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To cite this article: Alison Snow LCSW & Kristen Gilbertson LMSW MPH (2011) The Complexity of Cancer in Multiple Family Members: Dynamics of Social Work Collaboration, *Social Work in Health Care*, 50:6, 411-423, DOI: [10.1080/00981389.2011.579693](https://doi.org/10.1080/00981389.2011.579693)

To link to this article: <https://doi.org/10.1080/00981389.2011.579693>



Published online: 20 Jul 2011.



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The Complexity of Cancer in Multiple Family Members: Dynamics of Social Work Collaboration

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This article presents a case study of one family affected by a cancer diagnosis in both the father and the daughter, who were diagnosed within the same time interval and who underwent treatment at the same time. The article examines the relationship between the caregivers and the oncology patient as well as with one another when the stress of diagnosis is compounded by multiple, simultaneous, and similar diagnoses in a highly condensed period of time. A thorough examination of the literature reveals that there are significant gaps regarding how multiple cancer diagnoses in one family affect the family dynamic, individual and collective coping styles, and caregiver burden. The diagnoses can also dramatically exacerbate economic stressors in a family. The coordination of psychosocial care from the perspectives of the adult and pediatric oncology social workers at an urban academic medical center will be discussed. The social work role, importance of collaboration, and family centered care perspective will be discussed as a method of easing the treatment experience for families in psychosocial distress.

KEYWORDS *cancer, hematology/oncology, families, social work collaboration, caregivers*

Received September 14, 2010; accepted April 1, 2011.

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INTRODUCTION

A cancer diagnosis not only impacts the individual diagnosed, it significantly affects the entire family, especially the caregiver and the children. The cancer diagnosis “reverberates throughout the family system” (Ell, Nishimoto, Mantell, & Hamovitch, 1988, p. 429). An estimated 1,529,560 new cases of cancer diagnosed in 2010 reflects the large number of individuals and families affected by this disease (American Cancer Society, 2010). Since cancer is one of the leading causes of death in America, many families have had to struggle with the overwhelming impact of the disease (American Cancer Society, 2010). Furthermore, due to the high incidence of cancer and mortality rates among those between the ages of 25 and 44, people in this age range are most likely to be in the process of raising children and confront poignant issues about the impact of their illness on their abilities to care for their children (Steele, Forehand, & Armistead, 1997). Moreover, it is not that unusual for the disease to affect the same family twice (Cox, 2009). Despite the increasing occurrence of multiple family members undergoing treatment for cancer, to date there is little research on the psychosocial impact and effects on the family structure.

In exploring the literature, most of the existing research has focused on the experience of the patient with cancer, the spouse/caregiver of the patient, and the impact of parental cancer on children. Cancer has been rated as a significant stressor for patients and spouses and reports have indicated that the disease adversely affects the marital relationship and daily functioning of the family (Stenberg, Ruland, & Miaskowski, 2010; Braun, Mikulincer, Rydall, Walsh, & Rodin, 2007; Compas et al., 1994; Kaplan, Grobstein, & Smith, 1976; Lansky, Cairns, Hassanein, Wehr, & Lowman, 1978). There are numerous studies that provide evidence of the psychological distress experienced by family members during the phases of diagnosis, treatment, terminal disease, and bereavement (Swore Fletcher, Dodd, Schumacher, & Miaskowski, 2008; Nijboer et al., 1998; Ell et al., 1988; Faulkner & Davey, 2002). The psychological adjustment of children of cancer patients is less well understood than that of patients and spouses (Compas et al., 1994). It was reported that parental chronic illness disrupts children’s psychological adjustment by disrupting the family processes, including strained marital relationships, emotional distress of the parents, and the parent/child relationships (Steele et al., 1997; Faulkner & Davey, 2002). Furthermore, children experience loss during a parent’s illness as a result of hospitalizations, increasing limitations on parents’ physical and emotional accessibility and role functioning, and often a decrease in family financial resources (Siegel et al., 1992; Drotar, 1981).

Pediatric oncology incidence rates have increased in the past 30 years and cancer is now the leading cause of death from illness for children in the United States (National Cancer Institute, 2009). In 2009, there were an

estimated 10,730 new cases of cancer in pediatric patients between the ages of 0–14 years (National Cancer Institute, 2009). Although incidence rates have increased over the years, the survival rate for children with cancer has increased significantly as well, which speaks to the progress made in pediatric oncology treatment; however, for children enduring treatment there are still complex psychosocial issues associated with treatment. Experiencing cancer during childhood has a significant impact on a child's emotional and psychosocial well being. Moreover, children with cancer were found to have higher levels of anxiety and are at a higher risk for developing depression (Li, Chung, & Chiu, 2010).

