Family life is altered irrevocably when a young parent is diagnosed with or dies from cancer. This article tracks the genesis and transformation of a comprehensive psychoeducational support and bereavement program for children, adolescents, and parents affected by cancer. From the inception of the program, families with parents in active treatment participated in time-limited support groups. When a parent died, families transitioned out of support and into bereavement groups. As the cancer experience became more chronic, families remained in these respective groups for longer periods of time. This required clinicians to reconsider group structure to avoid the additional losses incurred as newly bereaved families transitioned from one group to another. Restructuring the program allowed participants to remain in familiar environments and to experience greater support and continuity in their care. Children, teens, and parents made clinical gains in communicating their needs and feelings to loved ones. Further, children and teens stayed on track developmentally, academically, and socially. Clinicians structuring these programs must be skilled in working simultaneously in both support and bereavement modalities. Recommendations for self-care and supervision are suggested.

KEYWORDS adolescents, bereavement, children, family members, neoplasms, program development, support groups
One in two men and one in three women will experience a cancer diagnosis in their lifetime (American Cancer Society, 2007). Currently, survivorship is defined by a 5-year remission. Remission is rarely absolute, however, and varies widely by the cancer’s primary site and how it is staged at the time of diagnosis (American Cancer Society, 2007). Over 85% of breast cancer patients survive 5 years after their initial diagnosis, compared to half of leukemia patients and only 15% of lung cancer patients. For those who reach their 5-year mark, relapse remains a real and frightening possibility. For families living in the shadow of possible recurrence, the disease becomes a feature of daily life, requiring pragmatic and psychological accommodations. Patients never truly become cancer free. This is especially true when anxiety about recurrence arises as periodic checkups and scans are scheduled. This ongoing concern about the possibility of relapse transforms the nature of cancer into a chronic disease whose impact on children, adolescents, and families must be recognized and integrated into psychosocial interventions.

While national databases do not collect statistics on the number of children under age 18 who are exposed to a parent’s cancer, data extrapolated from census (Fields, 2003) and Surveillance Epidemiology and End Results (SEER) data (Ries et al., 2007) suggest that over 375,000 children may experience such a trauma. While fewer people are dying of cancer than a generation ago, the younger a patient is at the time of diagnosis (i.e., under 45), the poorer their long-term prognosis (Ries et al., 2007). Adults under the age of 45 are a demographic group likely to have children under the age of 18 living at home, especially since current census data show young adults are postponing marriage and childbearing into the fourth or fifth generation of life (Fields, 2003). The combination of these statistical trends implies that children are potentially younger than a generation ago when they are first introduced to cancer and a parent’s mortality. This article will track the genesis and adaptation of a psychoeducational and supportive program designed to meet the needs of children, adolescents, and families living with cancer as a chronic and terminal illness.

Impact of Parental Cancer and Death on Children and Adolescents

Children’s quality of life diminishes significantly when a parent is diagnosed with cancer. The emotional and pragmatic structures that previously supported developmental, academic, and social achievements crumble (Wallerstein & Blakeslee, 1989). Children and adolescents may experience anxiety, dips in self-esteem, increased stress and sadness, and social isolation (Kataja & Bertram, 2006; Leedham, Meyerowitz, Harvey, & Miller, 2000; Nelson, Sloper, Charlton, & While, 1994; Nelson & While, 2002; Siegel et al., 1992; Welch, Wadsworth, & Compas, 1997), all of which may translate into academic or behavioral difficulty (Aponte, 1985; Stanko & Taub, 2002; Wellisch, 1985). Shifts in the marital dyad due to changing roles (i.e.,
caregiver, patient) may add stress and burden to parents and trickle down either implicitly or explicitly to children as well (Su, 2005).

Children's perception of control over their lives changes drastically when a parent becomes ill and dies (Compas, Worsham, Ey, & Howell, 1996; Rosenfeld et al., 1983). Routines are disrupted, parents are unavailable emotionally or physically for extended periods of time, new adults are introduced into family life as caretakers for ill parents or healthy children, and uncertainty over the future looms. Children may have particular difficulty understanding treatment side effects such as hair loss or the disappearance of playtime with formerly active parents due to their parents’ fatigue (Werner-Lin & Biank, 2006). They may not trust they are receiving complete or truthful information. Some children take on adult responsibilities and roles to compensate for absent parents (Aponte, 1985; Doka, 1995), frequently without the chance to choose how to participate in family life, leading to resentment and increased stress (Stanko & Taub, 2002).

