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Quality of Life of Family Caregivers: Challenges Faced in Care of the Lung Cancer Patient

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Abstract

Family caregivers (FCGs) of lung cancer patients face multiple challenges which impact their quality of life and well-being. Whether challenged physically, emotionally, socially or spiritually, distress in one area may compound challenges in other areas. In order to maintain function and health of FCGs as they provide valuable care for the health and well-being of the patient, attention must be given to the needs of FCGs for support and education. The purpose of this article is to describe the multifaceted challenges that FCGs of lung cancer patients experience using case studies selected from a National Cancer Institute (NCI)-funded Program Project Grant “Palliative Care for Quality of Life and Symptom Concerns in Family Caregivers of Lung Cancer Patients.” The cases are discussed in terms of how the FCG’s quality of life is impacted by the caregiver role as well as how stressors in one or more domains of quality of life compound difficulties in coping with the demands of the role. The importance of the oncology nurse’s assessment of FCGs’ needs for support, education, and self-care through the lung cancer illness trajectory is discussed while presenting accessible community resources to meet those needs.

Introduction

Lung cancer is the second most common cancer and the number one cause of death in the United States with over 200,000 cases diagnosed each year accounting for 14% of all new cancer cases (American Cancer Society, 2011; Siegel, Naishadham, & Jemal, 2012). Recommended treatment can be complex with surgery, radiation therapy and chemotherapy alone or in combination. Symptom burden of the disease or treatment is profound, and impacts the patient as well as the family caregiver (FCG) who supports the patient.

FCGs face multiple challenges throughout the illness trajectory, evolving over time from the initial diagnosis of a life threatening illness, throughout treatment, to living with the potential for disease progression and end-of-life care. Each FCG brings his/her own life experience, coping abilities, and support systems to the role. How FCGs respond to the challenges of their roles impacts their ability to continue care for their family member through the illness trajectory. Anticipating, assessing and addressing the challenges of the FCG are integral to caring for and supporting the lung cancer patient. The oncology nurse must address the FCG's needs throughout the illness trajectory to support the health and well-being of the lung cancer patient as well as his/her caregiver.

Examining lung cancer's impact on FCG quality of life (QOL) is one way to better understand the experience and assess the challenges of the caregiver. QOL was defined by Grant and colleagues (Grant, Padilla, Ferrell, & Rhiner, 1990) as 'a personal statement of the positivity or negativity of attributes that characterize one's life.' Each FCG brings his/her own physical, psychological, social and spiritual strengths and weaknesses to the role. The QOL of the FCG and the QOL of the patient with lung cancer affect each other throughout the illness trajectory (Northouse, 2005; Ryan, Howell, Jones, & Hardy, 2008; Siminoff, Wilson-Genderson, & Baker, 2010) (Figure 1). The demands of the FCG role as well as FCG's bearing witness to the patient's suffering impact FCG's QOL and ability to function.

The purpose of the article is to 1) describe the current science regarding QOL of FCGs of lung cancer patients, 2) utilize two FCG cases to describe QOL issues that impact FCGs while caring for someone with non-small-cell lung cancer (NSCLC), and 3) discuss assessment of FCGs and suggest interventions and resources to address the QOL deficits of FCGs of patients with NSCLC.

CAREGIVER QUALITY OF LIFE

Physical Well-being

The physical and emotional toll of caregiving in NSCLC with high potential for symptom burden may negatively impact the physical health of the FCG. FCGs are concerned about disease progression and treatment outcomes, while working with the practical demands of care (Bevans & Sternberg, 2012). In a study regarding sick leave usage of spouses of cancer patients, spouses of lung cancer patients had the most sick leave episodes, which may correlate with higher physical and emotional burdens of care (Sjovall et al., 2010). As disease progresses, physical care and assisting the patient with daily activities may be necessary. Added caregiver stress may result in sleep disturbance, fatigue, and unhealthy behaviors (Bevans & Sternberg, 2012). Sleep loss may result in changes in stress response, glucose regulation, and immune function (Bevans & Sternberg, 2012; Carter, 2003; Rivera, 2009; Wells-Di Gregorio et al., 2012).

Health behaviors and health changes of the FCG may be negatively impacted following cancer diagnosis (Beesley, Price, & Webb, 2011). This occurs when caregiving interferes with usual daily activities and is associated with negative lifestyle changes (Beesley et al., 2011). Caregivers appear to prioritize the care of the patient and lose focus on self care potentially resulting in decline of QOL (Bevans & Sternberg, 2012; Gibbins et al., 2009).

