, and implementer. I found this required a lot of time and energy and enabled the research process to be integrated into the everyday lives of the participants. Constantly switching my role was one major way I was able to maintain participant involvement.

I found that the prior existence of well-cultivated relationships between the Center and stakeholders was paramount. These relationships enabled the possibility of prolonged engagement as they allowed a degree of initial trust and continued trust-building. The fairness and trustworthiness of the concept mapping process was also confirmed by participants, which further solidified the relationships and provided a substantial foundation to continue this work.

While fulfilling, this research was also at times daunting. I perfunctorily considered every unveiled barrier to be insurmountable. In retrospect, I understand this experience as normal and customary for a beginning researcher. However, in the moment it seemed like the end of progress and the beginning of a life-long dissertation, and led me to question my capability and skill as a researcher.

The disquiet I often experienced while discussing sensitive and emotionally laden topics with participants was challenging. In many ways, I was entering the secret lives of others and for some it was during a time of significant crisis. In my clinical training I have had plenty of interactions like these. However, these interactions in the context of research are much different. There was the risk of role conflict. I worried about the emotional health of the participants and felt helpless for not being able to “check-in” with them as I do frequently with psychotherapy clients. In many ways I feared these interactions would result in me becoming known as a provocateur, rather than a caring and empathic helping professional. I relied on a fundamental clinical skill to get me and the participants through; to talk sensitively about sensitive topics. Since completing the research I am satisfied to say it was worth the risks involved. I think the results will beneficial for the stakeholders, and I think I am a better equipped researcher and practitioner because of my experiences.

This naturalistic research experience was indeed a privilege. It was a privilege to be entrusted with the stories that many of the participants would not share with their closest family member or confidant. It was a privilege to bear witness to and document their suffering and transcendence as their stories evolved into hopeful solutions. Embedded within this privilege is a felt a sense of responsibility to do something with what I have learned.

A Personal Account

I was six-years-old when my uncle became very sick and eventually died from cancer, I can barely remember. I do remember my mother talking about the impact the illness, and eventual death, had on her nieces and nephews (my cousins). I remembered her telling me and my siblings how sad and alone our cousins were. To me their pain felt so far away yet, at the same time so close to home. I barely new them, yet their experience unleashed my own selfish fears. I remember being most concerned with my own life and if my mother was at risk of dying from cancer. Did this mean I would be sad and lonely too?

When I was about 20 years old the cancer experience hit closer to home. One of my older siblings was diagnosed with melanoma, then soon after, thyroid cancer. This sibling had an elementary-school-aged daughter, my niece. I remember being immobilized with fear, thinking back to how scared I was of losing my mother when I was 6, to this disease. My fear and preoccupation with my own mortality inhibited me from supporting my sibling and her daughter in the way I now know to be important. I could not bring myself to call her or to be there for her during treatment. I could not offer my help with child care or household chores. All I could do was worry, and worry I did. We were one of those “pre-existing issues families.”

A few years went by and more cancer showed up. By this time, my sister had undergone multiple chemotherapy and radiation treatments and was oppressed by a life of one medical appointment and treatment after another. She was oppressed by the realities she would not be able to continue to work and provide for her daughter, as she was a single-working-mother at the time. I was amazed at her ability to remain strong. Unfortunately all of us, her whole family, wanted her to be strong; we needed her to be strong. We wanted this to be a breeze for her, after all, that would make it a breeze for us. While she struggled with her experience, she gave us what we wanted.

In 2004, the day I took the graduate record exam subject (GRE) test in psychology and one year before applying to graduate school in clinical psychology, my sister was in for another cancer-related major surgery. She had a tumor on one of the major structures of her heart. By this time I had not yet learned how to be effective in my role as her brother, to support her and my niece through this major life threatening operation. In spite of my own fears, I was able to be with her in the hospital the night before surgery, in the hotel with her daughter and my brother-in-law, and back at the hospital during her recovery that morning. I realized in these moments how important it was to support her, my niece, and brother-in-law. I didn’t have to save her or change her circumstance. I just had to be there, to acknowledge the difficulties of her experience, and to support those who needed it.

My sister was strong, and remains strong today. I evidently made it through the GRE subject test later that day, although I don’t remember much more about that day than holding my sister’s hand in recovery. I also remember the night before, in the hotel. While eating Chinese food with my niece and brother-in-law, I was able to comfort them and offer them my strength. They needed it. Their hearts and souls were tired from the experiences they had with this illness up until this point. It was hard for them to be hopeful and I am certain I was able to give them a little more.

Without a shadow of a doubt, this personal experience and my training experiences at the CR Wood Cancer Center motivated this research. As I went through the process of proposing the topic it felt as though I was fulfilling a duty that had gone unfulfilled my whole life. It was a calling that was answered this time, rather than being chased or stuffed away by my own consternation. In many ways, this dissertation is me finally taking care of my sister and her family in their time of most need. It was this understanding that kept me motivated throughout the process, which at times was as ambiguous as the stretches of time when we were not sure if my sister was going to make it through her latest recurrence of cancer. I hope with my heart and soul that something within the pages of this manuscript can create a positive shift in experience for young families living with a parental diagnosis of cancer, even if that shift is in the ability for an immobilized family member to be there, offer some hope, and acknowledge the difficulties of the experience.

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Appendix A – Informed Consent

INFORMED CONSENT FORM

Project Title: [C.A.R.E.S.] Cancer Resources Education and Support: an Investigation into the Needs and Effective Interventions for Young Families Living with and Beyond a Parental Diagnosis of Cancer

Principle Investigator: Richard Durant, MS
Doctoral Candidate
Department of Clinical Psychology
Antioch University- New England
40 Avon Street, Keene, NH 03431

Telephone: (518) 926-6596
E-mail: rpdurant@roadrunner.com

Thank you for volunteering to participate in this research project. This project is attempting to further understand the needs of young families living with and beyond a parental diagnosis of cancer. The results of the needs assessment process will inform empirically supported program development which will include identification and eventual implementation of services for this patient population and their families. This study involves 2 separate two hour meetings for the group of participants you have been assigned to. During the group meetings you will be asked to respond to a few prompt / questions that are designed for you and your group to com with answers to the few questions asked. You will have ample time to answer these questions and there is no right or wrong answer. We are interested in learning about how you perceive the answer to the questions to be. Some of you will be asked to participate in this study on a sustained term to last 2 – 3 months. If randomly selected, you will have the opportunity to participate as an advisory board member which will give you the opportunity to represent the group you belong to. You will be given more information about the time, effort, and specifics involved with this additional opportunity if you are selected. Your signature on this consent form shows that you have been informed about the conditions, risks, and safeguards of this project. If you are signing for a minor, please be sure that both the minor and parent sign this form.

1. Your participation is voluntary. You can withdraw from this study at any time, for any reason, without penalty. The researcher also has the right to ask you to leave the study at anytime without your consent.

2. There may be some unforeseen risk for some people with cancer or their families to talk about their experience of a cancer diagnosis and subsequent treatment. If it seems like there may be some risk for you at the time of reviewing this consent form, you should probably not participate. In the event that you participate and harmful emotions are evoked in this study, qualified mental health service providers will be made available to assist you with your difficulties on a referral basis.
3. Complete confidentiality is ensured. Your name will not be used. You will be given a coded identifier instead of your name to ensure confidentiality and anonymity. The typed

transcript of the interview, tape recordings, and other media will show this code identifier rather than your name. Your comments will be entered on a computer. Any identifying information will be changed for any written reports. All identifying information and data will be locked in a combination-safe filing cabinet. Only the primary investigator will have access to the information.

4. Questions about risk to you because of participation in this study or your rights as a participant may be addressed to the researcher at the phone number or e-mail listed at the top of this page or to George Tremblay, Director of Research, Department of Clinical Psychology, Antioch University- New England, 40 Avon Street, Keene, NH 03431, (603) 357-3122, george_tremblay@antiochne.edu.

We believe that your participation in this study will help us understand two very important things: 1) You will be helping the CR Wood Cancer Center staff better understand the needs of young families living with and beyond a parental diagnosis of cancer. 2) The information you provide will guide researchers to investigate potentially effective interventions or program components that can be put into action to directly meet the needs of the population under study. Ultimately this knowledge will also allow the researcher to demonstrate the effectiveness of empirically based program development in the context of family and chronic illness. If you would like any additional information.

