Supporting Family Caregivers from Diverse Communities

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Presenter Disclosure: Betty Ferrell

Relationships that may introduce potential bias and/or conflict of interest:
- No relationships to declare
Objectives

1. Describe palliative care needs for family caregivers.
2. Describe a palliative care intervention designed for family caregivers.
3. Apply the lessons from this research to family caregivers in other serious illness.

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.
Program Projects

Principal Investigator:
Betty Ferrell PhD, MA, FAAN, FPCN, CHPN

PROJECTS

Project 1
Early Stage Lung Cancer
Project Leader:
Betty Ferrell, PhD, MA, FAAN, FPCN
Co-Investigators:
Fred Grannis, MD
Mihaela Cristea, MD
Karen Reckamp, MD
Brian Tiep, MD
Jae Kim, MD
Dan Raz, MD
Research Nurse:
Anna Cathy Williams, RN, MSN, PHN

Project 2
Late Stage Lung Cancer
Project Leader:
Marianna Koczywas, MD
Co-Investigators:
Mihaela Cristea, MD
Betty Ferrell, PhD, FAAN, MA, FPCN, CHPN
Research Nurse:
Tami Borneman, RN, MSN, CNS, FPCN

Project 3
Family Caregiving in Lung Cancer
Project Leader:
Marcia Grant, RN, PhD, FAAN
Co-Investigators:
Betty Ferrell, PhD, FAAN, MA, FPCN, CHPN
Virginia Sun, RN, PhD
Shirley Otis-Green, MSW, LCSW
Research Nurses:
Becky Fujinami, RN, BA, OCN
Catherine Del Ferraro, MSN, RN, CCRP

Study Design

Intervention

Populations
Lung Cancer Groups
- Early Stage (I-IIIB)
- Late Stage (IV)
- Family Caregivers

Phase I
Prospective Baseline/Usual Care

VS

Phase II
Prospective Trial of Palliative Care Intervention Protocol

Outcomes
N=491 Patient
N=366 Family Caregivers

Patient
- QOL (FACT-L, FACIT-SP 12)
- Symptoms
- Resource use/Chart Audit
- Distress Caregivers

Caregivers
- QOL
- Skills Preparedness
- Caregiver Burden
- Distress
- Self Care
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

Project #3 Family Caregiving NSCLC

**Aim 1:** Test the effects of a Family Caregiver Palliative Care Intervention (FCPCI) for informal caregivers of patients with early and late stage lung cancer on caregiver burden and caregiving skills preparedness as compared to a group of FCG in a usual care situation.

**Aim 2:** Test the effects of a FCPCI for informal caregivers of patients with early and late stage lung cancer on FCG QOL and psychological distress as compared to a group of FCG in a usual care situation.

**Aim 3:** Describe early and late stage FCG self care behavior, comparing the usual care and FCPCI groups.

**Aim 4:** Describe resource use by early and late stage FCG comparing the usual care and FCPCI groups.

**Aim 5:** Identify subgroups of FCG who benefit most from the FCPCI in relation to sociodemographic characteristics, and clinical/functional factors.
### 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
## Results

### Demographic Characteristics

<table>
<thead>
<tr>
<th></th>
<th>Family Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Usual Care</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>57.23 (13.16)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>59 (36.2%)</td>
</tr>
<tr>
<td>Female</td>
<td>104 (63.8%)</td>
</tr>
<tr>
<td><strong>Race/Ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>115 (70.6%)</td>
</tr>
<tr>
<td>Asian</td>
<td>25 (15.3%)</td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>11 (6.7%)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>High School</td>
<td>61 (37.4%)</td>
</tr>
<tr>
<td>College</td>
<td>100 (61.3%)</td>
</tr>
<tr>
<td><strong>Smoking History</strong></td>
<td></td>
</tr>
<tr>
<td>Current Smoker</td>
<td>14 (8.6%)</td>
</tr>
<tr>
<td>Former Smoker</td>
<td>63 (38.7%)</td>
</tr>
<tr>
<td>Non-Smoker</td>
<td>86 (52.8%)</td>
</tr>
</tbody>
</table>
### Average length of teaching sessions (minutes)

<table>
<thead>
<tr>
<th>Session</th>
<th>Family Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>34.8</td>
</tr>
<tr>
<td>Psychological</td>
<td>27.8</td>
</tr>
<tr>
<td>Social</td>
<td>25.5</td>
</tr>
<tr>
<td>Spiritual</td>
<td>25.0</td>
</tr>
</tbody>
</table>

