LIVING WITH DEMENTIA: PATIENT AND FAMILY NARRATIVES TO BUILD UNDERSTANDING AMONG HEALTH CARE PROFESSIONALS

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Key Discussion Points

• Consider the impact of the dementia diagnosis on the following relationships:
  • Patient-provider relationship
  • Person-family relationship
• Explore the experience of dementia in the African American community
• Incorporate patient and family experiences of living with dementia into educational activities that promote person-centered dementia care.

Grand Challenge in Dementia Care

• What is a Grand Challenge?
  A complex problem with broad impact that requires a concerted effort of diverse perspectives and skills to resolve.

• What is the Grand Challenge in Dementia Care?
  A four day interprofessional continuing education program to learn practical dementia care approaches tailored to meet the needs of patients during the various stages of the disease.

What better way to start the four day program off, than with the perspective from a woman living with dementia and her sister....
Meet Joyce and Denise

Joyce
- Dean of Academic Support Services & Professor of Education, Nyack College, NY
- Appointed to the National Early Onset Alzheimer’s Association
- Testified in front of the Social Security Administration in Washington, DC.
- Implementation of changes to the Compassionate Allowance Law for individuals diagnosed with Alzheimer’s.
- Diagnosed with dementia at age 56

Denise
- Program Manager for Adult Medicine at Duke Regional Hospital, NC
- A Geriatric Resource Nurse with Duke Medicine
- Certified in Gerontological Nursing

Something isn’t right...

Joyce’s perspectives
- Recognizing errors
  - Car accident & near misses
- Finding words are difficult
  - I used to talk and talk…
- Worrying about impact

Denise’s perspectives
- Not the sister I knew...
- What I feared most...

Getting the Diagnosis

Joyce
- 2006 Diagnosed
- Medical Professional support during the diagnostic process:
  - What helped
  - What didn’t help
- Increased risk among people of color:
  - Diabetes
  - High blood pressure

Denise
- Accepting the diagnosis
Impact on Professional Relationships

Joyce
- Who knew about the diagnosis
- Feedback from colleagues
- Administrative Staff
- Helped with Slide Presentations
- Direct reports knew

Impact on Personal Relationships

Joyce’s perspectives
- Different family members’ responses:
  - Still nothing wrong with Mom...

Denise’s perspectives
- Changing expectations
- More sensitive
- Sometimes reluctant to seek assistance

Living with the Disease

Joyce
- Importance of early intervention:
  - Occupational therapy
  - Family therapy

Denise
- How family can help with coping
- Balancing safety and self-determination
- Higher percentages of undiagnosed African Americans
Emerging Public Health Crisis

What the research shows:
• Greater prevalence among African-Americans than among non-Hispanic whites – 14% to almost 100% higher;
• Vascular disease - a powerful factor
• Greater familial risk in African-Americans;
• Genetic and environmental factors - different in the African-American population
• Screening and assessment tools and clinical trials – do not address unique presentation of disease in African-Americans

A Call To Action

• Accelerate the research and develop effective methods for managing and preventing the disease
• Increase awareness of Alzheimer’s among the African-American population
• Expand research participation
• Develop and expand affordable and culturally appropriate services
• Early diagnosis

They didn’t start out where they are now....
Joyce’s perspectives
• Being disagreeable....
• What it may be is just frustration....
• You know what you want to say, but you just can’t say it
• I don’t like for people to finish my sentences for me... just give me a chance....
• Learn more about who the person was....
Summary

Joyce

• Staying true to one-self, finding ways for the “core person” to continue to live life to the fullest despite disease limitations
• Advocacy
• God’s purpose

Denise

• Family role in supporting the “core person”

Engaging Patient and Family Perspectives in the Grand Challenge in Dementia Care

Participant evaluation key takeaways:
• consider the diversity of family members' responses
• ensure full professional support throughout the diagnosis process
• early intervention, particularly occupational therapy should be a goal of all providers
• find ways to support the person to continue to live life to the fullest despite disease limitations.

"The guest speaker was a phenomenal way to put a face to dementia. She was very informative."

• Follow-up activities:
  • Duke now sponsors a monthly Dementia Round-Table hosted at the Durham Technical Community College that emphasizes narrative pedagogy-case study methods (Geriatric Workforce Enhancement Project: HRSA-funded)
  • NC Institute of Medicine Task Force on Alzheimer’s and Related Dementias Incorporate patient-family narratives into policy discussions

Questions and Discussion
REFERENCES


• Davidhizar, Ruth DNS, CS, RN, FAAN; Lonser, Giny BA, RN. Storytelling As a Teaching Technique. Nurse Educator, Volume 28(5), September/October 2003, pp 217-221
