Family Caregivers’ Perceptions of the Resistiveness to Care They Experience Caring for People With Dementia

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Disclosures

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• Learner objectives:
  – Describe how the descriptive scientific method can be used for nursing research relating to family caregiving
  – Apply the presented research findings in the formation of nursing evidence-based practice projects to support family caregivers experiencing resistiveness to care

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Prevalence of Caring for Someone with Dementia

- 5.3 million people in the US have some form of dementia
- 80% of all people with dementia are cared for at home by a family member or friend
Characteristics of Dementia Caregivers

- 8 years older than caregivers of other disease conditions
- Predominantly female (wife or daughter)
- Provide over 17.9 billion hours of unpaid care
- Saves the healthcare system an estimated $217 billion in care costs
Resistiveness to Care

- Resistiveness to care is:
  “invoked by a caregiving encounter and ...defined as the repertoire of behaviors with which a person with dementia withstands or opposes the efforts of a caregiver”

- As assistance with personal activities increases resistance is more likely to occur
Caring for Someone With Dementia

• 61% of family caregivers reported high amounts of stress
• 33% reported symptoms of depression
• 75% report concerns with their own health since becoming caregivers
• Nearly 2/3 of family caregivers admitted distress with behaviors displayed during caregiver assisted personal activities
Current Research Surrounding Resistiveness to Care

3 theoretical frameworks:

- Needs-Driven Dementia Compromised-Behaviors
- Progressively Lowered Stress Threshold Theory
- Stress Process model of caregiving
Identified Gap In Research

• Most challenging aspects of caring for someone with dementia is the behavioral symptoms of the disease

• Nurse caregiver interventions are proposed to:
  – improve recognition of resistive behaviors
  – decrease resistive behaviors

• Current lack of research on the family caregiver perspective of resistiveness to care
Purpose of This Study

• Understand family caregivers’ actual experiences during resistiveness to care
• Increase understanding for the development of interventions aimed at helping caregivers manage this stressful experience
• Assist nurses to holistically respond to the entire phenomenon
Research Questions

• What is the lived meaning of resistiveness to care as experienced by family caregivers when they assist people with dementia in daily activities?

• What is the general meaning structure of the phenomenon resistiveness to care as experienced by family caregivers when they assist people with dementia during daily activities?
Descriptive Phenomenology as a Method (Giorgi, 2009)

• Stays closer to the data
• Purely describes the lived event structurally without interpretation
• Outcome is a core meaning structure of the phenomenon
• Use of a “disciplinary” perspective during the analysis
Study Setting

5 Alzheimer’s Support Group meetings:

- 3 meetings were held in a nursing care facility
- 1 meeting was in a local church
- 1 meeting was in a local hospital
Data Collection

• Each family caregiver interview was digitally recorded
  ▪ 2 - family caregiver’s home
  ▪ 1 - support group meeting room
  ▪ 5 - nearby restaurant of family caregiver’s choosing

• Participants were given a $10 gift card to compensate them for their time during the interview
### Sample Compares With Current Literature

<table>
<thead>
<tr>
<th>Age: (in years)</th>
<th>Family Caregiver</th>
<th>Care Recipient</th>
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</thead>
<tbody>
<tr>
<td>Mean</td>
<td>71.1</td>
<td>82.1</td>
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<tr>
<td>Range</td>
<td>60-82</td>
<td>72-95</td>
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<tr>
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<td>3</td>
</tr>
<tr>
<td>Male</td>
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<td>5</td>
</tr>
<tr>
<td>Duration as Caregiver/Care Recipient: (in years)</td>
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<td></td>
</tr>
<tr>
<td>Median</td>
<td>4-5</td>
<td>4-5</td>
</tr>
<tr>
<td>Range</td>
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<td>0.5-20</td>
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<tr>
<td>Care Recipient Residence</td>
<td>Lives With Caregiver</td>
<td>Lives in Nursing Care Facility</td>
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<td></td>
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</tr>
<tr>
<td>Types of Resistiveness Described by Caregiver</td>
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<tr>
<td>Wanting to Leave</td>
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<tr>
<td>Refusing Personal Hygiene</td>
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<tr>
<td>Wanting to Drive</td>
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<tr>
<td>Not Wanting Help with Finances</td>
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<td></td>
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<tr>
<td>Resisting Everyday Caregiving</td>
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</table>
Analysis of the data using Scientific Phenomenology (Giorgi, 2009)

1. Assuming the attitude of phenomenological reduction and a nursing disciplinary perspective

2. Obtaining a sense for the whole of each description

3. Discriminating meaning units focused on resistiveness to care

4. Transformation of data from everyday language to nursing sensitive expressions of resistiveness to care

5. Synthesis of transformed meaning units to form essential consistent descriptions of the structure of resistiveness to care

6. Determinations of variations of the structure
We have solved the toothpaste problem, my daughter suggested that I just put the toothpaste on the brush and hand her the brush. So I did that sometimes, my wife got very shy, and she didn’t want me to be in the bathroom with her, so I was a little bit out of the picture as to what was going on. My daughter came and told me you know you have to make sure she cleans herself and all that stuff. But it seemed to be okay, she misses it myself.”

Sam has solved the toothpaste problem. Sam’s daughter said to put the toothpaste on the brush and hand it to PWD. Sam does that now. His wife got very shy and she didn’t want me to be in the bathroom with her, so I was a little bit out of the picture as to what was going on. My daughter came and told me you know you have to make sure she cleans herself and all that stuff.

Sam had difficulty knowing if his wife brushed her teeth so Sam and his daughter came up with the solution to put the toothpaste on the toothbrush and hand it to PWD to use. Sometimes PWD will not let Sam in the bathroom while she is performing her personal hygiene so Sam doesn’t know if she brushed her teeth.

As caregiver Sam doesn’t really know if his wife is getting clean as he tries to respect her privacy in the bathroom while bathing but his daughter doesn’t like this and insists that Sam be in the bathroom with her mother.
Partial Structure of Resistiveness to Care

**Triggers for Resistiveness:**

- Care Recipient Unexpected Behaviors
- Caregiver Agenda or Goal of the Encounter

**Resistiveness to Care - Essential Constituents**

- Sees Changed Person not the Disease
- Unexpected Emotional Responses
- Self-Questioning of Abilities
- Changed Perception of Personal Self
- Signal for Increased Future Caregiver Responsibilities
Caregivers’ Responses

• Use of Strategic Choices
  – Use of Logic/Reasoning
  – Telling “little white lies”
  – Relinquishing the goal or agenda

• Goal is to attain a transient “Stable State”
"I feel like I’m not doing enough for him [the care recipient]"

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“it [resistiveness to care] makes a lot of work. I know it’s not going to get any better because each day...I notice he’s doing something different”
“...So it’s like holy good god look what my life is cut out for. I’m getting [to be] more of a caregiver [than a significant other]”
“I don’t give a shit if he asked for it or not, I can’t... I can’t handle it”
“In my mind I’m thinking ‘why can’t you understand this?’ And she’s... screaming at me”

Resistiveness to Care - Essential Constituents

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- Signal for Increased Future Caregiver Responsibilities
Current Nursing Interventions

• Recipient unexpected behaviors
• Caregiver agenda or goals for the encounter
• Use of logic or reasoning
• Telling “little white lies”
• Achieving a “stable state”
Additional Opportunities for Research

• Utility of End-of-Life Caregiving trajectory and support of dementia family caregivers at the end of life
• Utility of the Chronic Illness trajectory to identify when family caregivers reach their “tipping point”
• Intervention research
• Clinical practice changes
Questions?
References


References continued

References continued