Appendix B

Table B1

Statement List

1	Ill parents may alienate themselves from their family.
2	Families need to be directed to resources.
3	Parents need to maintain boundaries with (not parentify) their kids even in times of extreme stress or grief.
4	Parents have to be aware of what they say to each other when the kids are around.
5	Age appropriate information needs to be shared with the kids at all times to keep them in the loop.
6	The family needs to be made aware of programs and services available to the children.
7	Need for spousal/partner individual or group support.
8	Lack of knowledge about services available for the patient.
9	Overwhelming concern with how kids are handling the diagnosis
10	There is not enough support for the husbands/fathers of the women with the diagnosis.
11	Families need to keep the lines of communication open.
12	Couples need couple's therapy throughout the illness experience.
13	Internet support groups for teenagers to share their feelings and concerns are needed.
14	Teenage caregivers burn-out with too many responsibilities.
15	Family members need to be a part of planning for the future, regarding the patient's personal health choices.
16	College aged children worry about leaving for school not knowing what the future holds for their ill parent.
17	Teenagers need someone to turn to for help with coping healthfully.
18	The parent diagnosed needs guidance for telling the spouse and children about their diagnoses.
19	Some parents shield children from diagnosis making it hard for child to understand.
20	Children unable to articulate what they feel so they act out.
21	The ill parent worries about their children more than they do themselves.
22	The ill parent may feel alone because the spouse cannot go to appointments due to home and work responsibilities.
23	Need assistance with childcare.
24	Families who are experiencing a parent diagnosis of cancer need family psychotherapy.
25	Ill parent has to comfort spouse and children because of their difficulties in accepting the illness.
26	Ill parent feels heartbreak when having to leave their young children.
27	Friends don't always react to your cancer diagnosis in a way you expected.
28	Your spouse has difficulty being "there for you", as they are dealing with your cancer diagnosis as well.
29	Learning how to effectively educate our children on the diagnosis and treatment of cancer without filling them with fear.

table continues

	Statement List
30	Need for a mentor who can work with patient during and after treatment
31	Emotional impact on children
32	Older sibling feels they have to take care of younger siblings because the parent is ill.
33	Parents have difficulty admitting they need help.
34	Families can start to isolate themselves from other families who are not dealing with cancer
35	Children miss their family life before cancer
36	Children will act out their anger with other caregivers and appear to be ill behaved children
37	Some children would fear talking about their parent's cancer diagnosis to their peers
38	Families are faced with so much information overload that they have a hard time understanding what is right for their family
39	Pre-existing family issues become exacerbated with the stress of cancer, making family life more difficult.
40	Parents need to grieve the "normal" family life they thought they'd have, and often don't have the time or space to do so.
41	Kids may need or want an opportunity to talk with their parent's doctor or member of the health care team.
42	All family members (including ill parent) have problems adjusting to ill parent's body image changes.
43	Uninsured and underserved "fall through the tracks" and may not seek treatment or help.
44	Parents worry about ability to get or keep health insurance for their family in the future.
45	Parents are uncertain of how much health status information to give to their employers.
46	Kids may have increased absences from school.
47	Kids experience role changes and are often expected to do more than they are capable of doing.
48	Parents have a hard time knowing how to deal with everyone giving them their advice and opinion.
49	Family members often experience anger and don't know how to deal with that.
50	Patient and family need education about illness and treatment.
51	Kids lack peer support.
52	Parents / partners rarely have peer support.
53	Parents can have many overwhelming emotions that impact their ability to be involved with their children.
54	Parents and families have little or no experience with the health care system, which can make this very difficult for them.
55	Parents are afraid to tell kids about negative prognosis or dying.
56	Family members are afraid parent / patient will die.
57	Spouses / partners who feel they have to protect each other from their own distress are isolated and distant from each other.
58	Parents may have difficulty in understanding what they can & cannot do with their kids after treatment.
59	Difficulties adjusting family priorities.
60	Hard for families to coordinate all the family, school, treatment, and supportive activities and resources.

table continues

Statement List

61 Kids need opportunities to connect and communicate with peers who are having similar experiences.
62 Kids are not sure who they can talk to.
63 Families need follow-up after an initial supportive contact because their needs and readiness change frequently.
64 Families can be reluctant or find it difficult to ask for help.
65 If non-custodial parent is ill, it can increase isolation for parents and kids.
66 Normal play group for kids.
67 An emergency financial fund or account.
68 Someone for kids to talk to outside of family.
69 Personal patient liaison who understands the diagnosis and treatment, as well as the realities of parenting.
70 Help with household management
71 Financial advocate to help family manage finances.
72 Families need organized extended family support.
73 Respite is needed for care giving parent / partner.
74 Family could use patient navigator to help them understand and make sense of all different sources of information.
75 Parent & family support group to talk with and learn from others.
76 Parents need information about how to help their kids emotionally.
77 Families need support in adapting / coping when fertility cannot be preserved.
78 Not enough utilization of technology to help connect kids.
79 Kids sometimes feel guilty when they enjoy themselves or do normal things.
80 Loss of contact with treatment team after treatment is done is a "social loss".
81 Family members don't always know how to talk about the situation.
82 After treatment the parent's relationship and relationship needs change so they don't always have their social needs met.
83 Working well parent may need help learning about and accessing benefits, FMLA, and legal rights.
84 Parents may have to give up parental rights or plan for custody after death, due to their illness.
85 Kids worry they will get cancer.
86 Parents worry they can pass along potential cancer genes to kids.
87 Illness disrupts normal sex life of the parent-partner couple.
88 Parents are concerned about fertility and reproductive issues.
89 Difficult for parents to enforce limits or discipline kids when they know kids are upset or when the parents have little energy.
90 Parents have difficulty letting go of control of how things are done in their home and family.
91 Parents need permission to be sick.

table continues

Statement List

92 Young families typically may have not made plans for illness or death, so no plans are in place.
93 Need assistance with daily meals and meal preparation.
94 Parent's may not always know how to experience their own fear and anxiety without worrying their kids.
95 Families don't always know what financial assistance is available or how to access it.
96 Help with making home handicap accessible.
97 Patient-parents need access to medical equipment when doing things with family.
98 Families are busy & need support delivered in places that are convenient and comfortable for them, such as home or school.
99 Kids don't understand how to express needs and concerns about how the family will move forward.
100 Difficult for parents to know how to prepare themselves and their kids about what to expect from treatment.
101 Kids can assume responsibility for cause of parent's illness.
102 Family norms, rules, values, may not allow children to express themselves.
103 Child care assistance during treatment, when coming into clinic and at home after treatment recovering.
104 Transportation assistance for the multiple family household needs
105 Financial assistance to help family keep up with normal activities and secure necessary things like school supplies.
106 Kids experience emotions that can be tough to deal with.
107 Treatment and illness disrupts normal routines and activities of kids and families.
108 Parenting support and assistance when patient is a single parent.
109 Parents may feel guilty for the disruption in their family's life.
110 Parents don't always know to help children preserve memories of ill parent when diagnosis is terminal.
111 Ill parents struggle with how to stay active in kid's lives when they are tired and weakened by illness and treatment.
112 Cognitive effects of treatment (chemo-brain) interferes with managing busy household and family.
113 Traveling to far places for treatment or consultations causes many child care problems for parents.
114 Illness needs can detract from attention kids should get for their normal developmental emotional needs.
115 Kids may not know how to access help or how to ask for it.
116 Kids can have academic problems when parents are sick.
117 Having an ill parent makes kids feel alone or isolated.
118 Young parents have few peers who have had to deal with like concerns and can feel isolated.
119 Parents want to know how kids feel, but it can be hard for them to actually hear about how their illness is impacting them.
120 Families need coordinator to help manage all concerns, appointments, and demands.
121 Kids can feel like everyone is keeping secrets from them or lying to them.
122 Logistical realities of treatment disrupts care and schedule of children.

table continues

	Statement List
123	Children have a hard time understanding a very complex and scary illness.
124	Illness can change or jeopardize the parents' job status.
125	Adolescents conceal their thoughts, fears, and feelings to protect the parent and not cause tension in the relationship.

Table B2

Pilot Study Statement List

1	**Need to know how to tell young kids about illness.**
2	Immediately need someone to sit and talk after diagnoses.
3	Need information on second opinions?
4	**Planning for the future of my kids.**
5	**The emotional well being of my children**
6	Dr. engagement concerning diagnosis & treatment plan.
7	**Need help teaching kids how to talk about illness.**
8	**Kids need an opportunity to connect with other young people.**
9	**Need information about legitimate web sites regarding illness.**
10	**Need to know what to do when you have no insurance.**
11	**Need for emotional support for spouse, adult care givers, or non diagnosed parent.**
12	**Need a survivor / mentor for support & education**
13	**Need a caregiver mentor / buddy who has had a spouse or partner diagnosed with cancer.**
14	**Need help dealing with parenting issues.**
15	Have difficulty knowing what to expect.
15	Have difficulty knowing what to expect.
16	Need to know when parents can call the treatment team after hours, if he or she is not well
17	**Need childcare during and after treatment days.**
18	**Need transportation to and from treatment**
19	Help with learning ways to explain pain to kids
20	**Help with navigating insurance**
21	**Need professional mental health / emotional support**
22	**Help with concerns about obtaining insurance in the future**
23	Need nutrition counseling going through treatment
24	**Need financial assistance because parents are often out of work during treatment**
25	**Need assistance with permanency planning**

Note. Bold type indicates a statement that is a close match to a statement generated in this study.

table continues

Table B2

Pilot Study Statement List

26	Help with learning relaxation techniques
27	Need information concerning alternative complimentary therapies
28	**Need help with infertility, foster planning, adopting issues due to treatment**
29	**Assistance with keeping children's lives as normal as possible**
30	**Help for well parent to learn how to support & comfort kids when the ill spouse is in treatment**
31	Activity resources available to kids during parent treatment
32	Information for ill parent on what exercises are safe / appropriate
33	**Learning to deal with lifestyle changes**
34	**Learning how to cope with limitations**
35	Learning how to maintain a germ-free environment
36	Need for kindness and compassion from Cancer Center staff during treatment
37	Help with coping when treatment becomes chronic
38	**Post-treatment education**
39	**Help with adjusting to "new normal"**
40	Education on long-term side effects of treatment
41	**Ongoing emotional support from other survivors**
42	**Help with fears of reoccurrence**
43	**Managing household demands with physical limitations**
44	Good information concerning post-treatment care plans
45	**Managing anxiety during post-treatment scans**
46	**Help with missing security of treatment team / treatment routine**
47	**Help with getting back to work**
48	**Dealing with people who provide too many limitations after treatment**

Note. Bold type indicates a statement that is a close match to a statement generated in this study.

