Palliative Care for Quality of Life and Symptom Concerns in Lung Cancer

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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.

Program Projects and Cores

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PROJECTS

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Late Stage Lung Cancer
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Project 3
Family Caregiving in Lung Cancer
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Cores

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Core B
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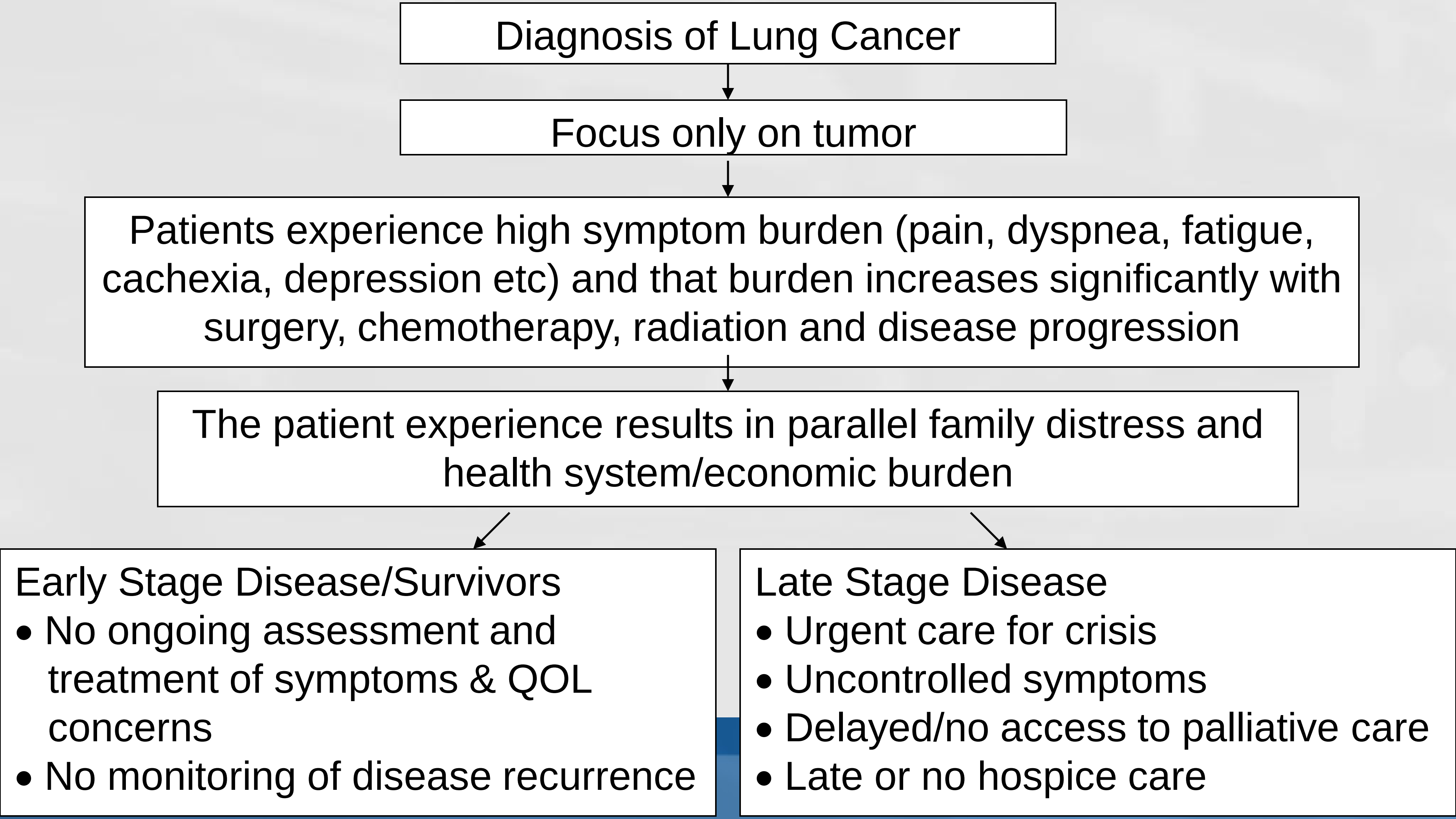
Project 3 – Family Caregiving in Lung Cancer
- Barbara Given, PhD, RN, FAAN (Michigan State University)
- Laurel Northouse, PhD (University of Michigan)

Geriatric Core
- Lodovico Balducci, MD (Moffit Cancer Center)

