In the Shadows: Parents of Seriously Ill Adult Children

Patricia Ringos Beach, MSN, RN, AOCN®, ACHPN, and Beth E. White, MSN, CNS

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