Psychological Well-being

Caring for a loved one with lung cancer is associated with both positive and negative psychological well-being (Ekwall & Hallberg, 2007). FCGs who are in strong relationships with ample support may find that their relationship grows stronger through the intimacy of caregiving, while those for whom the relationship is more complicated and who lack

adequate support for the intensity of this role may experience significant caregiver burden (Chen et al., 2009). Increased caregiver burden increases the risk for depression and anxiety (Bevans & Sternberg, 2012).

FCGs often report a parallel roller-coaster of emotions mirroring the impact of the disease trajectory with the patient (Murray et al., 2010). Both FCG and patient experience the uncertainties and fears associated with a new diagnosis, decisions about treatment choices, symptoms and loss of function. The potential for stress associated with the role of caregiver places those with a history of psychological challenges at increased risk for deepening depression or heightened anxiety (Carter & Acton, 2006; Nijboer, Tempelaar, Triemstra, van den Bos, & Sanderman, 2001). Those who rely upon alcohol or other substances to manage stress are at risk for increased usage and may benefit from additional education and support (Sherwood et al., 2008).

Social Well-being

Adequate social support is critical to success in caregiving (Fineberg & Bauer, 2011). The responsibilities of the caregiving role vary and are influenced by gender, age, culture, and ethnicity (Northouse, 2005). The increased intimacy and vulnerability associated with caring for an increasingly debilitated loved one alters the roles of all involved. Strong relationships may find that bonds are tightened through the caregiving experience, while conflicted relationships or those with limited resources may be overwhelmed (Northfield & Nebauer, 2010; Northouse, 2005).

Worsening illness places increasing burdens upon FCGs who become fatigued and lack the time to continue normal social activities. This loss of a social network increases a sense of isolation and is associated with worse psychological well-being (Glajchen, 2011). FCGs find that the increasing demands of care may lead to missed time from work, decreased productivity, and job resignation (Mazanec, Daly, Douglas, & Lipson, 2011). Financial burden and social isolation are exacerbated by these changes.

Increased caregiving responsibilities can alter sexual expression and increase tension between partners (Gallo-Silver, 2011). Partners can be challenged to maintain a loving intimate relationship when required to assist with wound care or worried about causing pain or symptom distress. Communication is vital to maintain a positive intimate experience while coping with the side effects of treatment and progressive illness (Lindau, Surawska, Paice, & Baron, 2011).

Spiritual Well-being

Spiritual or existential well-being involves a sense of meaning and purpose in life (Lehto, 2012). A diagnosis of lung cancer invites both the patient and caregiver to attempt to find meaning in the illness experience (Kim, Carver, Spillers, Crammer, & Zhou, 2011; Northouse, 2005). Each must find a source of inner strength to face the inherent uncertainties associated with lung cancer (Murray et al., 2010).

For both patients and FCGs, hope evolves over time and each may find that they are hoping for different things. Initially, both patients and their loved ones may hope that the diagnosis was a mistake, or hope that the treatment will be successful. If end of life approaches, FCGs may vacillate between hope that their loved one is “miraculously cured” and hope that they will die “in peace.” FCGs may feel guilt about their own good health while a loved one is dying. Culturally sensitive spiritual and existential care is especially important in addressing the anticipatory grief of FCGs and in providing compassionate bereavement support to families following the death of the patient (Otis-Green, 2011).

Integrated Palliative Care

Because of the multi-dimensional aspects of the caregiving experience, an interdisciplinary, team-based approach to providing bio-psychosocial-spiritual care is critical. Early integration of palliative care offers opportunities for delivery of services in anticipation of patient and family needs (Temel et al., 2010). Figure 2 illustrates the overlapping roles of the interdisciplinary team and highlights the importance of continuous collaborative communication in addressing the multi-dimensional needs of the FCG.

Methods

Two composite caregiver case studies were selected from a National Cancer Institute (NCI)-funded Program Project Grant to provide perspective of the complex issues faced by FCGs while caring for the patient with NSCLC. The primary purpose of the Program Project is to test the efficacy of an interdisciplinary palliative care intervention delivered by advance practice nurses for patients and families living with NSCLC. During Phase 1, FCGs (N=163) of patients receiving usual care for NSCLC were recruited over a one year period into an Institutional Review Board approved study from the Medical Oncology Adult Ambulatory Care Clinic at an NCI-designated comprehensive cancer center. Specially trained research nurses accrued each FCG who then completed surveys and self-reports at baseline, 7, 12, 18, and 24 weeks following accrual. FCGs were asked about demographics and chronic illnesses. Using validated tools, FCGs were assessed for QOL, distress level, functional level, level of preparedness for caregiving, and caregiver burden. The case studies presented are composites of FCGs and were informed by both the questionnaires and from interviews. The criteria for selection of the cases presented was to include those with major challenges in two or more domains of QOL (physical, psychological, social, spiritual) to provide a perspective of issues faced by FCGs of NSCLC patients.

