Characteristics of Informal Caregivers: An Integrative Review

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Objectives

At the end of this session, the participant will be able to

1. analyze characteristics of the informal caregiver.

2. discuss the needs of the informal caregiver independent of the terminally ill loved one.

3. help the nursing community assist the informal caregiver with care and services.
Background

- 36 million adults provide care to someone over age 65 (National Alliance for Caregiving, 2009)
- Pennsylvania is ranked 4th for population >65 (Choosing a nursing home, n.d.)
- As of March 2009 >81,000 Pennsylvanians were placed in nursing homes (Choosing a nursing home, n.d.)
Literature discusses the following in relationship of the caregiver and the terminally ill patient:

- Caregiver burnout
- Stress
- Feelings of the primary caregiver with dementia:
  - Anxiety, depression, emotional stress, isolation, hopelessness and helplessness
Problem Statement

Informal caregivers of the terminally ill are faced with a myriad of feelings and responsibilities.
Purpose Statement

Purpose: To assist the nursing community in identifying characteristics of the informal caregiver independent of the terminally ill patient through an integrative literature review.
Research Question

What are the characteristics of the informal caregiver, independent of the terminally ill loved one?
Theoretical Framework

Fineout-Overhalt, Melnyk, Stillwell
& Williamson’s Hierarchy of Evidence
Hierarchy of Evidence

Level 1
• Systematic review or meta-analysis

Level 2
• Randomized controlled trial

Level 3
• Controlled trial without randomization
Hierarchy of Evidence

- **Level 4**: Case-control study or cohort study
- **Level 5**: Systematic review of qualitative or descriptive studies
- **Level 6**: Qualitative studies or descriptive studies
- **Level 7**: Expert opinion or consensus
Project Approach

Literature Searching as an Iterative Process

- Topic Outline
- Research Sources
  (Research Summaries, Books, Journals, Conference Papers, Dissertations, etc.)
- Identify New Topics and Authors
Sample Size

22 articles were analyzed
Data Collection

- CINAHL
- MEDLINE
- MEDLINE with full text
- Academic Search Complete
- PsychArticles
- ERIC
- SocIndex with full text
- PsychINFO
Search Strings

Informal Caregiver
- Terminally ill
- Hospice
- Stressors

Formal Caregiver
- Terminally ill

Characteristics
- Informal
- Caregiver
- Terminally ill
Data Analysis

Critical Appraisal Guide
Critical Appraisal Guide

1. Why was the study done?

2. What is the sample size?

3. Are the instruments of the major variables valid and reliable?
Critical Appraisal Guide

4. How were the data analyzed?

5. Were there any untoward events during the study?

6. How do the results fit with previous research in the area?

7. What does this research mean for clinical practice?
Findings

- Level VII: Expert opinion or consensus
- Level VI: Qualitative or descriptive study
- Level V: Systematic review of qualitative or descriptive studies
- Level IV: Case-control or cohort study
- Level III: Controlled trial without randomization
- Level II: Randomized controlled trial
- Level I: Systematic review or meta-analysis review
Level V Studies

- Literature Reviews
  - Little research found regarding coping strategies used by informal caregivers
  - Role & responsibility of caregiving: overwhelming, demanding & draining
- Spouses, adult children/children-in-law & Children caregivers were compared
  - Compared sociodemographics, resources, Stressors & psychological distress
Systematic Review

- Home hospice services were ineffectively focused on helping informal caregivers obtain practical nursing skills.

- Peer-reviewed
  - Not focused on nursing, but social workers
  - Emphasized caring for the caregiver
Level VI Studies

- Caregiver Care and Support
  - Informal caregivers expected communication from health providers
  - Informal caregiver experienced support from religious affiliations
  - Informal caregivers coped by using distractions
  - Informal caregivers channeled positive feelings
  - Informal caregivers expressed relief when they providers
Caregiver Care and Support, cont’d

- Positive responses from informal caregivers when additional support was received from hospice agency
- Informal caregivers expressed satisfaction when they received support from family and friends
- Some informal caregivers expressed difficult time sharing/expressing the caregiver burden with others
Comparisons of Caregiver Groups

- Daily hands-on caregivers vs. intermittent hands-on caregivers
- Men vs. women informal caregivers
- End-of-life vs. long-term care vs. short-term care informal caregivers
- Rural vs. urban informal caregivers
Communicating Caregiver Needs

- Open communication between informal caregivers and terminally ill loved ones was length of caregiving for the terminally ill open communication
- Length of caregiving communication about end-of-life
- Length of stay on palliative care units, desire to want more communication
- Due to avoidance, some informal caregivers did not want more information regarding the prognosis
Various Emotional Responses to Caregiving

- Ugandan informal caregivers considered hiring help
- Informal caregivers indicated that more training would be beneficial
- High level of strain among younger informal caregivers
- Physical, psychological and social strain was less with informal caregivers of cancer patients
Various Emotional Responses to Caregiving cont’d

- High subjective stress
- Quality of life of the informal caregiver decrease significantly over time
- Anxiety related to the fear of the unknown
- Role disturbance in women
- Feelings of inattention and neglect
- Informal caregivers felt trapped
- Exhaustion, tiredness, insomnia, lack of focus, mental confusion
Various Emotional Responses to Caregiving cont’d

- Informal caregivers with poor health and those who were younger in age had high prediction of stress
- Increase caregiver stress when terminally ill loved ones independence decreased
- Caregiver depression, anxiety and cognitive distress
- Psychological distress among younger caregivers
Level VII Studies

- Caregiver burden
  - Health effects
  - Financial burden
  - Inadequate preparation
  - Illness
  - Feelings of inadequacies
Implications

- Characteristics of the informal caregiver focus
  - Sociodemographics
    - Age
    - Relationship status
    - Financial status
    - Educational status

- Characteristics of the informal caregiver were assessed in conjunction with the terminally ill loved one
One was unable to discern the characteristics of the informal caregiver without evaluating their relationship to the terminally ill loved one/patient.
➢ Nursing community shouldn’t ignore the characteristics of the informal caregiver

➢ Understanding the informal caregiver is beneficial to a holistic approach to care for the terminally ill patient/loved one
Embracing the informal caregiver is key

Get to know them personally & individually

Address holistic approaches to include the family and the patient
Recommendations

- Bridge the gap in literature
- Conduct informal caregiver assessment upon admission
- Questionnaire to address, psychosocial, spiritual, and health assessment
- Mixed-method research
- Change the focus from patient-focus to a holistic approach
- Train nursing community
Warning Signs of Caregiver Stress:

- Physically – exhausted and worn out
- Emotionally – resentful, stressed, bitter
- Relationally – feeling used or unappreciated
- Financially – overwhelmed or depleted
Closing

This concludes my presentation. I would like to invite your questions.
References


