Supporting Family Caregivers through Palliative Care

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❖ Family caregivers are the primary care providers.

❖ Models of care delivery are needed to support family caregivers.

❖ Family Caregiver support is needed across all Geriatric Illnesses including heart failure, COPD, dementia, cancer and frailty.
Case Example...

Juanita is a 56 year old Special Education teacher. She is single and 6 months ago her 35 year old daughter and 2 year old granddaughter have moved in with her so that her daughter can complete her college degree in the evenings.
...Case Example

Two months ago, her 87 year old widowed father Mario was diagnosed with colon cancer. He underwent surgery requiring a colostomy and is now receiving chemotherapy. He has now also moved in with Juanita. He has developed wound complications related to his diabetes, worsening CHF and a significant weight loss.
...Case Example

Mario's care includes transportation to frequent clinics visits, wound care, management of symptoms, ostomy care and management of multiple medications (14 prescriptions). He is ambulatory but very weak. He has also become depressed about his dependency on others and very anxious about his treatment.
Questions:

1. What is the best care that could be provided?
2. What are potential worst outcomes?
3. What support does Juanita need?
4. What can be done to support institutions / clinicians to deliver this care?
Palliative Care for Quality of Life and Symptom Concerns in Lung Cancer: Final Results in a 5 year Program Project

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This study builds on key recommendations from the Institute of Medicine on End of Life Care, ASCO Recommendations for Integrating Palliative Care in Cancer and extensive literature documenting deficiencies in usual care.
Usual Care

Diagnosis of Lung Cancer

Focus only on tumor

Patients experience high symptom burden (pain, dyspnea, fatigue, cachexia, depression etc) and that burden increases significantly with surgery, chemotherapy, radiation and disease progression

The patient experience results in parallel family distress and health system/economic burden

Early Stage Disease/Survivors
- No ongoing assessment and treatment of symptoms & QOL concerns
- No monitoring of disease recurrence

Late Stage Disease
- Urgent care for crisis
- Uncontrolled symptoms
- Delayed/no access to palliative care
- Late or no hospice care
Quality Care

Diagnosis

Focus on disease combined with concurrent palliative care to address QOL concerns

Patients with lung cancer and family caregivers receive attention to QOL domains (physical, psychological, social and spiritual)
- Symptoms are anticipated and controlled
  - Patient goals of care direct the care

Patient and family distress is minimized

Early Stage
- Palliative care for disease & treatment of symptoms
- Attention to QOL in survivorship

Late Stage
- Palliative care consultation at diagnosis
- Symptoms controlled
- Early referral to hospice
Lung Cancer QOL
A Model of Care for Patients with Lung Cancer and Family Caregivers

Assessment of QOL Concerns Including
• Physical
• Psychological
• Social
• Spiritual

Interdisciplinary Team Conference to plan care

Nursing Coordination of Care Based on IDT
• 4 Part Patient/Caregiver Education
• IDT Support
• Phone Support
Interdisciplinary Care Conference (ICC)

- Held after baseline questionnaires are completed
- Organized around the QOL domains (physical, psychological, social, spiritual)
- Patient reported data is summarized by the APN
- Each professional makes recommendations for post-op care (early stage) and palliative care related to QOL or symptom concerns (early and late stage)
- Tailored intervention is designed for each patient based on consensus of ICC team and input from the patient
# Key Teaching Points: Family Caregivers

## Part 1: Physical Well-Being and Self-Care

### Managing Patient Sx
- Appetite Problems/Weight Loss
- Skin, Nail, Hair Changes
- General Information on Caring for the Patient’s Physical Symptoms
- Breathing Problems and Cough
- Pain
- Constipation
- Fatigue
- Sleep Problems
- Nausea and Vomiting

### Caregiver Needs
- Caregiver’s Bill of Rights
- Caring for Your Own Health Needs
- Information on How to Quit Smoking

### Your Self-Care Plan

### Resources: Physical Well-Being
Part 2: Psychological Well-Being

- Worry and Fear
- Depression
- Anger
- Cognitive Changes
- General Information on Caring for the Patient’s Emotional Needs
- Caring for Your Own Emotional Needs

Refining Your Self-Care Plan

Resources: Psychological Well-Being
Part 3: Social Well-Being

- Changes with Relationships
- Communication
- Sexual Changes
- Social Support
- Financial Burdens
- Healthcare Planning
- General Information on Caring for the Patient’s Social Concerns
- Caring for Your Own Social Needs

Refining Your Self-Care Plan

Resources: Social Well-Being
Part 4: Spiritual Well-Being

- Purpose and Meaning in Life
- Hope
- Redefining Self and Priorities in Life
- Inner Strength
- Uncertainty
- Positive Changes
- General Information on Caring for the Patient’s Spiritual Concerns
- Caring for Your Own Spiritual Needs

Refining Your Self-Care Plan

Resources for Spiritual Well-Being
Key Findings

- Decreased caregiver burden
- Decreased caregiver distress
- Improved QOL for patients and family caregivers
- Increased use of Advanced Directives


Resources related to Family Caregiving

http://prc.coh.org

Family Caregiving
2016 IOM Report on Family Caregiving

http://www.nationalacademies.org/hmd/Activities/Aging/FamilyCaregivingforOlderAdults.aspx
Opportunities for Grantmakers in Family Caregiving

- Test models of support
- Extend to caregiving in other diseases
- Support workforce development / training of professionals in family caregiving
Summary

Family caregivers provide 24/7 care of patients. Support of both patient and family is essential to quality care.