The diagnosis of cancer during childhood is a major life stressor for the entire family. Parents and siblings are at risk for developing psychosocial and psychiatric problems throughout the course of the illness and its arduous treatment (Goldbeck, 2001; Fife, Norton, & Groom, 1987). Fife and colleagues (1987) found that families with preexisting problems experienced worsening in family life and had trouble in coping with cancer diagnosis. Decrease in parental quality of life as a result of cancer diagnosis in the child has also been reported (Goldbeck, 2001). For parents, having a child diagnosed with cancer is one of the most severe stressors the parent will experience in their lifetime. Parents experience a significant increase in emotional distress during diagnosis and treatment that impacts both their emotional health and their physical health (Rabineau, Mabe, & Vega, 2008). Parents are often described as “hidden sufferers” who may experience more psychological distress through watching their children undergo the diagnosis and the treatment process (Rabineau et al., 2008). Parents are highly aware of the emotional struggles their child undergoes during treatment and at times feel there are more supports in place for their child than the parent enduring treatment (McGrath & Phillips, 2008).

Many studies examined parental coping with a child with cancer or children's or caregivers adjustment to an adult with cancer in the family; however, there are significant gaps in the literature involving multiple family members with cancer. The following case example illustrates the difficult circumstances that patients and families face when cancer strikes the same family twice.

SOCIAL WORK COLLABORATION

In a medical setting, professionals often work closely within a multidisciplinary team to address the diverse medical and psychosocial needs of patients. Although working within a multidisciplinary team is common to address a patient's needs, it is not customary for social workers to partner with other social workers on a particular case. Social workers in a hospital setting are often assigned by unit or clinic and usually do not have

the opportunity to collaborate to address psychosocial needs of a particular patient or family (Berkman et al., 1996).

Intraprofessional collaboration involves two or more persons from the same agency (Lawson, 2004). Working in partnerships of two or more professionals is considered beneficial and can improve service delivery (Hudson, 2002). Moreover, partnerships or teams can be effective as long as members have a clear understanding of their role and responsibility and are willing to communicate well with each other (Lymbery, 1998). Collaboration involves interdependent, autonomous stakeholders with their respective competency areas, who mobilize resources, and coordinate their operations to solve shared problems. Social workers collaborating must determine shared responsibilities and accountabilities as well as share resources and reconfigure roles accordingly (Lawson, 2004).

Collaboration is a complex intervention for the right circumstance and can be an optimal practice (Lawson, 2004). According to Lawson (2004) collaboration is necessary when problems co-occur and become intertwined so that addressing one also requires addressing the others. Since social workers are primarily organized by area or subspecialty, their collaboration requires that they adjust their processes, decisions and actions toward issues associated to the problem area that brought them together (Wood & Gray, 1991).

This case study will highlight a successful collaboration among two social workers in a medical setting and illustrate how the social workers were able to work together to address the various psychosocial needs of a family. This case example will also provide insight into an immigrant family struggling not only with adjustment to this country and its customs, but further complicated by life threatening illness and having limited familial support through the disease process due to the fact that their families of origin are scattered around the world.

CASE EXAMPLE: THE DAUGHTER

Eva is a 5-year-old girl. She is the only child of a 36-year-old mother and 44-year-old father. Her parents immigrated to the United States from Eastern Europe several years ago in search of a better life for themselves. Eva was referred for social work services after being diagnosed with Acute Lymphocytic Leukemia (ALL). All pediatric patients diagnosed with cancer are referred for social work services at time of diagnosis within a medical setting. During the initial meeting with Eva she presented fairly withdrawn, quiet, and relied heavily on her parents for information regarding her diagnosis.

The social worker conducted an intensive psychosocial history of Eva prior to developing a treatment plan. Eva was developmentally appropriate

for her age and had successfully reached all significant milestones. Eva maintained good eye contact and engaged well with those around her. Prior to diagnosis, Eva had no behavioral problems or developmental delays. She was enrolled in school and considered to have above average intelligence for her age. She was able to develop strong peer relationships and did not exhibit any significant behavioral problems while at school or at home.

Eva came from a very intact and supportive family. The parents had been married for several years and had a loving supportive marriage. The family migrated to the United States in hopes of establishing a better life. As a result, the family had little to no family support in the United States but they had formed a good social support network of friends and neighbors. Eva's father was working multiple jobs to support his family and the mother worked full time to contribute to the financial stability of the family. Both parents felt strongly it was important to work hard and support the family in hopes of guaranteeing that Eva would have opportunities later in life.