Appendix C – Eight Clusters with Names and Bridging Values

Cluster 1: Emotional Impact on Parents

#	Statement	Value
94	Parent's may not always know how to experience their own fear & anxiety without worrying their kids.	.28
109	Parents may feel guilty for the disruption in their family's life.	.28
90	Parents have difficulty letting go of control of how things are done in their home and family.	.31
33	Parents have difficulty admitting they need help.	.31
48	Parents have a hard time knowing how to deal with everyone giving them their advice and opinion.	.31
110	Parents don't always know to help children preserve memories of ill parent when diagnosis is terminal.	.32
53	Parents can have many overwhelming emotions impacting ability to be involved with their children.	.34
40	Parents need to grieve "normal" family life they thought they'd have, & often don't have the time or space to do so.	.37
25	Ill parent has to comfort spouse and children because of their difficulties in accepting the illness.	.40
21	The ill parent worries about their children more than they do themselves.	.43
26	Ill parent feels heartbreak when having to leave their young children.	.43
118	Young parents have few peers who have had to deal with like concerns and can feel isolated.	.44
111	Ill parents struggle with how to stay active in kid's lives when they are tired & weakened by illness & treatment.	.47
65	If non-custodial parent is ill, it can increase isolation for parents and kids.	.47
42	All family members (including ill parent) have problems adjusting to ill parent's body image changes.	.48
91	Parents need permission to be sick.	.48
1	Ill parents may alienate themselves from their family.	.49
52	Parents / partners rarely have peer support.	.53
27	Friends don't always react to your cancer diagnosis in a way you expected.	.54
82	After treatment the parent's relationship & needs change so they don't always have their social needs met.	.59
86	Parents worry they can pass along potential cancer genes to kids.	.68
28	Your spouse has difficulty being "there for you", as they are dealing with your cancer diagnosis as well.	.68
34	Families can start to isolate themselves from other families who are not dealing with cancer	.69
88	Parents are concerned about fertility and reproductive issues.	.72
56	Family members are afraid parent / patient will die.	.72
22	The ill parent may feel alone because the spouse cannot go to appointments due to home & work responsibilities.	.75
57	Parents feel they have to protect each other from their own distress & become isolated & distant from each other.	.75
87	Illness disrupts normal sex life of the parent-partner couple.	.79

Statement Count	*M*	*Mdn*	*SD*	*Range*	*Variance*
28	.50	.47	.16	.28 – .79	.03

table continues

Cluster 2: Parents' Worries About Children

#	Statement	Value
119	Parents want to know how kids feel, but it can be hard for them to actually hear about how their illness is impacting them.	.27
9	Overwhelming concern with how kids are handling the diagnosis	.34
89	It is not easy for parents to enforce limits & to discipline their kids when they know kids are upset or when the parents have little energy.	.34
3	Parents need to maintain boundaries with (not parentify) their kids even in times of extreme stress or grief.	.35
55	Parents are afraid to tell kids about negative prognosis or dying.	.36
19	Some parents shield children from diagnosis making it hard for child to understand.	36
4	Parents have to be aware of what they say to each other when the kids are around.	.43
11	Families need to keep the lines of communication open.	.68

Statement Count	*M*	*Mdn*	*SD*	*Variance*	*Range*
8	.39	.35	.12	.01	.27 – .68

Cluster 3: Family Adaptation to Illness

#	Statement	Value
39	Pre-existing family issues become exacerbated with the stress of cancer, making family life more difficult.	.32
100	Difficult for parents to know how to prepare themselves and their kids about what to expect from treatment.	.33
76	Parents need information about how to help their kids emotionally.	.38
77	Families need support in adapting / coping when fertility cannot be preserved.	.43
18	The parent diagnosed needs guidance for telling the spouse and children about their diagnoses.	.46
15	Family members need to be a part of planning for the future, regarding the patient's personal health choices.	.46
108	Parenting support and assistance when patient is a single parent.	.47
92	Young families typically may have not made plans for illness or death, so no plans are in place.	.55
54	Families have little or no experience with the health care system, which can make this very difficult for them.	.57
58	Parents may have difficulty in understanding what they can and cannot do with their kids after treatment.	.58
10	There is not enough support for the husbands/fathers of the women with the diagnosis.	.60
84	Parents may have to give up parental rights or plan for custody after death, due to their illness.	.64
7	Need for spousal/partner individual or group support.	.67
12	Couples need couple's therapy throughout the illness experience.	.68
45	Parents are uncertain of how much health status information to give to their employers.	.74

table continues

112	Cognitive effects of treatment (chemo-brain) interferes with managing busy household and family.	.78
112	Cognitive effects of treatment (chemo-brain) interferes with managing busy household and family.	.78
80	Loss of contact with treatment team after treatment is done is a "social loss".	.83
124	Illness can change or jeopardize the parents' job status.	1.00

Statement Count	*M*	*Mdn*	*SD*	*Range*	*Variance*
18	.58	.58	.18	.32 – 1.00	.03

Cluster 4: Navigation

#	Statement	Value
70	Help with household management	.32
63	Families need follow-up after an initial supportive contact because their needs and readiness change frequently.	.34
120	Families need coordinator to help manage all concerns, appointments, and demands.	.36
74	Family could use patient navigator to help them understand and make sense of all different sources of information.	.38
38	Families are faced with so much information overload that they don’t know what is right for them.	.39
64	Families can be reluctant or find it difficult to ask for help.	.39
2	Families need to be directed to resources.	.40
103	Child care assistance during treatment, when coming into clinic and at home after treatment recovering.	.42
50	Patient and family need education about illness and treatment.	.43
73	Respite is needed for care giving parent / partner.	.44
98	Families are so busy that they often need support delivered in places that are convenient and comfortable for them.	.47
60	Hard for families to coordinate all the family, school, treatment, and supportive activities and resources.	.49
6	The family needs to be made aware of programs and services available to the children.	.52
72	Families need organized extended family support.	.68

Statement Count	*M*	*Mdn*	*SD*	*Variance*	*Range*
14	.43	.41	.09	.01	.32 – .68

Cluster 5: Case Management

#	Statement	Value
105	Financial assistance to help family keep up with normal activities and secure necessary things like school supplies.	.19
104	Transportation assistance for the multiple family household needs	.19
95	Families don't always know what financial assistance is available or how to access it.	.20
67	An emergency financial fund or account.	.21

table continues

96	Help with making home handicap accessible.	.24
71	Financial advocate to help family manage finances.	.27
43	Uninsured and underserved "fall through the tracks" and may not seek treatment or help.	.33
93	Need assistance with daily meals and meal preparation.	.37
97	Patient-parents need access to medical equipment when doing things with family.	.38
8	Lack of knowledge about services available for the patient.	.38
69	Personal patient liaison who understands the diagnosis and treatment, as well as the realities of parenting.	.39
113	Traveling to far places for treatment or consultations causes many child care problems for parents.	.43
83	Working well parent may need help learning about and accessing benefits, FMLA, and legal rights.	.44
30	Need for a mentor who can work with patient during and after treatment	.45
44	Parents worry about ability to get or keep health insurance for their family in the future.	.68

Statement Count	*M*	*Mdn*	*SD*	*Range*	*Variance*
15	.34	.37	.13	.19 – .68	.02

Cluster 6: Emotional Impact on Children

#	Statement	Value
79	Kids sometimes feel guilty when they enjoy themselves or do normal things.	.00
106	Kids experience emotions that can be tough to deal with.	.02
20	Children unable to articulate what they feel so they act out.	.03
116	Kids can have academic problems when parents are sick.	.05
37	Some children would fear talking about their parent's cancer diagnosis to their peers	.05
99	Kids don't understand how to express needs and concerns about how the family will move forward.	.06
36	Children will act out their anger with other caregivers and appear to be ill behaved children	.06
85	Kids worry they will get cancer.	.06
121	Kids can feel like everyone is keeping secrets from them or lying to them.	.06
31	Emotional impact on children	.07
35	Children miss their family life before cancer	.07
117	Having an ill parent makes kids feel alone or isolated.	.11
101	Kids can assume responsibility for cause of parent's illness.	.12
123	Children have a hard time understanding a very complex and scary illness.	.13
114	Illness needs can detract from attention kids should get for their normal developmental emotional needs.	.13
46	Kids may have increased absences from school.	.14

table continues

47	Kids experience role changes and are often expected to do more than they are capable of doing.	.15
32	Older sibling feels they have to take care of younger siblings because the parent is ill.	.24
102	Family norms, rules, values, may not allow children to express themselves.	.28
16	College aged children worry about leaving for school not knowing what the future holds for their ill parent.	.29
14	Teenage caregivers burn-out with too many responsibilities.	.32
5	Age appropriate information needs to be shared with the kids at all times to keep them in the loop.	.35
125	Adolescents may conceal their thoughts, fears, & feelings to protect parents and not cause tension in the relationship.	.35

Statement Count	*M*	*Mdn*	*SD*	*Variance*	*Range*
23	.14	.11	.11	.01	.00 – .35

Cluster 7: Kids' Support Needs

#	Statement	Value
51	Kids lack peer support.	.22
61	Kids need opportunities to connect and communicate with peers who are having similar experiences.	.26
62	Kids are not sure who they can talk to.	.30
41	Kids may need or want an opportunity to talk with their parent's doctor or member of the health care team.	.33
17	Teenagers need someone to turn to for help with coping healthfully.	.41
68	Someone for kids to talk to outside of family.	.45
115	Kids may not know how to access help or how to ask for it.	.50
66	Normal play group for kids.	.62
13	Internet support groups for teenagers to share their feelings and concerns without judgment are needed.	.64

