

TOWARD A BROADER UNDERSTANDING OF FAMILY CENTERED CARE: PARENTS OF SERIOUSLY ILL ADULT CHILDREN

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Objectives

- Discuss the effect of health care advances on family structure
- Utilize the principles of family centered nursing to examine helpful caregiving strategies for ill adult children and their parents



Adult Lifespan

- Adults are living longer and more often with chronic illnesses
- Chronic illnesses are being diagnosed at younger ages
- Health care advances in past 40 years
 - diabetes, hypertension, heart disease, stroke and some cancers are now chronic diseases, not always death sentences

Baby Boomers

- Those born between 1946 and 1964
- Over 50 percent have at least one living parent
- High risk for lifestyle related chronic disease
- Less certain that these adult children will outlive their parents

Baby Boomers and Health Care Advances

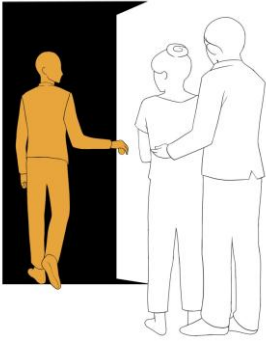
- First generation to receive massive immunization
- First generation with a choice about number of children they would bring into the world
 - Fathers in delivery room
 - Parent-child bonding
 - NICU care: very premature and babies with life threatening birth defects can now be saved
- Parenting became a verb

Parent/Child Relationship

- Close involvement of parents in young children's lives is an expectation
- Once children are grown, little guidance for what is an appropriate relationship
 - Life stage matters
 - Adult children and parents report having close ties
 - Parents of adult children report joy in adult children's accomplishments
 - Adult children report depending on their parents for comfort and support

Becoming My Own Person

- Goal of parenting: Raise an adult who:
 - Goal directed
 - Shows resilience
 - Interdependence
 - Contributes to wellbeing of their community
 - Spiritually connected
 - Able to form loving adult relationships
 - Contributes to the positive formation of the next generation
 - What is usually not a goal: leaving home and severing meaningful ties with parents
- *Parent/Child relationships are complex and evolving*



Parent/Adult Child Relationship

- Two importance factors to help nurses understand this complex relationship
 - The love between parents and children is not equal
 - Tension in adult child/parent relationships is normal
- Does not mean children do not love their parents or wish they would go away

Effect of Adult Child Illness on Parents

- Parents report grief reactions (sad, trouble thinking)
- Parents of younger adult children are more concerned with outcome vs. process
- Parents report worry, depression, feeling left out
- Some parents report resentment
- Most parents want to help



Family Centered Care

- Adult children look first to family members for help
- Spousal relationships are usually considered “front line”
- Parents are not next of kin to a married adult
- Parents report feeling left out of information and support from the health care team
- Do you think of parents of adult children as *extended family*?

Family Centered Care and Parents of Adults

- Family centered care means the family is included in all aspects of care planning
- But....what about HIPAA?
- But...what about protecting the autonomy of the adult child?

Family Centered Care and Parents of Adults

- Nurses can play a pivotal role in protecting the autonomy and privacy of adult children while practicing family centered care
- Parents typically understand intellectually that adults should make their own decisions....but may not transfer that knowledge
- Nurses can help adults decide how to include parents
- Nurses can help parents be the best help possible

Nursing Focus: Family Centered Care

- Ask patients if their parents are alive and active in their lives**
- If parents are part of the patient's life ask if they may receive information
- If parents may receive information, remember to include them in family conferences
- When adult children do not give permission for information, ask how they prefer we should respond if parents should ask
- **Some adult children are estranged from their parents. Respect those situations.

Nursing Focus: Family Centered Care

- Discuss HIPAA as a law that respects adults' rights to protect the privacy of their health information
- Avoid defensiveness: interpreted as dismissive and exerting power

The Right Words, The Right Tone

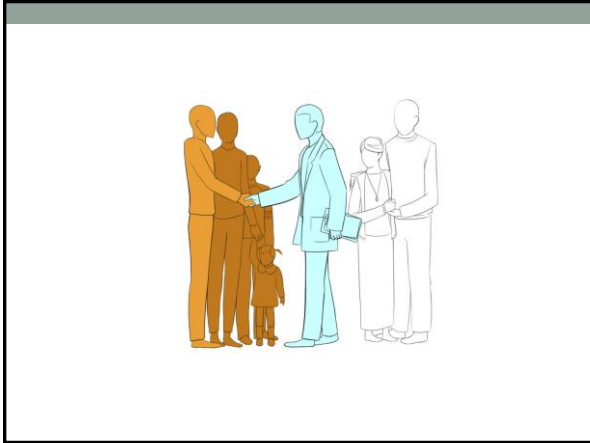
- Do use words such as,
 - “your daughter has chosen to keep this information private”
 - “your son as asked that he tell you what he has been told.”
- Avoid words such as:
 - “I’m not allowed to tell you,”
 - “I can’t tell you, it is against the HIPAA law.”
- Help parents try very hard not to feel hurt or angry
 - Use words such as “It is not always easy, since you may think you know best,”
 - Avoid words such as, “I can’t do anything to help you if your child won’t let me.”

Sources of Support for Parents

- *Advise parents to talk to others for advice and support. Trusted friends and clergy are good places to begin.
- *Web based support is a growing area. Explore it. Tell parents if your hospital or hospice has a web-based blog where parents can give out information they want others to have.
 - www.MyCareCommunity.org and www.caringbridge.org, and www.lotsahelpinghands.org.
- *Privately air angry or hurt feelings.
- *Gently remind parents to avoid negative comments about their adult child or spouse or their children in e-mails, blogs and other internet support sites.
- Write your story; Network with others
www.illadulthood.com

Once a Parent...

- Parents have taught their adult children how to live
- Parents may have to witness their adult child’s suffering and possibly death



Parents in the Shadows

- There is much to appreciate about this very strong bond between parents and adult children
- Let's bring parents of ill adult children out of the shadows

HELPING US VISUALIZE PARENTS IN THE SHADOWS:

ALEONA POLLAUFG, ARTIST

<http://aleonapollauf.com>



Thank you.

Please contact us with your stories
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