Eva's mother had no health issues and was the primary caregiver most of the time. In the social worker's initial assessment of the family, the parents reported that Eva's father, Henry, had been diagnosed with cancer a few years ago and at time of Eva's diagnosis he was still receiving active treatment. The family had been struggling emotionally with Henry's diagnosis for some time and now appeared to be severely distraught that they would now be forced to deal with cancer in yet another family member; especially their only child. The parents had told Eva that Daddy was sick but had not elaborated on his condition or explained in detail to her what cancer was or the seriousness of a cancer diagnosis. The parents initially were very overwhelmed on how much information to share with Eva regarding her own condition and the treatment process. The social worker and the medical team worked with the family on explaining the importance of relaying information to child in appropriate terms for their age and how increased knowledge of illness can help reduce trauma of medical intervention. The social worker and medical team were very clear in discussions with the family and Eva that her father had a different type of cancer and that the treatment protocols were considerably different.

Henry had expressed to the social worker how grateful he was for her assistance and the impact it had in helping them cope with diagnosis and treatment of Eva. The social worker began to notice during sessions with the family and Eva that the father was struggling emotionally with his own cancer and did not feel comfortable talking with the social worker about these feelings because he wanted the focus to remain on his daughter and not him. The social worker had noticed these issues for several months; however, at that time Henry had not been a patient in the hospital and had been seeking outpatient services at another facility. Several months into the treatment process for Eva, Henry was admitted to the same hospital as his daughter for complications related to his own diagnosis. At that time, the

pediatric oncology social worker visited Henry several times and began to see how much he yearned to express his own fears and emotions related to confronting cancer. It was at that time that the social worker was able to refer him to an adult oncology social worker.

Throughout treatment of these two family members the adult social worker and the child's social worker would formulate a strong collaboration and ensure this family received the appropriate supportive services needed when dealing with two family members undergoing treatment for cancer at the same time. The family would also appreciate having two different social workers available to deal with the diverse needs that arose. Unfortunately as treatment for Eva progressed, her father eventually became much more ill and developed several complications. Eventually he passed away during Eva's treatment and this would prove to be a huge emotional challenge and loss for Eva and her mother.

Social work services for Eva initially centered on helping her adjust to diagnosis and treatment, as well as, for allowing expression of emotions related to trauma. After initial meetings with Eva, it became evident that she was having a challenging time coping with medical interventions and life changes. Although Eva was a very talkative child she had a difficult time verbally expressing herself and her emotions. Play therapy was chosen as the modality of intervention for her because it allowed for her to express herself without having to use words. The social worker engaged Eva in play therapy on a weekly basis throughout treatment to allow for her to reenact trauma occurred during treatment and gain a sense of control and mastery over diagnosis and the treatment process.

Eva responded well to play therapy and over time began to feel much more comfortable with treatment and being in a medical setting. She continued to gravitate toward medical play therapy and would reenact treatment stages over and over again in play. Eventually, she obtained a sense of mastery over her medical experience and requested play therapy sessions less frequently. The social worker was able to decrease the frequency of sessions and provided more supportive counseling to both Eva and her mother during appointments.

However, during the treatment process Eva encountered a significant setback in her coping mechanisms when her father passed away after battling his own illness and Eva appeared to become re-traumatized by illness. At that time, the social worker worked extensively with Eva through play therapy as a means for her to express her feelings of grief, loss, fear, and her own depressive symptoms related to her own illness. Eva was very perceptive of her family's feelings of loss and grief. She did not want to verbalize any of her own emotions initially around her family because she felt fearful of adding to their pain. Instead she chose to express herself only through play and often incorporated imaginary play in sessions as a means of reconnecting to her father.

Eva was eventually able to deal with her own feelings of grief and began to process her emotions through play. The social worker allowed Eva to self direct her play sessions, which provided her the freedom to express any emotions she was feeling through play. The social worker and Eva never directly discussed the patient's loss of her father but instead discussed the impact of the loss in the metaphor because Eva felt most comfortable processing feelings indirectly. The social worker and medical team began to notice that over time Eva's behavior improved and she began to feel more comfortable discussing her father and focusing on her memories of him.

Eva's mother was very grateful of services provided to Eva throughout treatment but did not rely as heavily on social work intervention and treatment for her own emotional needs. Lana focused mostly on Eva's needs and would not emotionally express her feelings of loss or grief. The social worker's main intervention for the mother was providing concrete services to help ease stress and providing supportive counseling during medical visits. The mother remained grateful throughout treatment for services offered to both her husband and her daughter.