Statement Count	*M*	*Mdn*	*SD*	*Variance*	*Range*
9	.41	.41	.14	.02	.22 – .64

Cluster 8: Families' Support Needs

#	Statement	Value
81	Family members don't always know how to talk about the situation.	.27
49	Family members often experience anger and don't know how to deal with that.	.29
107	Treatment and illness disrupts normal routines and activities of kids and families.	.31
24	Families who are experiencing a parent diagnosis of cancer need family psychotherapy.	.35
29	Learning how to educate our children on the diagnosis and treatment of cancer without filling them with fear.	.42

table continues

59	Difficulties adjusting family priorities.	.43
75	Parent & family support group to talk with and learn from others.	.45
122	Logistical realities of treatment disrupts care and schedule of children.	.45
78	Not enough utilization of technology to help connect kids.	.56
23	Need assistance with childcare.	.61

Statement Count	*M*	*Mdn*	*SD*	*Variance*	*Range*
10	.41	.43	.11	.01	.27 – .61

Appendix D- Mean Statement Ratings of Patient and Professional Stakeholders

	Level of Importance			Level of Satisfaction			Level of Utilization		
Statement #	Patient	Professional	Difference	Patient	Professional	Difference	Patient	Professional	Difference
1	3.33	3.86	0.52	3.00	2.43	0.57	2.67	3.05	0.38
2	4.67	4.86	0.19	3.13	3.33	0.20	4.27	4.48	0.21
3	3.87	3.76	0.10	2.67	2.52	0.14	3.47	3.57	0.10
4	4.07	3.90	0.16	2.87	2.76	0.10	3.93	3.43	0.50
5	4.00	4.57	0.57	2.73	2.95	0.22	4.20	4.24	0.04
6	4.53	4.90	0.37	2.87	3.38	0.51	4.40	4.57	0.17
7	4.53	4.48	0.06	3.40	2.71	0.69	3.87	3.67	0.20
8	4.47	4.29	0.18	2.80	3.00	0.20	4.00	4.00	0.00
9	4.20	4.43	0.23	2.87	2.95	0.09	4.33	4.33	0.00
10	3.93	3.86	0.08	2.33	2.33	0.00	3.20	3.29	0.09
11	4.20	4.57	0.37	3.33	2.86	0.48	4.20	3.81	0.39
12	3.60	3.67	0.07	3.07	2.67	0.40	3.53	3.29	0.25
13	3.40	3.71	0.31	2.80	2.10	0.70	3.33	4.05	0.71
14	3.87	4.29	0.42	2.60	2.14	0.46	3.67	3.86	0.19
15	3.47	4.14	0.68	2.93	2.90	0.03	3.20	3.19	0.01
16	3.47	3.95	0.49	2.53	2.52	0.01	3.80	3.76	0.04
17	4.40	4.67	0.27	2.93	2.57	0.36	3.93	4.05	0.11
18	4.07	4.33	0.27	2.93	3.29	0.35	4.27	4.10	0.17
19	3.73	4.10	0.36	2.80	3.05	0.25	3.73	3.57	0.16
20	4.07	4.05	0.02	3.00	2.81	0.19	3.80	3.76	0.04
21	3.47	3.86	0.39	2.67	3.05	0.38	3.60	3.57	0.03
22	3.73	3.62	0.11	2.73	2.52	0.21	3.67	3.48	0.19
23	4.27	4.24	0.03	2.53	2.33	0.20	4.60	4.19	0.41
24	3.53	3.57	0.04	3.27	2.52	0.74	3.00	3.10	0.10
25	3.67	3.67	0.00	3.20	2.81	0.39	3.73	3.62	0.11
26	4.33	4.38	0.05	3.13	2.90	0.23	4.33	4.24	0.10
27	2.73	3.48	0.74	3.00	2.67	0.33	3.47	2.90	0.56
28	4.00	4.14	0.14	3.40	2.52	0.88	3.93	3.76	0.17

table continues

	Level of Importance			Level of Satisfaction			Level of Utilization		
Statement #	Patient	Professional	Difference	Patient	Professional	Difference	Patient	Professional	Difference
29	4.20	4.33	0.13	3.07	3.05	0.02	4.20	4.19	0.01
30	3.53	3.81	0.28	2.27	2.38	0.11	3.93	3.43	0.50
31	4.40	4.57	0.17	3.13	2.95	0.18	4.60	4.38	0.22
32	3.80	4.00	0.20	3.13	2.38	0.75	4.07	3.67	0.40
33	3.73	4.24	0.50	3.20	2.86	0.34	3.87	3.48	0.39
34	3.20	3.67	0.47	2.87	2.52	0.34	3.13	3.14	0.01
35	3.87	3.76	0.10	2.53	2.71	0.18	3.87	3.81	0.06
36	3.93	4.00	0.07	3.07	2.76	0.30	3.40	3.57	0.17
37	3.27	3.62	0.35	3.07	2.62	0.45	3.47	3.48	0.01
38	3.87	3.86	0.01	3.13	2.67	0.47	3.67	3.90	0.24
39	4.20	4.14	0.06	2.80	2.62	0.18	3.87	3.52	0.34
40	3.53	3.76	0.23	2.73	2.71	0.02	3.40	3.38	0.02
41	3.20	3.86	0.66	2.53	2.81	0.28	2.93	3.71	0.78
42	3.07	4.10	1.03	3.07	2.90	0.16	3.20	3.33	0.13
43	4.53	4.38	0.15	2.67	2.76	0.10	4.20	3.48	0.72
44	4.47	4.43	0.04	2.27	3.00	0.73	4.40	4.05	0.35
45	3.27	3.81	0.54	2.67	2.90	0.24	3.93	3.76	0.17
46	3.33	3.76	0.43	2.80	2.62	0.18	2.87	3.52	0.66
47	3.73	4.05	0.31	2.67	2.76	0.10	3.60	3.48	0.12
48	2.93	3.57	0.64	3.00	3.10	0.10	3.47	3.19	0.28
49	3.67	3.90	0.24	3.07	3.00	0.07	3.87	3.52	0.34
50	4.47	4.67	0.20	3.80	3.67	0.13	4.27	4.38	0.11
51	4.00	4.10	0.10	2.93	2.57	0.36	4.13	3.48	0.66
52	4.00	4.05	0.05	3.60	2.86	0.74	2.93	3.10	0.16
53	3.93	4.19	0.26	2.87	2.76	0.10	3.60	3.76	0.16
54	4.33	4.24	0.10	2.60	3.10	0.50	3.93	3.71	0.22
55	4.40	4.62	0.22	2.47	3.00	0.53	4.47	4.33	0.13
56	4.40	4.71	0.31	2.67	3.10	0.43	4.20	3.76	0.44
57	4.33	4.29	0.05	2.67	2.76	0.10	3.87	3.33	0.53
58	3.47	4.05	0.58	3.07	3.38	0.31	3.40	3.76	0.36

table continues

	Level of Importance			Level of Satisfaction			Level of Utilization		
	Level of Importance			Level of Satisfaction			Level of Utilization		
Statement #	Patient	Professional	Difference	Patient	Professional	Difference	Patient	Professional	Difference
59	3.60	4.00	0.40	2.73	2.95	0.22	3.20	3.24	0.04
60	3.93	3.76	0.17	2.80	2.48	0.32	4.13	3.71	0.42
61	4.20	4.19	0.01	3.07	3.00	0.07	4.20	4.00	0.20
62	4.13	4.24	0.10	2.93	2.86	0.08	3.80	3.76	0.04
63	4.13	4.14	0.01	2.80	3.05	0.25	4.13	3.62	0.51
64	3.93	4.24	0.30	2.73	2.62	0.11	3.87	3.38	0.49
65	3.60	3.95	0.35	2.47	2.38	0.09	3.53	3.33	0.20
66	3.87	3.48	0.39	3.00	2.95	0.05	3.93	3.14	0.79
67	4.47	4.29	0.18	2.07	2.05	0.02	3.67	3.76	0.10
68	4.33	4.14	0.19	2.93	3.10	0.16	4.20	3.62	0.58
69	4.07	4.43	0.36	2.27	2.43	0.16	4.33	3.95	0.38
70	4.13	3.95	0.18	2.13	2.33	0.20	4.27	3.48	0.79
71	4.00	4.24	0.24	2.20	2.24	0.04	3.87	3.62	0.25
72	4.13	4.10	0.04	2.80	2.95	0.15	4.20	3.43	0.77
73	4.53	4.14	0.39	2.80	2.52	0.28	4.13	3.52	0.61
74	4.20	4.14	0.06	2.73	2.76	0.03	3.93	3.86	0.08
75	4.27	4.19	0.08	3.60	3.10	0.50	4.00	3.71	0.29
76	4.20	4.52	0.32	2.93	3.14	0.21	4.27	4.24	0.03
77	3.73	3.81	0.08	3.00	2.95	0.05	4.20	3.52	0.68
78	3.20	3.48	0.28	2.33	2.52	0.19	3.40	3.48	0.08
79	3.67	4.05	0.38	2.93	2.90	0.03	3.53	3.38	0.15
80	3.27	3.48	0.21	2.87	2.71	0.15	3.87	3.14	0.72
81	3.67	3.86	0.19	3.07	2.76	0.30	4.13	3.33	0.80
82	3.47	3.62	0.15	2.47	2.76	0.30	3.53	3.29	0.25
83	4.20	4.33	0.13	3.13	2.95	0.18	4.20	3.95	0.25
84	4.47	4.67	0.20	2.20	2.67	0.47	3.53	4.10	0.56
85	3.93	4.05	0.11	2.93	3.00	0.07	3.87	3.57	0.30
86	3.80	3.90	0.10	2.87	3.00	0.13	4.00	3.71	0.29
87	3.67	3.67	0.00	3.20	2.62	0.58	4.33	3.29	1.05
88	3.73	3.86	0.12	2.87	3.00	0.13	4.27	3.24	1.03