Lung Cancer

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

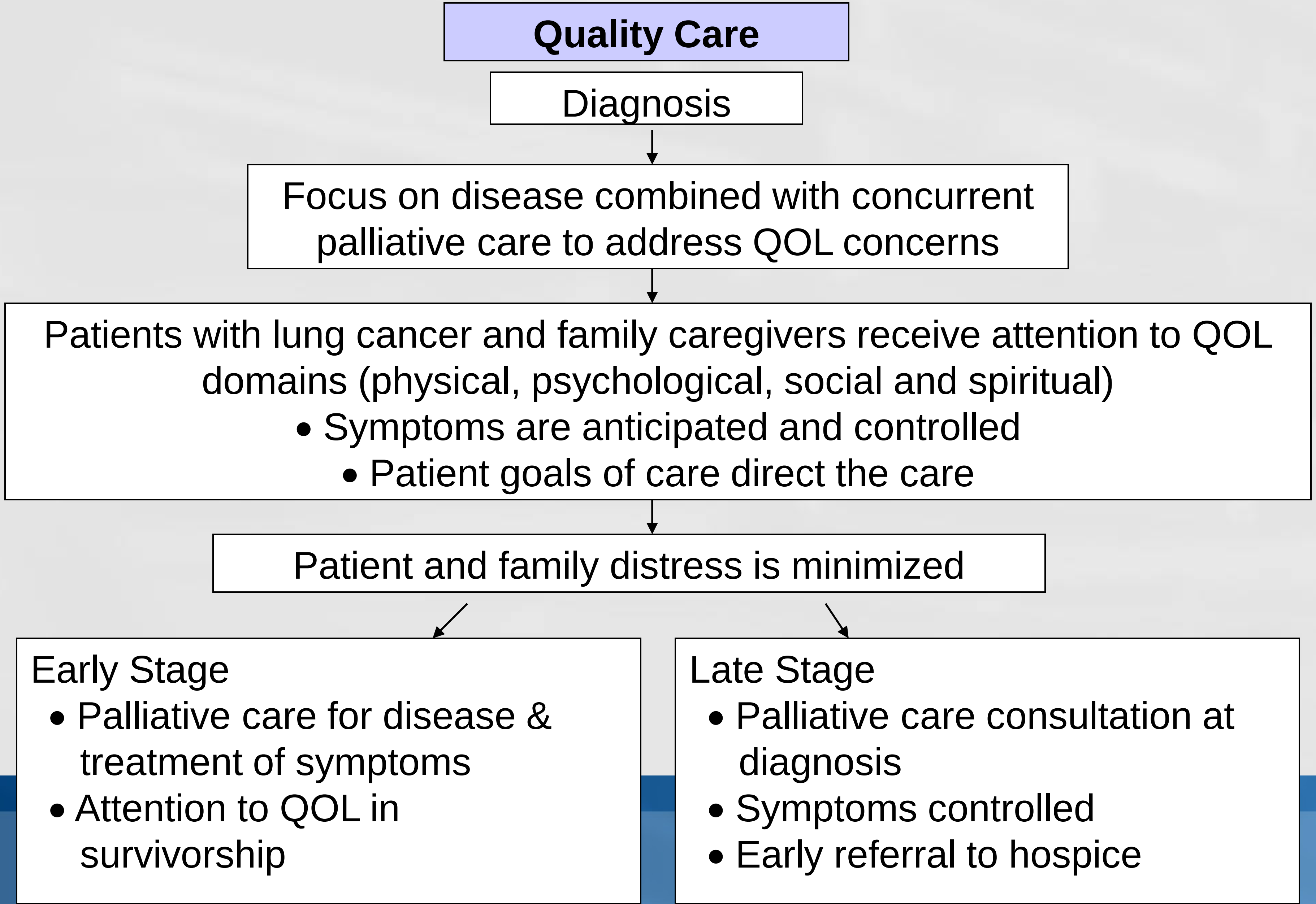
Early Stage Disease/Survivors

- 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

Lung Cancer cont.