Family support networks frequently shift during the course of cancer diagnosis and treatment and at the end of life. Unstable support networks can contribute to uncertainty about who will care for a child and whom children can trust (Werner-Lin & Biank, 2006). Clinical and empirical evidence suggests children and adolescents are more likely to exhibit emotional and behavioral problems when a mother is sick (Christ, 2000; Lewis, Hammond, & Woods, 1993). In our clinical work, we have found children have more trouble when the nurturing parent is ill, leaving children without their usual emotional supports to guide them (Werner-Lin, Biank, & Rubenstein, 2009).

Children and families facing the death of a loved one frequently become consumed by anticipatory grief (Rando, 1995). Surviving relatives, particularly spouses, may be too preoccupied with their own grief to attend fully to the needs of a grieving child (Healy-Romanello, 1993). Without regular or stable supports, children's grief reactions may inhibit their ability to cope with common reactions such as anger, fear, and depression. Many fear abandonment, and children with more limited knowledge of cancer physiology frequently fear contagion (Compas et al., 1996). Some believe they caused the cancer or death (Doka, 1995) or that talking about cancer made the disease progress faster. Many need greater education about the dynamics of cancer, how it develops, how treatments work or fail to work, and what it means when someone dies.

CONTINUITY IN SUPPORT AND BEREAVEMENT GROUP WORK

Around the United States, a variety of group intervention programs are offered to children and adolescents who have a parent with cancer (Bedway & Smith, 1996; Biank, 2002; Christ, 2000; Davey, Gulish, Askew,
Family Matters: Group Interventions With Families Coping With Cancer and End of Life

Through a series of educational programs, support groups, family therapy sessions, and social events, Family Matters supports families during the journey through cancer and beyond. A team of health care professionals provide these services, including social workers, psychologists, dieticians, nurses, exercise specialists, and marriage and family therapists. The programs contain both educational and psychosocial supportive features: clinicians teach children about illness, death, and dying, answer questions, clarify misconceptions (Bacon, Corr, & Corr, 1996; Taylor-Brown et al., 1993), and provide a safe, familiar, and consistent space to express feelings, doubts, fears, and hopes (Bacon et al., 1996). Group content is constructed to clarify misconceptions about cancer and its treatment, while group process facilitates family communication, supports improved self-esteem and self-efficacy, and teaches coping skills to improve grief symptomatology (Bacon et al., 1996).

Family Matters programs are built on the conceptual pillars of family systems, developmental, and attachment theories. A family systems frame informs interventions that normalize and validate the challenges of parental illness and recognize the pervasive impact of serious and terminal illness on family structure and organization. This approach allows the clinician to “join” family life and reshape the family system to maximize resources and build on areas of vulnerability. Clinicians help families to maintain structure and to function within the context of a crisis by providing stability and continuity. A developmental perspective informs our aim to balance energy directed toward illness management with the need to keep children on track developmentally, socially, and academically. Programs attend to the range in cognitive, emotional, and moral development of young participants as they struggle to integrate novel illness information and family change.

The focus on attachment theory addresses new limits that illness may have imposed on parents’ responsiveness and availability to children and the anticipated separation from the ill parents as a threat to attachment. The latter was especially poignant given the empirical finding that children with more secure attachments to their parents experienced poorer adaptation to parental loss (Su, 2005). While attachments develop over long periods of
time, they can be quickly disrupted, as in the case of illness and death. To navigate uncertain terrain, children seek out important others for guidance, reassurance, and comfort (Werner-Lin, Biank, & Rubenstein, 2009). Yet when the availability of primary attachment figures is compromised, children may be left without an emotional compass. As attachment figures become increasingly unavailable, children may develop representations of themselves as unworthy of care. To combat this powerful perception, individual, group, and family work aims to build self-esteem and improve family communication (Lewis et al., 1993), clarify misconceptions about illness and death (Taylor-Brown et al., 1993), address magical thinking, and build a strong support network. While attachments to primary caregivers are in crisis and as family life changes irrevocably, the basic support group structure and chemistry acts as a transitional object (Winnicott, 1965), remaining unaltered. Connections with the homelike space, clinicians, and group members provide supplementary attachments to shore up children emotionally as their parents approached death.

