

Caregiving to CHF/COPD Patients

Australasian Association of Gerontology
Conference

Professor Anne Wilkinson
WA Cancer Council Chair in Palliative and Supportive Care
Edith Cowan University Perth, Australia
presented by Jo Hale from the WACCPC



Impact of Longevity & Disability

- ◆ Approximately 33% of baby boomers will reach at least 85 years of age
- ◆ The fastest growing segment of the elderly population is 85 + and most are women

Living longer something to celebrate; but comes with a price: a number of years of decline and disability – avg. 11/20 healthy years


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Facts About Caregivers

- ◆ Family caregivers provide 80% of all long-term care services - 30% supplement w/ paid providers
- ◆ Most caregivers (60%) are women
 - often “sandwich” generation (73% vs. 23% male)
- ◆ Most (70%) are middle aged or older
 - 30% are aged 65 or older (15%=45-54 yrs)
- ◆ 70% of those needing assistance over age 75+ are women – w/ few resources to meet needs

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Facts About Caregivers

- ◆ Caregiving now a more complex multifaceted role:  numbers in the community
 - Caregiving now vital to treatment goals/management
- ◆ Average number of caregiving hours/week has increased along with complexity:
 - 25% of caregivers report spending 21-59 hours/week
 - 16% report spending “constant care.”
- ◆ Value of informal caregiving: \$306 billion
 - 2 X annual expenditures on homecare/NH

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Caregiving and Illness Trajectory

- ◆ While substantial body of research exists on caregiving in general
 - Most on Alzheimer’s or EOL Cancer caregiving /disease
 - Little on distinctions or similarities across CG trajectories
- ◆ The illness trajectory is likely to play a significant role on patient/caregiver experience

What about Organ System Failure ?

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Study Design - Qualitative Study

AIM: explore various aspects of caring for patients with CHF or COPD

- ◆ 9 Focus Groups, conducted in Los Angeles, CA; May-August, 2006
- ◆ Each group = 3-11 adults providing care for a living patient with advanced CHF/COPD
- ◆ The groups lasted 1 1/2 to 2 hours, followed a standardized protocol.
- ◆ A trained moderator led the groups, audio /video taped.

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Focus Group Participants

- ◆ N= 66 (14 males/ 52 females (77%)
- ◆ Age: 20 + to 80's, 91% between ages 40 -69
- ◆ 66 % White; 21 % African-American; 9 % Hispanic - 4 % Asian, Am Indian, Native Hawaiian
- ◆ Income: range \$35,000 - \$55,000+
- ◆ Education: 79% some/graduate college
- ◆ 60% work FT, 21% PT
- ◆ Length of caregiving: median of 5 years

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ANALYSIS

- Data systematically analyzed using Atlas.ti (v. 5)
- Two trained coders independently reviewed transcripts
- Transcripts text analyzed for themes
- Analytical framework grounded in data
- Discrepancies/conflicts resolved by PI/Co-PI

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FINDINGS

5 themes emerged from the data:

1. Uncertainty/unpredictability of disease course
2. Understanding of Prognosis by CG/Care Receiver
3. Caregiving tasks
4. Impact of Caregiving
5. Caregiving Satisfaction

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1. Uncertainty/Unpredictability

- Defining characteristic of this trajectory: unpredictability of worsening symptoms
 - speed/quickness of worsening symptoms=crisis
 - usual result: ED visit or hospitalization in ICU
 - total disruption of patient/caregiver's lives
- Others described the stress/demands/disruption of these episodes
 - Demands on the CG: "always having to be present, to manage the situation"
 - Require constant adjustments in the CG's life that were highly disruptive

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1. Uncertainty/Unpredictability

- ◆ Caregivers described their own experience as constantly being:
 - "afraid," "scared" "worried" "in a panic" and "anxious"
 - "living on an "emotional roller-coaster," "sitting on a time-bomb," "living in a chronic/continuous emergency"
- "I lie awake at night waiting for it to happen... waiting... listening...are they breathing? Are they not breathing?"*
- CG constantly "check in" for reassurance

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2. Understanding of Prognosis