Level of Importance Level of Satisfaction Level of Utilization

table continues

	Level of Importance			Level of Satisfaction			Level of Utilization		
Statement #	Patient	Professional	Difference	Patient	Professional	Difference	Patient	Professional	Difference
89	3.93	3.76	0.17	2.80	2.62	0.18	3.93	3.43	0.50
90	3.47	3.71	0.25	3.33	2.76	0.57	3.93	3.10	0.84
91	3.60	3.76	0.16	2.80	3.19	0.39	3.53	3.14	0.39
92	4.20	4.38	0.18	3.00	2.81	0.19	4.47	4.10	0.37
93	4.07	3.86	0.21	2.87	2.76	0.10	4.07	3.57	0.50
94	4.07	4.05	0.02	3.20	2.67	0.53	4.20	3.90	0.30
95	4.47	4.38	0.09	2.80	2.81	0.01	4.40	4.24	0.16
96	3.80	3.71	0.09	3.00	2.52	0.48	4.00	3.95	0.05
97	3.87	3.86	0.01	3.13	3.19	0.06	3.93	4.05	0.11
98	3.33	3.95	0.62	2.87	2.67	0.20	4.07	3.81	0.26
99	3.87	4.29	0.42	3.60	2.67	0.93	3.87	3.67	0.20
100	4.20	4.38	0.18	3.47	3.48	0.01	4.27	3.95	0.31
101	3.33	4.05	0.71	3.07	2.86	0.21	3.00	3.38	0.38
102	3.40	3.81	0.41	2.87	2.57	0.30	3.13	3.24	0.10
103	4.53	4.24	0.30	2.47	2.62	0.15	4.33	3.71	0.62
104	4.27	4.14	0.12	2.67	2.57	0.10	4.13	3.81	0.32
105	4.33	4.29	0.05	2.33	2.24	0.10	4.13	3.81	0.32
106	4.27	4.33	0.07	2.87	2.90	0.04	4.00	3.86	0.14
107	3.93	4.05	0.11	2.60	2.81	0.21	4.07	3.29	0.78
108	4.67	4.52	0.14	2.93	2.57	0.36	4.47	4.19	0.28
109	3.60	3.86	0.26	2.80	3.05	0.25	4.00	3.38	0.62
110	3.13	4.33	1.20	2.93	3.10	0.16	4.00	3.62	0.38
111	3.73	4.10	0.36	2.53	3.05	0.51	3.73	3.71	0.02
112	3.93	4.00	0.07	2.27	2.67	0.40	3.93	3.52	0.41
113	4.07	4.24	0.17	2.53	2.62	0.09	4.27	3.90	0.36
114	4.00	4.19	0.19	2.80	2.76	0.04	3.67	3.57	0.10
115	4.13	4.24	0.10	2.93	2.86	0.08	3.93	3.67	0.27
116	3.73	4.19	0.46	3.13	3.05	0.09	3.87	3.62	0.25
117	4.20	4.43	0.23	2.87	2.52	0.34	4.27	3.76	0.50

	Level of Importance			Level of Satisfaction			Level of Utilization		
118	3.67	4.19	0.52	2.80	2.62	0.18	4.27	3.57	0.70

table continues

Statement #	Patient	Professional	Difference	Patient	Professional	Difference	Patient	Professional	Difference
119	3.87	4.29	0.42	2.80	2.67	0.13	3.80	3.57	0.23
120	3.67	4.10	0.43	2.60	2.48	0.12	3.73	3.38	0.35
121	3.53	4.05	0.51	3.00	2.71	0.29	3.47	3.52	0.06
122	3.93	4.10	0.16	2.73	2.52	0.21	4.07	3.43	0.64
123	4.00	4.43	0.43	3.07	3.00	0.07	4.07	3.71	0.35
124	4.27	4.33	0.07	2.73	2.76	0.03	4.27	3.71	0.55
125	3.93	4.38	0.45	3.13	2.52	0.61	3.80	3.62	0.18

Appendix E

Table E1

Level of Importance Cluster Ratings for All Stakeholders

Cluster 1: Emotional Impact on Parents

#	Statement	Average Rating
56	Family members are afraid parent / patient will die.	4.59
26	Ill parent feels heartbreak when having to leave their young children.	4.32
57	Parents feel they have to protect each other from their own distress get more isolated & distant from each other.	4.27
28	Your spouse has difficulty being "there for you", as they are dealing with your cancer diagnosis as well.	4.11
53	Parents can have many overwhelming emotions that impact their ability to be involved with their children.	4.08
33	Parents have difficulty admitting they need help.	4.05
52	Parents / partners rarely have peer support.	4.05
94	Parent's may not always know how to experience their own fear and anxiety without worrying their kids.	4.00
118	Young parents have few peers who have had to deal with like concerns and can feel isolated.	3.97
111	Ill parents struggle with how to stay active in kid's lives when they are tired and weakened by illness and treatment.	3.89
86	Parents worry they can pass along potential cancer genes to kids.	3.86
88	Parents are concerned about fertility and reproductive issues.	3.81
110	Parents don't always know to help children preserve memories of ill parent when diagnosis is terminal.	3.78
65	If non-custodial parent is ill, it can increase isolation for parents and kids.	3.76
109	Parents may feel guilty for the disruption in their family's life.	3.73
40	Parents need to grieve the "normal" family life they thought they'd have, & don't have the time or space to do so.	3.68
42	All family members (including ill parent) have problems adjusting to ill parent's body image changes.	3.68
21	The ill parent worries about their children more than they do themselves.	3.68
87	Illness disrupts normal sex life of the parent-partner couple.	3.68
1	Ill parents may alienate themselves from their family.	3.65
25	Ill parent has to comfort spouse and children because of their difficulties in accepting the illness.	3.65
91	Parents need permission to be sick.	3.62
22	The ill parent may feel alone because the spouse cannot go to appointments due to home and work responsibilities.	3.62

table continues

90	Parents have difficulty letting go of control of how things are done in their home and family.	3.59
82	After treatment the parent's relationship needs change so they don't always have their social needs met.	3.57
34	Families can start to isolate themselves from other families who are not dealing with cancer	3.46
48	Parents have a hard time knowing how to deal with everyone giving them their advice and opinion.	3.27
27	Friends don't always react to your cancer diagnosis in a way you expected.	3.14

Statement Count	*M*	*Mdn*	*SD*	*Range*	*Variance*
28	3.81	3.74	.31	3.14 – 4.59	.09

Cluster 2: Parents' Worries About Children

#	Statement	Average Rating
55	Parents are afraid to tell kids about negative prognosis or dying.	4.54
11	Families need to keep the lines of communication open.	4.41
9	Overwhelming concern with how kids are handling the diagnosis	4.30
119	Parents want to know how kids feel, but it can be hard for them to actually hear how their illness is impacting them.	4.08
4	Parents have to be aware of what they say to each other when the kids are around.	4.00
19	Some parents shield children from diagnosis making it hard for child to understand.	3.92
3	Parents need to maintain boundaries with (not parentify) their kids even in times of extreme stress or grief.	3.84
89	It is not easy for parents to enforce limits & to discipline their kids when they have little energy.	3.81

Statement Count	*M*	*Mdn*	*SD*	*Range*	*Variance*
8	4.11	4.04	.26	3.81 – 4.54	.07

Cluster 3: Family Adaptation to Illness

#	Statement	Average Rating
108	Parenting support and assistance when patient is a single parent.	4.59
84	Parents may have to give up parental rights or plan for custody after death, due to their illness.	4.54
7	Need for spousal/partner individual or group support.	4.49
76	Parents need information about how to help their kids emotionally.	4.38
92	Young families typically may have not made plans for illness or death, so no plans are in place.	4.30
54	Young families have little experience with the health care system, which can make this very difficult for them.	4.30
100	Difficult for parents to know how to prepare themselves and their kids about what to expect from treatment.	4.30

table continues

124	Illness can change or jeopardize the parents' job status.	4.30
18	The parent diagnosed needs guidance for telling the spouse and children about their diagnoses.	4.22
39	Pre-existing family issues become exacerbated with the stress of cancer, making family life more difficult.	4.19
112	Cognitive effects of treatment (chemo-brain) interferes with managing busy household and family.	3.97
10	There is not enough support for the husbands/fathers of the women with the diagnosis.	3.89
15	Family members need to be a part of planning for the future, regarding the patient's personal health choices.	3.86
77	Families need support in adapting / coping when fertility cannot be preserved.	3.76
58	Parents may have difficulty understanding what they cannot do with their kids after treatment.	3.76
12	Couples need couple's therapy throughout the illness experience.	3.68
45	Parents are uncertain of how much health status information to give to their employers.	3.59
80	Loss of contact with treatment team after treatment is done is a "social loss".	3.32

Statement Count	*M*	*Mdn*	*SD*	*Range*	*Variance*
18	4.08	4.20	.35	4.59 – 3.32	.12