### Most Frequently Selected Teaching Topics

<table>
<thead>
<tr>
<th>QOL Domain</th>
<th>Early</th>
<th>Late</th>
<th>FCG</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Well-Being</td>
<td>Fatigue (76%) Pain (49%) Sleep (37%) Constipation (31%) Dyspnea (30%)</td>
<td>Fatigue (63%) Dyspnea (35%) Skin, hair, nail changes (32%) Cough (30%) Constipation (28%)</td>
<td>Fatigue (63%) Pain (49%) Appetite (38%) Dyspnea / Cough (36%) Sleep (26%)</td>
</tr>
<tr>
<td>Psychological Well-Being</td>
<td>Worry &amp; Fear (85%) Depression (48%) Anger (15%) Cognitive Changes (7%)</td>
<td>Worry &amp; Fear (77%) Depression (59%) Cognitive Changes (59%) Anger (30%)</td>
<td>Worry &amp; Fear (88%) Depression (58%) Anger (42%) Cognitive Changes (41%)</td>
</tr>
<tr>
<td>Social Well-Being</td>
<td>Social Support (79%) Communication (43%) Changes in Relationship (36%) Financial Burden (21%) Sexuality (16%)</td>
<td>Health Care Planning (67%) Communication (57%) Changes in Relationship (52%) Social Support (51%) Financial Burden (27%)</td>
<td>Communication (78%) Health Care Planning (61%) Changes in Relationship (55%) Social Support (50%) Financial Burden (15%)</td>
</tr>
<tr>
<td>Spiritual Well-Being</td>
<td>Hope (89%) Inner Strength (84%) Uncertainty (75%) Purpose/Meaning in Life (23%) Spiritual or Religious (11%)</td>
<td>Hope (55%) Positive Changes (47%) Inner Strength (45%) Redefining Self &amp; Priorities (37%) Uncertainty (35%)</td>
<td>Purpose/Meaning in Life (54%) Hope (49%) Inner Strength (49%) Redefining Self &amp; Priorities (39%) Positive Changes (28%)</td>
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</tbody>
</table>
Multivariate Analysis of FCG Outcomes at 12 Weeks

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Usual Care (N=157)</th>
<th>Intervention (N=197)</th>
<th>p-Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological Distress (Range=0-10; higher=more distress)</td>
<td>4.61 2.88</td>
<td>4.20 2.36</td>
<td>.010</td>
</tr>
<tr>
<td>Physical QOL²</td>
<td>7.06 1.76</td>
<td>7.26 1.73</td>
<td>.886</td>
</tr>
<tr>
<td>Psychological QOL²</td>
<td>5.24 1.62</td>
<td>5.53 1.38</td>
<td>.803</td>
</tr>
<tr>
<td>Social QOL²</td>
<td>6.00 1.89</td>
<td>6.48 1.71</td>
<td>&lt;.001*</td>
</tr>
<tr>
<td>Spiritual QOL²</td>
<td>6.54 1.80</td>
<td>6.32 1.59</td>
<td>.043</td>
</tr>
<tr>
<td>Total QOL²</td>
<td>5.93 1.42</td>
<td>6.16 1.27</td>
<td>.484</td>
</tr>
</tbody>
</table>

Main Effect of Group

*Range = 0-10; higher scores = better QOL.

Conclusions

- Significant improvements in FCG’s social well-being and psychological distress
- Application to family caregivers in other diseases
Current/Future Research

- Palliative Care Research Cooperative (PCRC) Family Caregiver Core
- American Cancer Society funded project “Palliative Care Intervention for Poor and Underserved Family Caregivers” (2013-2018), B, Ferrell PI

Family Communication and Caregiving

- Longitudinal interviews with family/cancer patient from diagnosis to EOL care/death
- Family Communication Theory
- Family stories used to identify communication characteristics determining acceptance of palliative care

Wittenberg-Lyles, Goldsmith, Ragan, & Sanchez-Reilly, 2010

Isolated, Rescued & Comforted Journeys
Family Communication and Caregiving

Family caregivers have a vital role in facilitating and sharing information about illness, revealing a need to develop caregiver health literacy skills to support caregiver communication.

Only three of the 28 print materials we evaluated were written at the recommended sixth grade reading level

Wittenberg, Goldsmith, Ferrell, and Ragan (In review)

Family Communication and Caregiving

A Communication Guide for Caregivers™

Written at the sixth grade level

Evaluated by family caregivers

Contents considered relatable

Rated useful and easy to read

Evaluated by healthcare providers

Rated the guide as easy for patient/family members of diverse backgrounds and varying levels of literacy to understand and use
**Family Communication and Caregiving**

**COMFORT Caregiver Intervention**

- Nurse-delivered communication intervention for family caregivers
- Written and digital copy of the guide plus communication coaching by phone
- Identification of a communication concern
- Exploration of impact of communication challenge
- Review of guide
- Role-play

(Wittenberg, Ferrell, Koczywas, In progress)
Family Communication and Caregiving

Digital version of the guide for free download available from

The COMFORT Communication Project
CommunicateComfort.com