- Research suggests CHF/COPD pts/CGs lack an understanding of the condition, its prognosis, care needs are poorly addressed, and coordination & continuity are suboptimal
- Contrary to this literature: participants seemed well aware of ultimate prognosis;
 - a few had direct discussion with health care providers
 - most gradually recognized through successive exacerbations
- Little “false optimism” that the patient would “get better” and death the likely outcome

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3. Caregiving Tasks

- Wide range of CG tasks identified, ranging from “doing it all,” to just transportation/companionship and/or “checking in on them”
- Many described “confusion” of Pts regarding medications, diet regimens, and doctor appointments - cognitive deficits
- Underlying all caregiving tasks was the *explicit goal* of keeping the Pt “independent” / “stable” for as long as possible ; though many acknowledged it was “only a matter of time”

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4. Impact of Caregiving

- ◆ Caregiving was described as “unremitting,” they were “on call 24/7” and the job was “never ending.”

Unique feature:

having to always “be prepared” and “think ahead”
to ensure the safety and stability of the patient in the event of a crisis

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4. Impact of Caregiving

- ◆ Most caregivers felt unprepared to perform their role,
“It’s hard, hard work to take care of someone...”
- ◆ Many felt a sense of “helplessness” to relieve Pt suffering, esp. symptoms
- ◆ Most had little idea what to do to help – except ER
- ◆ Caregiving had a profound impact had CG lives, esp. their obligations to other family members & their social and work life

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4. Impact of Caregiving

Major Issue: The uncertain nature and ambiguous relationship with the Pt’s healthcare provider(s)

- ◆ The healthcare team ignored them & didn’t provide important information about the condition or what to do
- ◆ Taking an “active role” as Pt “advocate” as a way to control their own difficult situation
- ◆ Others felt that the quality of care for their family member was dependent on their participation

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5. Caregiving Satisfactions

- Positive relationship with the patient
- Positive view of oneself
- Satisfaction with the CG experience -- enjoyment of the tasks/role
- Sense of fulfilling a life purpose by providing care
- Improvement of the patient’s quality of life
- “Giving back” to the patient for what the patient has done for them
- Positive connection with their families through caregiving

A final theme:

avoidance of later “regret” for not having done “enough” or not spending this precious time with their loved one.

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Cancer Caregiving

Caregiving to Ca patients:

Substantial amount of CG provided, primarily at EOL

High out-of-pocket costs due to active treatment

Caregiving tends to focus on:

- patient needs for comfort (e.g., pain mgmt affecting pt Q of life)
- caregiver's need for information, support, assistance

Most Significant CG Tasks:

Managing patient's pain and fatigue and EoL issues

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Dementia Caregiving

Long, downhill course of progressive decline and disability- 75% care at home

- Mean survival from diagnosis to death 8.5 years; most in NH at death

Caregiving tends to focus on:

- CGs feel "on duty" 24 hr/day due care tasks
- long trajectory/length of time of caregiving

Most Significant CG Tasks:

- Managing Pt behavioral problems/functional decline/incontinence
- Many "losses": Loss of 'person', Loss to institutionalization
- CGs usually elderly also

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CHF/COPD Caregiving

Unique features place special demands on Caregivers

Complicated treatment routine: diet restrictions, exercise therapies, complex medication regimens, oxygen therapy, etc.-non-adherence= hospitalization; "sudden" death

Caregiving tends to focus on:

- Balancing and monitoring complex medications & symptom mgmt., "maintaining the status quo;"
- less information or support from providers than cancer/Alzheimer's

Most Significant CG Tasks:

managing breathlessness; erratic trajectory and uncertain prognosis; focus on treatment; pt/CG anxiety, depression unaddressed, few referred to hospice/palliative care

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Conclusion

◆ This study fill a major gap in CG research

- explores the demands on caregivers by advanced, chronic illness patients; starting point for other comparative examinations

◆ Findings from this exploratory work suggest that there are large unmet needs:

- communication, information on disease progression and "what to expect," training in symptom management

◆ Future research should explore the unique and consistent features of the advanced chronic illness caregiving compared to Alzheimer's Disease and Cancer caregiving.

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