Cluster 4: Navigation

#	Statement	Average Rating
2	Families need to be directed to resources.	4.76
6	The family needs to be made aware of programs and services available to the children.	4.73
50	Patient and family need education about illness and treatment.	4.57
103	Child care assistance during treatment, when coming into clinic and at home after treatment recovering.	4.38
73	Respite is needed for care giving parent / partner.	4.32
74	Family could use patient navigator to help them understand and make sense of all different sources of information.	4.19
63	Families need follow-up after an initial supportive contact because their needs and readiness change frequently.	4.16
64	Families can be reluctant or find it difficult to ask for help.	4.08
72	Families need organized extended family support.	4.08
70	Help with household management	4.05
120	Families need coordinator to help manage all concerns, appointments, and demands.	3.95
38	Families are faced with so much information overload they have difficulty knowing what is right for their family	3.84
60	Hard for families to coordinate all the family, school, treatment, and supportive activities and resources.	3.81
98	Families are so busy they need support delivered in places that are convenient and comfortable for them	3.73

table continues

Statement Count	*M*	*Mdn*	*SD*	*Variance*	*Range*
14	4.19	4.12	.32	.10	3.73 – 4.76

Cluster 5: Case Management

#	Statement	Average Rating
43	Uninsured and underserved "fall through the tracks" and may not seek treatment or help.	4.46
44	Parents worry about ability to get or keep health insurance for their family in the future.	4.43
67	An emergency financial fund or account.	4.38
95	Families don't always know what financial assistance is available or how to access it.	4.38
8	Lack of knowledge about services available for the patient.	4.38
105	Financial assistance to help family keep up with normal activities and secure necessary things like school supplies.	4.32
69	Personal patient liaison who understands the diagnosis and treatment, as well as the realities of parenting.	4.30
83	Working well parent may need help learning about and accessing benefits, FMLA, and legal rights.	4.27
104	Transportation assistance for the multiple family household needs	4.22
113	Traveling to far places for treatment or consultations causes many child care problems for parents.	4.19
71	Financial advocate to help family manage finances.	4.16
Table E1 continued		
93	Need assistance with daily meals and meal preparation.	3.97
97	Patient-parents need access to medical equipment when doing things with family.	3.89
30	Need for a mentor who can work with patient during and after treatment	3.73
96	Help with making home handicap accessible.	3.73

Statement Count	*M*	*Mdn*	*SD*	*Range*	*Variance*
15	4.19	4.27	.24	3.73 – 4.46	.06

Cluster 6: Emotional Impact on Children

#	Statement	Average Rating
31	Emotional impact on children	4.49
5	Age appropriate information needs to be shared with the kids at all times to keep them in the loop.	4.35
117	Having an ill parent makes kids feel alone or isolated.	4.32
106	Kids experience emotions that can be tough to deal with.	4.32

table continues

123	Children have a hard time understanding a very complex and scary illness.	4.24
125	Adolescents may conceal their thoughts, fears, & feelings in an attempt to not cause tension in the relationship.	4.16
14	Teenage caregivers burn-out with too many responsibilities.	4.14
114	Illness needs can detract from attention kids should get for their normal developmental emotional needs.	4.14
99	Kids don't understand how to express needs and concerns about how the family will move forward.	4.11
20	Children unable to articulate what they feel so they act out.	4.05
116	Kids can have academic problems when parents are sick.	4.00
36	Children will act out their anger with other caregivers and appear to be ill behaved children	4.00
85	Kids worry they will get cancer.	4.00
47	Kids experience role changes and are often expected to do more than they are capable of doing.	3.95
32	Older sibling feels they have to take care of younger siblings because the parent is ill.	3.92
79	Kids sometimes feel guilty when they enjoy themselves or do normal things.	3.86
35	Children miss their family life before cancer	3.81
16	College aged children worry about leaving for school not knowing what the future holds for their ill parent.	3.78
121	Kids can feel like everyone is keeping secrets from them or lying to them.	3.78
101	Kids can assume responsibility for cause of parent's illness.	3.76
102	Family norms, rules, values, may not allow children to express themselves.	3.62
46	Kids may have increased absences from school.	3.62
37	Some children would fear talking about their parent's cancer diagnosis to their peers	3.49

Statement Count	*M*	*Mdn*	*SD*	*Variance*	*Range*
23	4.00	4.00	.25	.06	3.49 – 4.49

Cluster 7: Kids' Support Needs

#	Statement	Average Rating
17	Teenagers need someone to turn to for help with coping healthfully.	4.57
115	Kids may not know how to access help or how to ask for it.	4.22
68	Someone for kids to talk to outside of family.	4.22
62	Kids are not sure who they can talk to.	4.22
61	Kids need opportunities to connect and communicate with peers who are having similar experiences.	4.22
51	Kids lack peer support.	4.08
66	Normal play group for kids.	3.68

table continues

#	Statement	Average Rating
13	Internet support groups for teenagers to share their feelings and concerns without judgment are needed.	3.62
41	Kids may need or want an opportunity to talk with their parent's doctor or member of the health care team.	3.62

Statement Count	*M*	*Mdn*	*SD*	*Variance*	*Range*
9	4.05	4.22	.31	.10	3.62 – 4.57

Cluster 8: Families' Support Needs

#	Statement	Average Rating
29	How to effectively educate our children on the diagnosis and treatment of cancer without filling them with fear.	4.30
23	Need assistance with childcare.	4.27
75	Parent & family support group to talk with and learn from others.	4.24
107	Treatment and illness disrupts normal routines and activities of kids and families.	4.03
122	Logistical realities of treatment disrupts care and schedule of children.	4.03
49	Family members often experience anger and don't know how to deal with that.	3.81
81	Family members don't always know how to talk about the situation.	3.78
59	Difficulties adjusting family priorities.	3.76
24	Families who are experiencing a parent diagnosis of cancer need family psychotherapy.	3.59
78	Not enough utilization of technology to help connect kids.	3.41

Statement Count	*M*	*Mdn*	*SD*	*Variance*	*Range*
10	3.92	3.92	.29	.08	3.41 – 4.30

Appendix E

Table E2

Level of Utilization Cluster Ratings for All Stakeholders

Cluster 1: Emotional Impact on Parents

#	Statement	Average Rating
26	Ill parent feels heartbreak when having to leave their young children.	4.27
94	Parent's may not always know how to experience their own fear and anxiety without worrying their kids.	4.03
56	Family members are afraid parent / patient will die.	3.97
118	Young parents have few peers who have had to deal with like concerns and can feel isolated.	3.86
28	Your spouse has difficulty being "there for you", as they are dealing with your cancer diagnosis as well.	3.84
86	Parents worry they can pass along potential cancer genes to kids.	3.81
110	Parents don't always know to help children preserve memories of ill parent when diagnosis is terminal.	3.73
87	Illness disrupts normal sex life of the parent-partner couple.	3.73
111	Ill parents struggle with how to stay active in kid's lives when they are tired and weakened by illness and treatment.	3.70
88	Parents are concerned about fertility and reproductive issues.	3.68
25	Ill parent has to comfort spouse and children because of their difficulties in accepting the illness.	3.68
53	Parents can have many overwhelming emotions that impact their ability to be involved with their children.	3.65
33	Parents have difficulty admitting they need help.	3.62
109	Parents may feel guilty for the disruption in their family's life.	3.62
21	The ill parent worries about their children more than they do themselves.	3.54
22	The ill parent may feel alone because the spouse cannot go to appointments due to home and work responsibilities.	3.54
57	Parents feel they have to protect each other from their own distress get more isolated & distant from each other.	3.51
90	Parents have difficulty letting go of control of how things are done in their home and family.	3.43
65	If non-custodial parent is ill, it can increase isolation for parents and kids.	3.41
40	Parents need to grieve the "normal" family life they thought they'd have, & don't have the time or space to do so.	3.38
82	After treatment the parent's relationship needs change so they don't always have their social needs met.	3.35
42	All family members (including ill parent) have problems adjusting to ill parent's body image changes.	3.30
91	Parents need permission to be sick.	3.30

table continues

#	Statement	Average Rating
48	Parents have a hard time knowing how to deal with everyone giving them their advice and opinion.	3.27
34	Families can start to isolate themselves from other families who are not dealing with cancer	3.16
27	Friends don't always react to your cancer diagnosis in a way you expected.	3.14
52	Parents / partners rarely have peer support.	3.08
1	Ill parents may alienate themselves from their family.	2.86

Statement Count	*M*	*Mdn*	*SD*	*Range*	*Variance*
28	3.55	3.58	.31	2.86 – 4.27	.09

Cluster 2: Parents' Worries About Children

#	Statement	Average Rating
55	Parents are afraid to tell kids about negative prognosis or dying.	4.41
9	Overwhelming concern with how kids are handling the diagnosis	4.32
11	Families need to keep the lines of communication open.	3.95
89	It is not easy for parents to enforce limits to discipline their kids when they have little energy.	3.65
119	Parents want to know how kids feel, but it can be hard for them to actually hear how their illness is impacting them.	3.65
4	Parents have to be aware of what they say to each other when the kids are around.	3.62
19	Some parents shield children from diagnosis making it hard for child to understand.	3.62
3	Parents need to maintain boundaries with (not parentify) their kids even in times of extreme stress or grief.	3.51

Statement Count	*M*	*Mdn*	*SD*	*Range*	*Variance*
8	3.84	3.65	.32	3.51 – 4.41	.11