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

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

Patient
-QOL (FACT-L, FACIT-SP 12)
-Symptoms
Resource use/Chart Audit
-QOL
-Skills Preparedness
-Caregiver Burden
-Psychological Burden
-Self Care

Phase I Usual Care

Patient Accrual – 11/09 – 3/11

Early Stage	N= 105
Late Stage	N = 113
Family Caregiver	N = 162

Phase II

QOL/Palliative Care Intervention

Began June, 2011

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

PCI Interdisciplinary Care Plan

Initial RN Assessment From Baseline Tools Overall Impression: Strengths, Challenges& Patient Priority	**MD Medical Tx Plan**
Physical: (i.e. chemo toxicity)	Surgery:
Psychological:	Chemo:
Social:	Radiation:
Spiritual:	Chest Conference Comments
Family Caregiver:	Consultations:

Table 1: Overall Program Project Plan Illustration Design for Intervention Visits and Evaluation Visits Across Projects

Project	Early Stage Lung Cancer		Late Stage Lung Cancer		Family Caregivers	
Week	Evaluation	Intervention	Evaluation	Intervention	Evaluation	Intervention
1	Baseline	Surgery	Baseline	ICC*	Baseline	Intervention RN attends patient ICC
2		ICC*		Chemotherapy Begins		
3		Teach 1		Teach 1		
4		Teach 2		Teach 2		
5		Teach 3		Teach 3		
6	6 week	Teach 4	6 week	Teach 4		
7					7 Week (Pre-Intervention)	Teach 1
8						Teach 2
9		Phone 1		Phone 1		
10						Teach 3
12	12 Week		12 Week		12 Week (Post Intervention)	Teach 4
13		Phone 2		Phone 2		
16						Phone 1
17		Phone 3		Phone 3		
18					18 Week	
20						Phone 2
21		Phone 4		Phone 4		
24	24 Week		24 Week		24 Week (Post Phone Call)	Phone 3
36	36 Week					
52	52 Week					

* ICC = Interdisciplinary Care Conference

Project #1 Early Stage NSCLC

- **Aim1**: Test the effects of the Palliative Care Intervention (PCI) on overall **QOL** and **psychological distress** for patients with Early (Stage I-III) resectable NSCLC compared to a group receiving usual care.
- **Aim 2**: Compare **symptoms** in the PCI group versus the usual care group in Early Stage NSCLC.
- **Aim 3**: Compare **patient assessment outcomes** (OARS Instrumental Activities of Daily Living, MOS Social Activities Limitation Scale, and the Karnofsky Performance Scale) in the PCI group versus the usual care group.
- **Aim 4**: Test the effects of the PCI on **system use** as compared to the usual care group.
- **Aim 5**: Identify **subgroups of patients who benefit most** from the PCI in relation to sociodemographic characteristics, treatment factors, and patient assessment predictors at the 12-week primary end-point.

Phase I
Usual Care Key Findings

- Multiple sx on diagnosis
- Symptoms worsen / additional sx with treatment
- QOL impact across domains is similar to stage IV disease
- Limited referral to supportive care services or palliative care
- Support services initiated at “crisis”

Early Stage I-III

Key Teaching Points: Early Stage Part 1: Physical Well-Being

- Breathing Problems
- Pursed Lip Breathing
- Breathing: Relaxation Exercises
- Cough
- Pain
- Constipation
- Bowel Regimen for Constipation
- Fatigue
- Sleep Problems
- Nausea and Vomiting
- Appetite Problems/Weight Loss
- Skin, Nail, Hair Changes
- Information on How to Quit Smoking

*Additional Resources

Post-Operative Care

Keeping Your Lungs Clear After Surgery:

- Breathing & Coughing Exercises Using an Incentive Spirometer
- Pain After Surgery
- Bowel Function After Surgery
- Nausea After Surgery
- Eating After Surgery
- Preventing Infections
- Chest Tube Care
- Patient Instructions: Jackson Pratt/Hemovac Drain Care
- Preventing Blood Clots
- Recovering Function After Surgery

Action Plan for Physical Well-Being

- Patient prioritizes 3 key concerns
- Teaching focuses on those topics
- Teaching includes demonstration, verification of learning, completion of action plan

Part 2: Psychological Well-Being

- Worry and Fear
- Depression
- Anger
- Cognitive Changes

Action Plan for Psychological Well-Being

Resources for Psychological Well-Being

“If You’ve Just Been Diagnosed”

“Relaxation Techniques and Mind/Body Practices”

Part 3: Social Well-Being

- Changes with Relationships
- Communication
- Sexual Changes for Women
- Sexual Changes for Men
- Social Support
- Financial Burdens
- Healthcare Planning

Action Plan for Social Well-Being

Resources for Social Well-Being

“Taking Care of Business” Forms

“Forms for Advance Directives”