Time Out! for Teens

Teen Talk and Time Out! For Teens were designed as separate groups, the former a support group for teens with parents in active cancer treatment, the latter a bereavement group for teens that had lost a parent to cancer. The groups are time-limited with the opportunity for rejoining, semistructured, open to siblings, and frequently co-facilitated. Teen participants come from villages and townships in the western and southwestern suburbs of Chicago, and few attendees are generally enrolled in the same school district. This limited contact between participants to the group experience. For many years, groups experienced significant turnover in participants at the start of each quarter.

Generally, the passage of children and teens through the Family Matters programs was limited and linear. Movement between teen groups occurred when parents experienced remission and teens left the group entirely, or after the death of a parent, when teens transitioned into the bereavement group. At the time of a parent’s death, the newly bereaved teen would return to their support group for closure, to discuss the experience of the loss and say goodbye to their peers. This process allowed all group participants to process the loss together and experience a therapeutic and controlled goodbye. The psychosocial needs of the teens shifted at this point, and they joined the bereavement group to gain support through the mourning process.

After a decade of success with this model, we began to observe more frequent cancer recurrences among Family Matters parents. This new pattern kept teens in groups for longer stretches of time or brought them back to group after extended periods away. Teen participants developed meaningful and therapeutic bonds with each other and with facilitators over the course of prolonged and intense contact. The planned passage through the
programmatic sequence required reexamination as the move from support
group to bereavement group precipitated a number of challenges and
additional losses for newly bereaved teens. As groups stayed together longer,
the transition of a friend to another group was experienced as a significant
loss and required newly bereaved teens to mourn their familiar supportive
network. Simultaneously, this model required newly bereaved teens to adjust
to a new setting, meet a new set of group participants, build new relation-
ships, and become socialized into a new group process. Those teens left
behind in the support group struggled with the disappearance of a member
of their ranks and faced the potential loss of their own parent as a more sub-
stantial possibility. Since their friends were removed from the group setting,
these teens had limited exposure to life after catastrophic loss, increasing fear
of the unknown.

In the fall of 2002, two groups for adolescents became particularly close
and therapeutically cathartic: one, a support group for teens whose parents all
had advanced cancer, the other a bereavement group composed of six girls,
all of whom had lost their nurturing parent. Many of the teens in the bereave-
ment group had “grown up” in our programs, joining the family groups years
earlier at the time of their parent’s diagnosis, and staying with the program
over several years through their parent’s death and family reorganization.

In mid-spring, the parent of a teen in the support group died suddenly
and unexpectedly. Normally this would have prompted the transition of that
teen, after appropriate closure, to the bereavement group. Yet, he was one of
three boys in the support group and had built solid, trusting relationships
with the other boys and girls in the group. The bereavement group at the
time was composed of girls who had been together for over a year and were
very close. Moving this particular boy to the bereavement group was
clinically contraindicated due to the close relationships between participants
in each group that would have been disrupted with the change. All other ill
parents of teens in the support group at that time had terminal prognoses.
The decision was made to restructure the philosophy of the program at this
point to emphasize continuity in clinical relationships between participants,
rather than illness stage, which was previously the prevailing model.

First, this readjustment required facilitators to simultaneously support
teens with disparate concerns and experiences. With the first death of a
parent, this group transitioned into a mixed bereavement or support group.
Some teens became more fearful of losing their parents, yet they remained
supportive to each other and invested in each other’s lives. Over the passage
of 6 months each ill parent died, and the group shifted its focus to bereave-
ment issues. This model provided adolescent participants a number of
opportunities not afforded in the earlier model. Those expecting the death
of a parent had a roadmap for the impending loss; they had seen peers go
through the process, and they could learn from and garner strength from
their friends. Second, this model empowered students who experienced
losses earlier in the process to help guide others through, sharing strengths and challenges.