Cluster 3: Family Adaptation to Illness

#	Statement	Average Rating
108	Parenting support and assistance when patient is a single parent.	4.32
76	Parents need information about how to help their kids emotionally.	4.24
92	Young families typically may have not made plans for illness or death, so no plans are in place.	4.22
18	The parent diagnosed needs guidance for telling the spouse and children about their diagnoses.	4.19
100	Difficult for parents to know how to prepare themselves and their kids about what to expect from treatment.	4.08
124	Illness can change or jeopardize the parents' job status.	3.97
45	Parents are uncertain of how much health status information to give to their employers.	3.86

table continues

77	Families need support in adapting / coping when fertility cannot be preserved.	3.81
84	Parents may have to give up parental rights or plan for custody after death, due to their illness.	3.81
54	Young families have little or no experience with the health care system, which makes this very difficult for them.	3.81
7	Need for spousal/partner individual or group support.	3.73
112	Cognitive effects of treatment (chemo-brain) interferes with managing busy household and family.	3.70
39	Pre-existing family issues become exacerbated with the stress of cancer, making family life more difficult.	3.62
58	Parents may have difficulty understanding what they can and cannot do with their kids after treatment.	3.54
12	Couples need couple's therapy throughout the illness experience.	3.43
80	Loss of contact with treatment team after treatment is done is a "social loss".	3.38
10	There is not enough support for the husbands/fathers of the women with the diagnosis.	3.27
15	Family members need to be a part of planning for the future, regarding the patient's personal health choices.	3.16

Statement Count	*M*	*Mdn*	*SD*	*Range*	*Variance*
18	3.79	3.81	.34	3.16 – 4.32	.11

Cluster 4: Navigation

#	Statement	Average Rating
6	The family needs to be made aware of programs and services available to the children.	4.51
2	Families need to be directed to resources.	4.38
50	Patient and family need education about illness and treatment.	4.32
103	Child care assistance during treatment, when coming into clinic and at home after treatment recovering.	4.00
74	Family could use patient navigator to help them understand and make sense of all different sources of information.	3.92
60	Hard for families to coordinate all the family, school, treatment, and supportive activities and resources.	3.92
98	Families are so busy that they often need support delivered in places that are convenient and comfortable for them.	3.92
63	Families need follow-up after an initial supportive contact because their needs and readiness change frequently.	3.86
70	Help with household management	3.84
73	Respite is needed for care giving parent / partner.	3.81
38	Families are faced with so much information they have difficulty understanding what is right for their family	3.78
72	Families need organized extended family support.	3.70
64	Families can be reluctant or find it difficult to ask for help.	3.59
120	Families need coordinator to help manage all concerns, appointments, and demands.	3.57

table continues

Statement Count	*M*	*Mdn*	*SD*	*Variance*	*Range*
14	3.94	3.89	.27	.07	3.57 – 4.51

Cluster 5: Case Management

#	Statement	Average Rating
95	Families don't always know what financial assistance is available or how to access it.	4.32
44	Parents worry about ability to get or keep health insurance for their family in the future.	4.22
69	Personal patient liaison who understands the diagnosis and treatment, as well as the realities of parenting.	4.14
113	Traveling to far places for treatment or consultations causes many child care problems for parents.	4.08
83	Working well parent may need help learning about and accessing benefits, FMLA, and legal rights.	4.03
97	Patient-parents need access to medical equipment when doing things with family.	4.00
8	Lack of knowledge about services available for the patient.	4.00
96	Help with making home handicap accessible.	3.97
104	Transportation assistance for the multiple family household needs	3.97
105	Financial assistance to help family keep up with normal activities and secure necessary things like school supplies.	3.97
93	Need assistance with daily meals and meal preparation.	3.81
43	Uninsured and underserved "fall through the tracks" and may not seek treatment or help.	3.78
67	An emergency financial fund or account.	3.76
71	Financial advocate to help family manage finances.	3.76
30	Need for a mentor who can work with patient during and after treatment	3.68

Statement Count	*M*	*Mdn*	*SD*	*Range*	*Variance*
15	3.97	3.97	.18	3.68 – 4.32	.03

Cluster 6: Emotional Impact on Children

#	Statement	Average Rating
31	Emotional impact on children	4.46
5	Age appropriate information needs to be shared with the kids at all times to keep them in the loop.	4.16
117	Having an ill parent makes kids feel alone or isolated.	3.97
106	Kids experience emotions that can be tough to deal with.	3.92
32	Older sibling feels they have to take care of younger siblings because the parent is ill.	3.84

table continues

35	Children miss their family life before cancer	3.84
123	Children have a hard time understanding a very complex and scary illness.	3.78
16	College aged children worry about leaving for school not knowing what the future holds for their ill parent.	3.76
14	Teenage caregivers burn-out with too many responsibilities.	3.76
99	Kids don't understand how to express needs and concerns about how the family will move forward.	3.73
116	Kids can have academic problems when parents are sick.	3.73
20	Children unable to articulate what they feel so they act out.	3.73
85	Kids worry they will get cancer.	3.68
114	Illness needs can detract from attention kids should get for their normal developmental emotional needs.	3.65
125	Adolescents may conceal their thoughts, fears, & feelings in an attempt to protect the parents.	3.65
36	Children will act out their anger with other caregivers and appear to be ill behaved children	3.51
47	Kids experience role changes and are often expected to do more than they are capable of doing.	3.51
37	Some children would fear talking about their parent's cancer diagnosis to their peers	3.49
79	Kids sometimes feel guilty when they enjoy themselves or do normal things.	3.46
121	Kids can feel like everyone is keeping secrets from them or lying to them.	3.46
46	Kids may have increased absences from school.	3.27
101	Kids can assume responsibility for cause of parent's illness.	3.22
102	Family norms, rules, values, may not allow children to express themselves.	3.14

Statement Count	*M*	*Mdn*	*SD*	*Variance*	*Range*
23	3.68	3.73	.29	.08	3.14 – 4.46

Cluster 7: Kids' Support Needs

#	Statement	Average Rating
61	Kids need opportunities to connect and communicate with peers who are having similar experiences.	4.11
17	Teenagers need someone to turn to for help with coping healthfully.	4.00
68	Someone for kids to talk to outside of family.	3.86
62	Kids are not sure who they can talk to.	3.81
115	Kids may not know how to access help or how to ask for it.	3.78
13	Internet support groups for teenagers to share their feelings and concerns without judgment are needed.	3.78
51	Kids lack peer support.	3.78
66	Normal play group for kids.	3.51

table continues

41	Kids may need or want an opportunity to talk with their parent's doctor or member of the health care team.	3.38

Statement Count	*M*	*Mdn*	*SD*	*Variance*	*Range*
9	3.78	3.78	.21	.04	3.38 – 4.11

Cluster 8: Families' Support Needs

#	Statement	Average Rating
23	Need assistance with childcare.	4.38
29	How to effectively educate our children on the diagnosis & treatment of cancer without filling them with fear.	4.22
75	Parent & family support group to talk with and learn from others.	3.81
122	Logistical realities of treatment disrupts care and schedule of children.	3.70
49	Family members often experience anger and don't know how to deal with that.	3.65
107	Treatment and illness disrupts normal routines and activities of kids and families.	3.65
81	Family members don't always know how to talk about the situation.	3.62
78	Not enough utilization of technology to help connect kids.	3.49
59	Difficulties adjusting family priorities.	3.22
24	Families who are experiencing a parent diagnosis of cancer need family psychotherapy.	3.08

Statement Count	*M*	*Mdn*	*SD*	*Variance*	*Range*
10	3.68	3.65	.38	.14	3.08 – 4.38

Appendix E

Table E3

Patient Level of Satisfaction Ratings

Cluster 1: Emotional Impact on Parents

#	Statement	Average Rating
52	Parents / partners rarely have peer support.	3.14
48	Parents have a hard time knowing how to deal with everyone giving them their advice and opinion.	3.05
110	Parents don't always know to help children preserve memories of ill parent when diagnosis is terminal.	3.05
**91*	*Parents need permission to be sick.*	*3.03*
90	Parents have difficulty letting go of control of how things are done in their home and family.	3.00
25	Ill parent has to comfort spouse and children because of their difficulties in accepting the illness.	3.00
26	Ill parent feels heartbreak when having to leave their young children.	2.97
**56*	*Family members are afraid parent / patient will die.*	*2.95*
33	Parents have difficulty admitting they need help.	2.95
**109*	*Parents may feel guilty for the disruption in their family's life.*	*2.95*
42	*All family members (including ill parent) have problems adjusting to ill parent's body image changes.*	*2.92*
**21*	*The ill parent worries about their children more than they do themselves.*	*2.92*
86	Parents worry they can pass along potential cancer genes to kids.	2.92
88	Parents are concerned about fertility and reproductive issues.	2.89
94	Parent's may not always know how to experience their own fear and anxiety without worrying their kids.	2.86
28	Your spouse has difficulty being "there for you", as they are dealing with your cancer diagnosis as well.	2.86
**53*	*Parents can have many overwhelming emotions that impact their ability to be involved with their children.*	*2.84*
**111*	*Ill parents struggle with how to stay active in kid's lives when they are weakened by illness and treatment.*	*2.84*
**27*	*Friends don't always react to your cancer diagnosis in a way you expected.*	*2.81*
87	Illness disrupts normal sex life of the parent-partner couple.	2.81
40	Parents need to grieve the "normal" family life they thought they'd have, & don't have the time or space to do so.	2.73
**118*	*Young parents have few peers who have had to deal with like concerns and can feel isolated.*	*2.70*
**57*	*Parents feel they have to protect each other from their own distress get more isolated & distant from each other.*	*2.70*

table continues

_*1_	_Ill parents may alienate themselves from their family._	_2.68_
_*34_	_Families can start to isolate themselves from other families who are not dealing with cancer_	_2.62_
_*82_	_After treatment the parent's relationship needs change so they don't always have their social needs met._	_2.62_
_*22_	_The ill parent may feel alone because the spouse cannot go to appointments due to home and work responsibilities._	_2.59_
_*65_	_If non-custodial parent is ill, it can increase isolation for parents and kids._	_2.41_