CASE EXAMPLE: THE FATHER

Henry was a 44-year-old Caucasian man originally from Bulgaria who came to the United States to seek a better life for himself, his wife and their daughter. He was diagnosed with chronic lymphocytic lymphoma in richter transformation to large cell aggressive lymphoma and had been undergoing chemotherapy treatment for his disease for about a year, when he met his social worker. Henry met his social worker upon his first hospital admission. The adult oncology social worker received the referral from the pediatric oncology social worker, since Henry's daughter was being treated for ALL and she noticed that there was no social worker involved with him yet. Although Eva's pediatric oncology social worker knew Henry, she could not provide support around his illness or be his primary social worker.

Prior to his admission to the hospital, Henry had been going to a private practice in Queens and was eventually transferred to Mount Sinai Medical Center because his illness progressed and he required more specialized treatment and an opportunity to participate in clinical trials.

Henry worked for a credit card company in New York City; however, he was a physician in Bulgaria. His wife, Lana, worked as a teacher's aide in a public elementary school in Queens close to where they lived. Henry immediately opened up about his financial concerns primarily with doctor bills because he stated that he had received numerous hospital bills and he steered the conversation around his financial concerns rather than his concerns about his life threatening illness. Therefore, the social worker's initial treatment with Henry focused around identifying and applying for

numerous financial resources since Henry was very concerned with providing for his family. After his discharge, social work continued to work with Henry by phone.

Henry was not responding to the chemotherapeutic treatments that he had received; therefore, Henry was admitted to the hospital several times and was enrolled in a clinical trial. He was being worked up for a bone marrow transplant. When Henry was re-admitted he knew that he was very ill as he understood the disease process and what was happening to him. Henry continued to express concern about his finances but began to open up more about his worries and feelings about needing to be there for his wife and daughter. Henry also felt terrible about the chemotherapy treatments that his daughter was taking, since he had taken some of the same agents and he knew the side effects and how powerful the medication was.

Henry's condition began to significantly deteriorate. He was transferred off of the oncology unit to the medical intensive care unit (MICU) and then to the respiratory care unit (RCU), where he subsequently died. During the social work visits to the MICU and RCU, Henry would always light up and smile. While Henry was in the RCU he was alert and aware, however, he could not speak because he was intubated and did not have the strength to write. Henry maintained his youthful and strong appearance, despite his advanced illness. Once he was admitted to the ICU the social work relationship shifted to more work with his wife and helping her to cope with the severity of Henry's illness and her difficulty being a caregiver for both her daughter and her husband. Social work provided supportive counseling to Lana as she expressed fear of losing Henry and how she would manage everything without him, her protector. Lana also expressed financial concerns, therefore, social worker continued to pursue financial assistance for the family. Lana's mother flew in from Bulgaria to help her caring for Eva while Henry was in the hospital.

While Henry was in the RCU, social work arranged for Henry to have a visit by the Musician-On-Call (a non-profit agency that provides weekly musicians who play at the bedside for cancer patients). The musician sang him the Beatle song, "In My Life." Henry's face lit up and it was evident that he was touched by the music and the musicians visit. Several days after that visit, Henry passed away on the day before his forty-fifth birthday.

Social work remained in close contact with his wife after his death and provided her with bereavement support. His wife discussed her appreciation for social worker's involvement with Henry, as she said that she felt it was important that he had someone neutral to talk to and to share his feelings with.

For many reasons this was a challenging and unique case. A father and daughter in the same institution both with hematological malignancies and both underwent treatments simultaneously. As a result the adult

oncology and pediatric oncology social workers were able to work together in providing support to a family in an extremely challenging situation.

Each social worker performed assessments of their respective patients and the primary caregiver, Lana. The social workers in this case were also able to collaborate on providing supportive counseling to Lana. Since Lana was so overwhelmed and in need of support, it was very helpful for the social workers to share that task. They were able to provide support without duplicating efforts, due to their constant communication. Lana's need for support was determined by which family member was requiring her attention. This allowed for shared responsibility among social workers and at times of high distress it provided Lana with more attention. Lana was understandably stressed throughout the treatment of her husband and daughter. Lana's stress was compounded by a shift in family structure. Family systems theory emphasizes patterns of relationships and this theory can be utilized when assessing how families adapt to cancer within in the context of the family's unique experience. In this case the family structure was formed years before and the existing boundaries and rules shifted due to the crisis of two cancer diagnoses. Lana and her husband both discussed how he was the caretaker of the family in terms of handling all of the finances. Lana had to adjust to becoming the sole caretaker of their daughter and to take on the role of dealing with their finances in addition to all of the emotional stress. Role changes including changes in expectations, responsibilities and relationships are common when a family member is diagnosed and treated for cancer (Stenberg et al., 2010). This reassignment of roles also creates a shift in power and responsibilities, which is common at the diagnostic and recurrence phase of cancer (Veach, Nicholas & Barton, 2002). In crisis families tend to share responsibility in decision making; however, Lana did not have this opportunity to the same degree as she might have if only one family member was sick (Veach et al., 2002). According to Veach and colleagues (2002) families tend to pull together and mobilize their resources to support each other through a crisis. With a cancer diagnosis the family is forced to adjust to the new treatment regimens and altered roles while mourning the loss of the life they had prior to the illness. Families have their own individual responses to cancer diagnosis, treatment, and recurrence; however, relationships with social workers can assist families to gain a sense of control and to discover meaning during a time of crisis (Veach et al., 2002).