This new clinical model required a number of conceptual shifts to our organizing principles. First, the group was now simultaneously a support group and a bereavement group. This required facilitators to integrate two disparate clinical orientations, each with its own psychosocial agenda. Teens in the mixed group were conceivably in three distinct stages of the cancer process at once: cancer treatment, dying, and bereavement. Supporting teens with ill parents in this environment required clinicians to maintain a specific hope in the face of insurmountable and highly visible odds, given the presence of bereaved peers in the group. Furthermore, we were initially concerned that teens with parents still alive would feel inhibited talking about their fears, perceiving them to pale in comparison to losing that ill parent. We were concerned, too, that the first bereaved teen would feel out of place, singled out, placed in the position of expert on death and dying for soon-to-be bereaved peers. These concerns proved to be unfounded. The common thread was that all had experienced the unthinkable, and their lives were changed forever. The reality of this change enabled cohesiveness. Each teen may have been in a unique place on the cancer continuum, but they realized, as did we, that they were all on the same boat, just in different seats.

Turtles: Support for Children and Parents

The clinical successes of this new organizing principle on service provision to children and teens guided the redesign of a number of different programs. Our first planned application of the new model occurred during enrollment for a new support group for children and their parents. Services for younger children at Wellness House included a program of concurrent groups for parents and children aged 5 to 11. Each group met separately for an hour, coming together for 15 minutes at the end for children to share their work with parents. The passage of families through these programs was also quite linear: Children progressed from Kids I to Kids II, stayed in Kids II for up to several years, and sometimes returned during a recurrence. Similarly, while Turtles, the bereavement program for children and parents, initially moved children through in 8 to 10 weeks, families enrolled for multiple consecutive quarters, staying for as long as 18 to 24 months. We used the metaphor of the “turtle” throughout the bereavement group experience. Parentally bereaved children may become withdrawn and emotionally detached from their family and social worlds (Webb, 2002) and “hide like a turtle.” The clinicians’ job is to facilitate emotional expression, to reconnect children with their environmental supports, and to encourage communication with loved ones about their experience or to help children “come out of their shell.”

The parent component of the Family Matters programs was initially designed to support engaged parenting throughout the cancer experience.
As the children’s program grew, the parent component evolved to serve traditionally supportive as well as psychoeducational functions. Ill parents tended to be much younger than their counterparts in traditional support groups and were grappling with disparate life cycle issues. Further, limited energy and resources for childcare prevented parents from attend evening support groups aimed more generally at adult cancer patients. The clinical team thus adapted the Family Matters parent programming to meet the needs of parents holistically. Parents were able to participate consistently and fully, knowing their children were well cared for in the next room.

During the period after our initial success with the new model in the teen program, five new families contacted us for services, and 10 children were enrolled in Kids I. Four ill parents out of five had a terminal prognosis, and expectations were that the deaths were imminent within a number of months. After the first few meetings, the fifth family dropped out of the program; the parents wanted to protect their children and themselves from the anxiety that was clearly palpable after exposure to families with more serious prognoses. This highlighted the notion that placement consideration must be given to where a family is on the diagnostic and treatment continuum. We decided at the start of the group to keep the remaining group of families together through the losses instead of folding them into the already very large Turtles program, where many of the children were already over a year away from their parents’ death.

The children in this group showed marked improvement in communicating their needs and feelings to parents and loved ones. They led family discussions, opening up blocked or taboo subjects for their families. After addressing burial and cremation in one group meeting, a 4-year-old girl went home, jumped up on the bed with her terminally ill father, and asked if he would rather be buried under a tree or in a garden. Her parents had been unable to discuss his wishes up until that point. The girl's frankness enabled this much-needed discussion. A 5-year-old girl was afraid to go into her kitchen after our discussion of cremation for fear of being near the family's stove. She shared her concerns with her father, and he immediately allayed her fears. A neighborhood bully teased a 6-year-old boy about his mother being sick. It was, in fact, his father that was ill. Through role-play and group support, this child was able to successfully confront the bully and end the harassment. As a group, these children became unafraid to discuss what was happening in their lives; they shared feelings and worries with their parents, and they stayed on track developmentally, academically, and socially.