Statement Count	_M_	_Mdn_	_SD_	_Range_	_Variance_
28	2.85	2.88	.16	2.41 – 3.14	.03

Cluster 2: Parents’ Worries About Children

#	Statement	Average Rating
11	Families need to keep the lines of communication open.	3.05
19	Some parents shield children from diagnosis making it hard for child to understand.	2.92
9	Overwhelming concern with how kids are handling the diagnosis	2.89
55	Parents are afraid to tell kids about negative prognosis or dying.	2.78
4	Parents have to be aware of what they say to each other when the kids are around.	2.78
_*119_	_Parents want to know how kids feel, but it can be hard for them to hear about how their illness is impacting them._	_2.73_
89	It is not easy for parents to enforce limits and to discipline their kids when they know kids are upset.	2.65
_*3_	_Parents need to maintain boundaries with (not parentify) their kids even in times of extreme stress or grief._	_2.54_

Statement Count	_M_	_Mdn_	_SD_	_Range_	_Variance_
8	2.79	2.78	.15	2.54 – 3.05	.02

Cluster 3: Family Adaptation to Illness

#	Statement	Average Rating
100	Difficult for parents to know how to prepare themselves and their kids about what to expect from treatment.	3.46
58	Parents have difficulty in understanding what they can and cannot do with their kids after treatment.	3.24
18	The parent diagnosed needs guidance for telling the spouse and children about their diagnoses.	3.14
76	Parents need information about how to help their kids emotionally.	3.03
7	Need for spousal/partner individual or group support.	2.97
77	Families need support in adapting / coping when fertility cannot be preserved.	2.95
15	Family members need to be a part of planning for the future, regarding the patient's personal health choices.	2.86

table continues

92	Young families typically may have not made plans for illness or death, so no plans are in place.	2.86
12	Couples need couple's therapy throughout the illness experience.	2.84
**54*	*Families have little or no experience with the health care system, which can make this very difficult for them.*	*2.84*
80	Loss of contact with treatment team after treatment is done is a "social loss".	2.78
**45*	*Parents are uncertain of how much health status information to give to their employers.*	*2.76*
**124*	*Illness can change or jeopardize the parents' job status.*	*2.70*
108	Parenting support and assistance when patient is a single parent.	2.68
**39*	*Pre-existing family issues become exacerbated with the stress of cancer, making family life more difficult.*	*2.68*
**112*	*Cognitive effects of treatment (chemo-brain) interferes with managing busy household and family.*	*2.49*
84	Parents may have to give up parental rights or plan for custody after death, due to their illness.	2.43
10	There is not enough support for the husbands/fathers of the women with the diagnosis.	2.32

Statement Count	*M*	*Mdn*	*SD*	*Range*	*Variance*
18	2.83	2.84	.27	2.32 – 3.46	.07

Cluster 4: Navigation

#	Statement	Average Rating
50	Patient and family need education about illness and treatment.	3.76
2	Families need to be directed to resources.	3.22
6	The family needs to be made aware of programs and services available to the children.	3.16
**63*	*Families need follow-up after an initial supportive contact because their needs and readiness change frequently.*	*2.92*
38	Families are faced with so much information they have a hard time understanding what is right for their family	2.89
**72*	*Families need organized extended family support.*	*2.84*
**98*	*Families are so busy they often need support delivered in places that are convenient and comfortable for them.*	*2.70*
**74*	*Family needs a patient navigator to help them understand and make sense of all different sources of information.*	*2.70*
**64*	*Families can be reluctant or find it difficult to ask for help.*	*2.65*
73	Respite is needed for care giving parent / partner.	2.59
**60*	*Hard for families to coordinate all the family, school, treatment, and supportive activities and resources.*	*2.57*
103	Child care assistance during treatment, when coming into clinic and at home after treatment recovering.	2.51
**120*	*Families need coordinator to help manage all concerns, appointments, and demands.*	*2.49*
70	Help with household management	2.22

table continues

Statement Count	*M*	*Mdn*	*SD*	*Variance*	*Range*
14	2.80	2.70	.37	.14	2.22 – 3.76

Cluster 5: Case Management

#	Statement	Average Rating
97	Patient-parents need access to medical equipment when doing things with family.	3.11
83	Working well parent may need help learning about and accessing benefits, FMLA, and legal rights.	3.03
8	Lack of knowledge about services available for the patient.	2.89
95	Families don't always know what financial assistance is available or how to access it.	2.78
93	Need assistance with daily meals and meal preparation.	2.76
96	Help with making home handicap accessible.	2.68
43	Uninsured and underserved "fall through the tracks" and may not seek treatment or help.	2.68
44	Parents worry about ability to get or keep health insurance for their family in the future.	2.65
104	Transportation assistance for the multiple family household needs	2.57
113	Traveling to far places for treatment or consultations causes many child care problems for parents.	2.54
**69*	*Personal patient liaison who understands the diagnosis and treatment, as well as the realities of parenting.*	*2.32*
30	Need for a mentor who can work with patient during and after treatment	2.30
105	Financial assistance to help family keep up with normal activities and secure necessary things like school supplies.	2.24
**71*	*Financial advocate to help family manage finances.*	*2.19*
67	An emergency financial fund or account.	2.05

Statement Count	*M*	*Mdn*	*SD*	*Range*	*Variance*
15	2.59	2.65	.30	2.05 – 3.11	.09

Cluster 6: Emotional Impact on Children

#	Statement	Average Rating
99	Kids don't understand how to express needs and concerns about how the family will move forward.	3.03
116	Kids can have academic problems when parents are sick.	3.03
31	Emotional impact on children	3.03
123	Children have a hard time understanding a very complex and scary illness.	2.97
85	Kids worry they will get cancer.	2.92

table continues

101	Kids can assume responsibility for cause of parent's illness.	2.92
79	Kids sometimes feel guilty when they enjoy themselves or do normal things.	2.89
36	Children will act out their anger with other caregivers and appear to be ill behaved children	2.86
106	Kids experience emotions that can be tough to deal with.	2.86
20	Children unable to articulate what they feel so they act out.	2.86
5	Age appropriate information needs to be shared with the kids at all times to keep them in the loop.	2.84
37	Some children would fear talking about their parent's cancer diagnosis to their peers	2.78
121	Kids can feel like everyone is keeping secrets from them or lying to them.	2.78
114	Illness needs can detract from attention kids should get for their normal developmental emotional needs.	2.76
125	Adolescents may conceal their thoughts, fears, & feelings in an attempt to protect the parent and not cause tension.	2.73
32	Older sibling feels they have to take care of younger siblings because the parent is ill.	2.68
_*47_	_Kids experience role changes and are often expected to do more than they are capable of doing._	2.68
_*102_	_Family norms, rules, values, may not allow children to express themselves._	2.65
_*46_	_Kids may have increased absences from school._	2.65
_*35_	_Children miss their family life before cancer_	2.65
_*117_	_Having an ill parent makes kids feel alone or isolated._	2.62
_*16_	_College aged children worry about leaving for school not knowing what the future holds for their ill parent._	2.49
_*14_	_Teenage caregivers burn-out with too many responsibilities._	2.30

Statement Count	_M_	_Mdn_	_SD_	_Variance_	_Range_
23	2.78	2.78	.18	.03	2.30 – 3.03

Cluster 7: Kids’ Support Needs

#	Statement	Average Rating
68	Someone for kids to talk to outside of family.	3.03
61	Kids need opportunities to connect and communicate with peers who are having similar experiences.	2.97
66	Normal play group for kids.	2.92
115	Kids may not know how to access help or how to ask for it.	2.84
62	Kids are not sure who they can talk to.	2.84
51	Kids lack peer support.	2.70
_*17_	_Teenagers need someone to turn to for help with coping healthfully._	2.68
_*41_	_Kids may need or want an opportunity to talk with their parent's doctor or member of the health care team._	2.65

table continues

**13*	*Internet support groups for teenagers to share their feelings and concerns without judgment are needed.*	2.35

Statement Count	*M*	*Mdn*	*SD*	*Variance*	*Range*
9	2.77	2.84	.19	.04	2.35 – 3.03

Cluster 8: Families' Support Needs

#	Statement	Average Rating
75	Parent & family support group to talk with and learn from others.	3.30
29	Lear how to effectively educate our children on the diagnosis and treatment of cancer without filling them with fear.	3.08
49	Family members often experience anger and don't know how to deal with that.	3.03
81	Family members don't always know how to talk about the situation.	2.86
**59*	*Difficulties adjusting family priorities.*	2.84
24	Families who are experiencing a parent diagnosis of cancer need family psychotherapy.	2.81
107	Treatment and illness disrupts normal routines and activities of kids and families.	2.70
122	Logistical realities of treatment disrupts care and schedule of children.	2.57
**78*	*Not enough utilization of technology to help connect kids.*	*2.41*
**23*	*Need assistance with childcare.*	*2.38*

Statement Count	*M*	*Mdn*	*SD*	*Variance*	*Range*
10	2.80	2.82	.28	.08	2.38 – 3.30