While numerous articles highlight the negative aspects of caregiving for cancer patients including depression and marital dissatisfaction, Nijboer and colleagues (1998) pointed out that women at a younger age tend to perceive caregiving as a more negative experience and report higher levels of distress. Cho, Dodd, Lee, Padilla, and Slaughter (2006) reported that women were found to have higher fatigue levels thereby making female caregivers more vulnerable. Additionally, higher fatigue was associated with lower incomes (Gaston-Johansson, Lachica, Fall-Dickson, & Kennedy, 2004). Lana, a woman

in her thirties, who emigrated from Eastern Europe, was in a vulnerable position as a result of the loss of her husband's income, her low salary as a school aide and her responsibilities as a caregiver, mother, and wife.

For families with young children the unexpected diagnosis of cancer within the family disrupts the progression of life events and the family's natural development (Veach et al., 2002). The untimely occurrence of the cancer diagnosis twice within this family made this case particularly devastating. Moreover, Nijboer and colleagues (1998) reported that a caregiver's physical and psychological endurance tends to diminish as the exposure to multiple and long-term stressors continue. Lana coped by receiving assistance from her mother and friends in her community. Additionally, each social worker was also able to locate financial resources to assist this family from the pediatric oncology foundations and from the adult oncology foundations.

The social workers in this case also helped the physicians and multidisciplinary team to understand the family dynamics. They were able to explain Lana's high level of distress and communicated the family's complex situation to various health care providers as way to ensure continuity of care and appropriate levels of sensitivity in both the adult and pediatric services.

The collaboration between the pediatric and adult social worker not only helped to support this family in need, it helped the providers to ventilate their own feelings of sadness related to this case. The case was particularly emotional for the social workers involved in this family's case because of the extent of emotional turmoil the family endured throughout treatment and the loss of the father. Oncology practitioners work with traumatic cases often and it is important for them to process their own feelings in order to prevent emotions from negatively impacting their work (Delvaux, Razavi, & Farvacques, 1988; Turner, 2004). The two social workers involved in this case not only relied on the support of each other throughout their work with the family in formulating the best treatment plans for the family, but they relied heavily on each other to help process their own feelings of grief and loss related to the father's death. Attention to self care for oncology practitioners is essential, especially since chronic stress may lead to the development of burnout for oncology health professionals (Delvaux et al., 1988).

IMPLICATIONS FOR FUTURE RESEARCH/CONCLUSION

As medicine advances, the course of cancer is shifting to a chronic illness where families and caregivers will face increasing challenges in caring for patients at home and increasing odds of a double occurrence of cancer within the same family. As the primary psychosocial care providers in the health care setting social workers can be helpful in guiding families through a double occurrence of cancer in the same family (Cox, 2009). In

the situation where multiple family members are going through treatment, social workers need to be particularly attuned to the needs of the individual family both during treatment and after a patient completes cancer treatment.

It is important for the patient to identify that there are two members of the family unit with cancer receiving treatment at the same time, so that the health care team can appropriately provide support to this vulnerable patient population. Since patients and relatives involved with caring for two family members with cancer are often in need of psychological support, particular attention should be paid to this group. It is also important for social workers assessing newly diagnosed patients to screen for incidents of cancer diagnosis within family units, as many patients may have family members currently receiving treatment or having received treatment in the recent past. Additionally, attention should be paid to the experience of the caregiver(s) to ensure that quality care is being delivered to the patient's caregiver, especially since they are important to the clinical outcomes for cancer patients. Oncology patients may have more psychological stress if they have already experienced the treatment process with another family member and may have lasting emotional scars from treatment that could impact their own treatment decisions. We acknowledge that this single case study has limitations and encourage future researcher's to explore the incidence of multiple family members experiencing cancer diagnosis and the psychosocial distress that can occur, so that psychosocial supports and interventions can address these issues appropriately.

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