Part 4: Spiritual Well-Being

- Spiritual or Religious?
- Purpose and Meaning in Life
- Hope
- Redefining Self and Priorities in Life
- Inner Strength
- Uncertainty
- Positive Changes

Action Plan for Spiritual Well-Being

Project #2 Late Stage NSCLC

- **Aim 1:** Test the effects of the Palliative Care Intervention (PCI) on overall **QOL** and **psychological distress** for patients with Late Stage (IV) NSCLC compared to a group receiving usual care.
- **Aim 2:** Compare **symptoms** in the PCI group versus the usual care group in Late Stage NSCLC.
- **Aim 3**: Compare **patient assessment outcomes** (OARS Instrumental Activities of Daily Living, MOS Social Activities Limitation Scale, and the Karnofsky Performance Scale) in the PCI group versus the usual care group.
- **Aim 4**: Test the effects of the PCI on **system use** as compared to the usual care group.
- **Aim 5**: Identify **subgroups of patients who benefit** most from the PCI in relation to sociodemographic characteristics, treatment factors, and patient assessment predictors at the 12 week primary end point.

Phase I
Usual Care Key Findings

- Multiple sx including fatigue, dyspnea, pain, insomnia, worrying, sexuality concerns
- 71% have at least 1 other chronic illness, 20% have a prior cancer dx
- Moderate / severe concerns across all QOL Domains, Distress Scales, FACIT-Spiritual
- Limited use of palliative care

Late Stage IV

Part 1: Physical Well-Being

- Breathing Problems
- Pursed Lip Breathing
- Breathing: Relaxation Exercises
- Cough
- Pain
- Information on How to Quit Smoking
- Constipation
- Bowel Regimen for Constipation
- Fatigue
- Sleep Problems
- Nausea and Vomiting
- Appetite Problems/Weight Loss
- Skin, Nail, Hair Changes

Action Plan for Physical Well-Being

Resources for Physical Well-Being

Part 2: Psychological Well-Being

- Worry and Fear
- Depression
- Anger
- Cognitive Changes

Action Plan for Psychological Well-Being

Resources for Psychological Well-Being

Part 3: Social Well-Being

- Changes with Relationships
- Communication
- Sexual Changes for Women
- Sexual Changes for Men
- Social Support
- Financial Burdens
- Healthcare Planning

Action Plan for Social Well-Being

Resources for Social Well-Being
“Taking Care of Business” Forms
“Forms for Advance Directives”

Part 4: Spiritual Well-Being

- Spiritual or Religious?
- Purpose and Meaning in Life
- Hope
- Redefining Self and Priorities in Life
- Inner Strength
- Uncertainty
- Positive Changes

Action Plan for Spiritual Well-Being

Resources for Spiritual Well-Being

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.


PAIN & FATIGUE

Phase I
Usual Care Key Findings

- 60% female; 70% spouse/partners
- 60% have chronic illnesses
- Key QOL concerns are distress of dx, family distress, fear of metastasis/worse disease, living with uncertainty
- Greatest need is assistance with accessing resources
- No attention to self care

Family Caregiver

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

Phase II Case Examples

Early Stage Patient

- 53 yo African American male
- NSCLC Stage II at dx
- Married with no children
- Spouse is caregiver / cardiac disease, obesity and arthritis comorbidities
- High school education
- Disabled truck driver
- Hx of smoking one pack daily for 22 years. Quit 1998
- Comorbidities of:
  - Afib/HTN/Morbid obesity
- Symptoms of:
  - SOB/Cough/Fatigue
- Tx chemo and stereotactic radiation tx brain
- Now on Phase I study with stable disease
- Has gained 40 lbs since dx

Early Patient (cont’d)

Teaching interventions consisted of:

- Physical –
  - Education regarding chemo regimen, prioritizing activities
  - Side effects/symptoms of Fatigue, N/V, Constipation
- Psychological –
  - Worry/Fear/Guilt
  - Identifying triggers, acknowledging feelings, asking for help
- Social –
  - Communication/Role Change & Relationships
  - Talking with spouse about feelings
  - Intimacy / sexuality
- Spiritual -
  - Abandonment, Hope, Redefining Priorities
  - Staying in touch with friends & family, make a list of things you hope for, listing priorities in order of importance to your life as it is now

Referrals were made to:

- CSW, Chaplain, Nutrition, Pain Clinic, Pulmonary Rehabilitation

Late Stage Patient: Mrs. K

Mrs. K is a 65 year old Jewish woman who never smoked, history of breast ca in 1989. She has received three lines of chemotherapy for her lung ca with disease progression but is responding to the present treatment. Her KPS is 90, needing only minimal help with housework. Most disturbing sx is SOB upon exertion. Mrs. K has been happily married for 43 years and has 2 adult sons and 1 daughter. Great support from family and friends.