The parent component of this particular Kids II group was initially run as a couples support group, with ill and caregiving spouses attending together. As the ill partners became increasing disabled, the group transitioned slowly to address anticipatory grief and the challenges of caregiving. During this transition, the clinical team worked to balance support of those couples struggling with end-of-life issues with the needs of newly bereaved
husbands and wives. After a matter of months, as each ill parent died, the process transitioned again to focus on bereavement. The dynamic nature of this group allowed parents to have their needs met and to return to their children with increased time and emotional energy.

LESSONS LEARNED: BALANCING RESOURCES WITH POSSIBILITY

Teaching children coping skills and providing them with concrete, age-appropriate, medical, and psychosocial information about cancer and its treatments reduces anxiety and parental burden. A significant part of the intervention in both groups was to give families a common language and structure to talk about the changes and challenges they were facing. This shared language helped families feel their challenges were manageable and promoted resilience. As the work was conducted with parents and children concurrently, families experienced greater communication at home. Parents became accustomed to their children’s matter-of-fact approach to asking questions and talking about fears. The children became unafraid to discuss with their parents what was happening in their lives; they shared feelings and worries with their parents. Open communication allowed children to trust parents to tell them the truth.

The preservation of continuity that marked the most significant shift in our program enabled a multifamily group structure to contain the distress of the cancer journey. Families came together in a safe and consistent space to support each other and to ask for help. The community enabled parents to express vulnerabilities and fears and to share triumphs and tragedies. Families in the group maintained social ties beyond the group structure, enabling socializing in a context where the cancer journey was shared and understood.

Maintaining Flexibility on Limited Resources

As cancer transformed into more of a chronic illness, we saw cohorts of families coming through together. The longer they stayed, the more heavily invested they were in each other’s well-being. The unifying factor across families was not disease type or staging. It was the intensity of a relationship forged in adversity, the common challenge of leading a family through crisis and reconstruction. Yet a significant motivating factor in adapting the new model was our lack of human and financial resources. We were unable to run three simultaneous teen groups or add an additional child bereavement group at the time these conceptual shifts occurred. Yet the new group structure required us to work simultaneously in both supportive and bereavement modalities. Our decisions, therefore, were made with attention to the careful balance between what was clinically indicated and what was feasible.
We recognized at the time that the decision to place people in groups that address the psychosocial needs of families at multiple points along the cancer continuum may only be indicated where all group members are in similar situations. Otherwise, the process may risk causing harm to families not facing an imminent death. The newly diagnosed may only have their fears exacerbated and their distress and hopelessness increased. At the time the children’s group formed, we did not have another program option for the fifth family, and we lost them. One of our toughest lessons was that we could not help everyone.

The Team Approach: Implications for Supervision and Self-Care

During many group cycles, it was common that the adolescents in our teen program were big brothers and sisters to children in the Kids and Turtles programs. Frequently, the clinical team had weekly contact with each member of a family. The team approach facilitated our work with these families, enabling us to frame cancer as a family challenge. With all family members present, the clinical team was able to help families to negotiate a novel family structure and process in the midst of crisis and recovery.

Joining families with young children at the point they enter the dying process invited a high degree of ambiguity and continued to be emotionally exhausting for clinicians. Clinicians frequently become a crucial part of family life through the illness experience and mourned each death with bereaved spouses and children. We attended wakes and funerals, coached bereaved children as they constructed eulogies, and worked regularly with rage and extreme sadness. Doing this work was an extraordinary privilege, yet we found ourselves constantly grieving. The support of our colleagues was crucial to remaining engaged with the work and to preventing burnout. To preserve longevity, we recommend this work be carried out, wherever resources allow, by a team of clinicians who can provide each other with technical and emotional support through group and peer supervision. In the safety of the team context, clinicians must monitor and explore their own relations with loss and terminal illness. They must be willing to be vulnerable about their feelings and aware of their propensity to rescue the family to remove the pain of the loss that is ultimately a natural part of this process.

REFERENCES


