What Matters Most to Carers of People with Mild to Moderate Dementia as Evidence for Transforming Care

Debra Hain DNS, GNP-BC1, Theris A. Touhy DNP, GCNS-BC1, Gabriella Engström PhD, RN, RNT2

1Christine E. Lynn College of Nursing Florida Atlantic University 2School of Health Care, and Social Welfare, Mälardalen University, Eskilstuna, Sweden

PURPOSE

• To explore what matters most to family carers of persons with mild to moderate dementia in order to support them on their journey

METHOD

• Research conducted as part of free GNP consultations at Louis and Anne Green Memory & Wellness Center at FAU
• Audio-taped semi-structured interview:
  - Tell me about having your loved one diagnosed with a memory disorder?
  - What matters most to you right now?
  - What support and/or information, if any, do you need?
  - Describe what you think your future will be as a carer of someone with a mild to moderate dementia?
  - What are some of your future hopes and dreams?

DATA ANALYSIS

• Descriptive phenomenological approach using steps adapted from Giorgi’s method by Omery

DEMOGRAPHICS OF CARERS

• All female (n=10)
  - 7 spouses aged 61-80 (M 71.7); 3 daughters aged 45-68 (M 55.6)
  - Lived in single family home with person with dementia
  - 30% employed; 60% with more than high school education

FINDINGS

THREE KEY THEMES EMERGED:

• Seeking guidance
• Giving up self for the good of the other
• Being uncertain and frightened of the future

1. SEEKING GUIDANCE

As needs change, family carers frequently don’t know what is best approach and where to go for assistance

Sub-Themes:
- Not knowing what to do
- Having so many questions and finding nobody with all the answers

Not knowing what to do
Captures the ambiguity often associated with caring for someone with a progressive decline in cognitive function

“I just want help to guide me how to handle him and I have to change my whole personality because I can’t yell and scream at him.”

Having so many questions and finding nobody with all the answers
Difficulty knowing where to turn for advice and guidance; finding expert who will consider uniqueness of their situation

“Don’t know what to expect, everyone overwhelming me with their input.”

2. GIVING UP SELF FOR THE GOOD OF THE OTHER

Felt saddened by what was happening to their family member but they also wanted relief from the daily challenges and felt guilty for being frustrated and angry

Sub-Themes:
- I’m suffering too
- Doing it alone
- Struggling to keep normalcy

I’m suffering too
Carers described many stresses but often apologized for feeling selfish or getting angry and frustrated with their loved one

“You know I feel sadness for him because he is very sick, then I get so angry.”

“He deserves it and I will do it, but what about me.”

3. BEING UNCERTAIN AND FRIGHTENED OF THE FUTURE

Unable to control the future, they felt insecure and had no belief in the future

Sub-Themes:
- Living day to day
- Accepting the reality and not giving up

Living day to day
Learned not to plan ahead or think about the future because they didn’t know what was going to happen tomorrow so they struggled one day at a time

“My kind of refused to look at the future because it’s nothing I have control over. All I can do is just deal with a day by day situation.”

Accepting the reality and not giving up
They had to try to adjust to the situation and reorient themselves towards a different way of life in order to make life pleasurable as possible

“This is the kind of husband he is so he deserves anything I can do for him. How can you give up on someone.”

IMPLICATIONS FOR PRACTICE

• Avoid a one-size fits all approach. Dialogue about what matters most can be the basis for designing individualized interventions to meet expressed needs
• Extending support to carers must begin at the time of initial diagnosis and continue throughout the disease trajectory
• Information, support and interventions should be individualized and match the stage-specific needs
• Closer follow up care is important during the early stages of caregiving when formal services are lacking
• Caregiver intervention programs should include both individual and group modalities, education, counseling, support group, and care management

IMPLICATION FOR RESEARCH

• HCP consultation role; GNP particularly suited for this role
• Unique needs of male and ethnically and culturally diverse caregivers
• Longitudinal studies across the caregiving trajectory
• Evaluation of effectiveness of programs and services in meeting individual needs