Parents were Holocaust survivors. Two younger sisters are alive and well, her 2 older brothers died at a young age during the Holocaust. She was deeply affected negatively by these experiences.

Her Jewish beliefs do not provide strength in coping with lung cancer. She believes that “God is too busy to care about one person.” For her, long term hope is gone because she knows she will die from her cancer, but it is the uncertainty of ‘when’, and leaving behind family that is more depressing to her. Her parents taught her to live a good life and to help others , because of their beliefs based in their Jewish faith, that in helping one person you help the whole world. She feels good when she can help others and it gives her a sense of purpose.

She declined a visit by the Rabbi. For her, she said “God is silent.”

Patient Summary Late Stage: Mrs. K

ICCP Meeting

- Pulmonary rehab – for SOB and better breathing techniques
- Social Work - to provide interventional listening and coping strategies
- Chaplaincy (Rabbi) – for spiritual care
- RN teaching focus on symptoms of late stage disease

Outcomes

- Pulmonary rehab appointment with positive response. SW continues to connect with the patient and her husband on appointment days.
- The Rabbi contacted the patient to say hello, acknowledge Pt’s decline to visit with her, and to let her know she was available should the Pt need anything.

Family Caregiver of Early Stage Patient

- 57 y.o. African American female spouse
- Chronic illnesses: arthritis, obesity, osteoporosis, depression
- Fatigue, appetite changes, pain, sleep changes
- Distress with initial diagnosis, depression, fear
- Distress thermometer 8/10
- History of drug addiction with rehabilitation
- Disabled
- History of being a caregiver for her mother
- Interference with her sexuality, financial burden
- Protestant, connected with church, supported by spiritual practices
- Preparation for caregiving: worries about being able to care for her husband’s physical needs

Family Caregiver

Interdisciplinary Team Conference

- Biller Patient and Family Resource Center
- Oncology Social Worker
- Dietician

Intervention and Self Care Plan using QOL model

Physical

- Schedule appointment with MD to address chronic health issues
- Deep breathing and relaxation exercise
- Speak with Dietician

Psychological

- Schedule appointment with social worker
- Journaling about feelings
- Do something that brings joy

FC
QOL

Social

- Call financial counselor
- Contact CLRC regarding insurance and financial issues
- Write goals of communication

Spiritual

- Call church pastor
- Journal hopes for today
- Connect with church community

Family Caregiver of Late Stage Patient

- 36 y/o Hispanic male
- Single; never married; no children
- He is the youngest son of the patient who is his 72 y.o. Mother patient has Stage IV disease with brain and liver mets.
- College educated
- Unemployed; School Teacher
- Catholic
- Hx. Of smoking 1 pack per day for 8 years. Quit 4/2003.
- Comorbidities:
    - Recovering Alcoholic

Family Caregiver Teaching Interventions:

- ***Physical:*** Physical stress/Neglecting own health needs/Poor nutrition

  -Education regarding importance of doing stress reducing activities; yearly PE, Maintain good physical health.
- ***Psychological:*** Worry/Anxiety/Fear

  -Identify triggers, acknowledging feelings, asking for help, participation in AA support group. Maintain good psychological health.
- **Social:** Changing roles/Relationships/How to communicate with family

  -Speak openly, honestly about how you are managing your role as the caregiver, ask for help, stay connected with AA sponsor to talk about feelings.
- **Spiritual:** Uncertainty, meaning of illness, Religious beliefs

  -Redefine goals and priorities of own life and as a caregiver. Attend weekly mass w/loved one, attend weekly bible study, pray daily.
- **Referrals made to:**

  -Nutrition for guidance in caregiving, CSW

Future Research Plans

- Application of the Palliative Care Intervention to other Diseases (Pancreatic, Ovarian, Colon, Liver)
- Palliative Care Intervention for Patients participating in Phase 1 trials.

Summary

- Our intent is to test a model of care for lung cancer that will become a national model for other cancer settings and will improve QOL for patients with lung cancer and their family caregivers
- We welcome any input as we develop and implement our intervention
- Email: tborneman@coh.org