In the Shadows: Parents of Seriously Ill Adult Children

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Life-threatening diseases are being diagnosed at younger ages and successfully managed for longer periods of time. Adult patients increasingly will have parents who want to be present and help during treatment. Little is known about how best to include parents of adult children in the nursing plan of care. Healthcare professionals must balance the independence and privacy needs of adult patients with parents’ desire to help and provide care.

Luann and her mother Jean have both had breast cancer; Luann now at the age of 34 and her mother 10 years before. Luann comes to the cancer center for chemotherapy every two weeks, accompanied by her husband or her mother. Her planned course of treatment includes bilateral mastectomies with reconstruction, chemotherapy, and radiation therapy.

Jean’s help is constant, quiet, and frequently not noticed by the healthcare team. Luann says, “My mother just knows what to do. She got in the shower with me to hold my drains right after the mastectomy. She is always there for me.”

Jean’s biggest contribution to Luann’s care is helping with her three young children. “Her help with the kids lets me focus on treating the cancer,” Luann explains. “If my mom is taking care of my kids, I can take care of the cancer. That includes educating myself and attending my appointments.”

Nursing Assessment

Illness involves the whole family, and nursing history includes identification of important family members. Adult patients are asked about spouses, significant others, and children; however, frequently, the role of parents in patients’ lives is not considered essential beyond the pediatric age group.

Family science has begun to research relationships among parents and healthy adult children, but understanding is in the nascent stages (Beach, in press). However, when previously healthy adult children become seriously ill, information on parental reactions and helpful interventions is primarily anecdotal.

That so few guidelines exist is not surprising. Adulthood is a long life phase, and developmental reactions to illness are complex. The stage of development influences the relationship between parents and ill adult children.

A young adult is developmentally focused on achieving independence. In this stage, the two most important tasks are establishing an independent lifestyle and building intimate personal relationships. Serious illness threatens this drive to independence. In addition, the meaning of illness and treatment may be seen differently by young adults than by parents.

Parents may see medical treatment, no matter how long or aggressive, as the acceptable price that must be paid for good care and survival. The young adult child may view it as a much larger forfeiture and long for the normal that they see with their friends, resenting the intrusion of the illness and treatment. “How much will this treatment get in the way of my lifestyle?” may be more important to the young adult than “Will I really die if I don’t [seek treatment]?” (Grinyer, 2009).

For an adult child who is older and has well-established independence apart from parents before the illness strikes, illness and treatment are viewed differently. Adults in their 30s and 40s may be actively involved in their communities. Work life is in its prime and childrearing takes time and attention. When serious illnesses occur, middle-aged adult children think of the effect of illness on their work, growing family, and social obligations. Parents and adult children are the most equal during this stage than at any other time in life. Serious illness requires renegotiation of the parent and adult child relationship. That is true particularly if a disconnect occurs between parents and adult children’s expectations of appropriate parental caregiving behaviors.

Sometimes the life cycle of dependence and independence does a full rotation, and the “elderly” parent becomes dependent on the adult child. Perhaps socially isolated, they rely on the adult child to visit and keep them in touch with the family. If the adult child becomes seriously ill and the visiting decreases, it may bring additional isolation and resentment from the parent.

Etiology

Luann’s mother, Jean, raised her and her sister as a single mother. Now 57 years old, Jean feels as if she has been a
Adult children will ask for advice when they want it. Advice that is meant to help should be given with love and kindness.

Once words of wisdom have been given, stop. The adult child decides what to accept or decline. This is not always easy. Parents may believe they know what is best.

Obtain education about the illness.

Ask what help is needed. Do what is possible, such as running errands, babysitting, or letting the dog out. If you say you will do something, do it.

If the relationship was strained before the illness, be patient. Dependable presence, without demand for attention, is best received.

Seek support for yourself and apply humor to otherwise difficult situations.

Find other parents who also have an ill adult child. Ill Adult Children is a Web site that offers support for parents (www.illadultchildren.com).

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**FIGURE 1. Guidance for Parents of Seriously Ill Adult Children**

Parent. More than 50% of all adults older than age 60 have at least one living parent. The reality is that parents and their children are together becoming at risk for cancer, heart disease, stroke, and other major illnesses (Croker, 2007).

The uncertainty of where parents of adult patients fit into plans of care may lead to labels such as “support systems” or “extended family.” Although they may no longer be considered next of kin, parents do not feel like extended family.

**Management Strategies**

“I admit I didn’t know what to do when Luann first got sick,” said Jean. “I knew how to be a mom to a sick young child. . . . But Luann was grown up and a mother of her own children when she got sick. . . . I didn’t want to get in the way. Luann and I are close. I wanted to help.”

Family-centered care is founded on the understanding that the family plays a vital role in ensuring the health and well-being of patients and provided in the context of the person’s physical condition, developmental stage, living situation, family, and community ties. Originally focused on the pediatric population, family-centered care became the ideal in health care for infants, children, and adolescents in the mid-70s (Klaus & Kennell, 1976). As the lifespan approach to health care gained momentum, family-centered care became an important characteristic of an effective patient and primary physician partnership (American Academy of Pediatrics, 2012; American College of Physicians, 2012).

Parents of ill adult children may be unsure how to help. Oncology nurses, because their relationships with patients are frequently long-term, often are in the best position to assist parents in helping seriously ill adult children. In addition, parents need to understand how the privacy of adult health information is protected. The Health Insurance Portability and Accountability Act of 1996 (HIPAA) gives adults control over the release of health information. Nurses should explain HIPAA with a courteous approach. Rather than emphasize their exclusion (“I’m not allowed to tell you”), highlight the positive respect that the privacy laws allow (“Your child has asked to tell you herself what the doctors have said”). With the consent of the adult child, some additional interventions may help parents adjust to having an ill adult child (see Figure 1).

**Conclusion**

Luann describes her mother and herself as fighters. “Attacking a new diagnosis is a different attitude if you have been exposed to other difficulties, to other fights. . . . It is not to say one is better or stronger, but it is just different.”

The parent and child relationship is important at any age, and recognizing that is essential to effective oncology care planning (Oncology Nursing Society, 2012). When parents are seen with adult patients, the healthcare team should talk to parents about their understanding of their adult child’s illness and listen to their concerns. In addition, adult patients should be asked about including their parents in care planning. Nurses must support the parent and child bond. But first, the critical relationship and needs of adult patients and parents must be brought out of the shadows.

**References**


Beach, P.R. (in press). *In the shadows: Caring for your seriously ill adult child*. Pittsburgh, PA: Oncology Nursing Society.