Caregiver Case Study 1

Mr. B. is a 62-year-old Caucasian male who is caring for his 72-year-old Filipino wife with stage IV NSCLC. Mrs. B. has completed several lines of chemotherapy with disease progression. Mr. B is in excellent health with no chronic health problems, and he works full time as a manager. They have two children and five grandchildren. Mrs. B. is especially close to one grandson who she spends time with on a regular basis. Mr. and Mrs. B and their grandson were recently able to travel to her family homestead in the Philippines.

Mr. B and his wife do not 'see eye to eye' on important issues and they have different styles of coping. They have accrued a large debt with home remodeling. Mrs. B would like to take another trip to the Philippines. Although Mr. B would like to accommodate her wishes, he feels they cannot afford more debt. He also cannot afford more time away from work as he needs to conserve time to care for her at home when her condition declines.

Mr. B was raised as a Protestant but does not subscribe to any religion as an adult. Mrs. B. is a Catholic and gains support from her faith and church community. Mr. B finds meaning and purpose in life from his family and providing for their needs. He also derives meaning from his work while experiencing the stress of multiple demands on his time.

Mr. B has great difficulty coping with his wife's disease and treatment. He rates himself on a scale from 0 to 10 as having very little control in life (2/10), high levels of depression (7/10), and distress (7/10). He consistently accompanies his wife to her appointments with the medical oncologist. He states he has questions that he would like to ask the oncologist but feels it is his wife's desire to be the one to ask questions and relay symptom information. Mr. B. expresses concern that his questions or discussion of Mrs. B.'s symptoms may cause

her to lose hope. He also expresses that his needs and concerns when seeing the medical oncologist are not priorities.

Mr. B describes waves of emotion and an inability to control his feelings of helplessness, anger and fear. He chooses not to share his feelings with his wife fearing he may cause her more distress. While struggling with many unknowns, he is anticipating being alone in the home they have shared for over 40 years. He perceives that his responsibility as a caregiver is to protect Mrs. B. from suffering and negativity.

Discussion 1—This case study demonstrates multiple challenges in three domains of one FCG's QOL. Table 1 "Assessment of the Family Caregiver" summarizes the oncology nurse's approach to assessment of FCG needs.

Needs may be prioritized according to which are most distressing or which may, once addressed, help alleviate distress in other areas. Mr. B's communication with his wife may be considered a priority need. His decision to not share his concerns with his wife may negatively impact their relationship, creating emotional distance that contributes to a sense of isolation and loneliness for them both. One way to help bring them to 'the same page' may be by having them speak separately and as a couple with the oncology social worker about their feelings and stressors of dealing with lung cancer. Once they have shared their feelings, fears, and hopes for their future, they may be assisted to reconcile their goals and as a couple create a plan to meet those goals. This may have the additional benefit of relieving Mr. B's psychological and spiritual distress. Referral to a caregiver support group may normalize Mr. B's concerns as he benefits from the shared knowledge and experience of other caregivers. Figure 3 shows resources the oncology nurse may offer to Mr. B to meet his needs.

Caregiver Case Study 2

Mrs. M. is a 53-year-old Hispanic caring for her 55-year-old Hispanic husband with advanced NSCLC. Mr. M. worked as a truck driver until his recent diagnosis and is now disabled. Mrs. M. has chronic illnesses including obesity, osteoporosis, arthritis, diabetes and depression. She was a hair dresser who has been disabled for 10 years. Mrs. M. has major problems with fatigue, pain, and insomnia. She rates herself on a scale of from 0 to 10 as having poor physical health (3/10). She is dealing with chronic lower back and right hip pain. At times the pain is so severe that she is in a wheelchair when she accompanies her husband to the medical oncology clinic.

Mrs. M. reveals that her mother died 1 1/2 years ago after a 2 year battle with breast cancer. Mrs. M was the caregiver for her mother. She rates her distress with her husband's diagnosis as high (9/10). She fears that she will not be physically capable of caring for her husband as she did for her mother.

Mrs. M. rates her level of depression as high (8/10). Her treatment for depression has included seeing a psychiatrist and taking antidepressants. She stopped both about one year ago when she decided she could no longer drive on the freeway limiting her ability to continue in therapy. She also revealed that she and her husband have histories of alcohol abuse for which they were both rehabilitated.

Mrs. M. is Catholic and has a strong faith. Prayer and reading the Bible everyday help her to stay positive and feel supported. When she feels afraid, angry, isolated, or alone she reads biblical passages for support, and this helps her to work through her troubles.

Mrs. M. manages the couple's finances. They are stressed financially since both are on disability. His job was terminated after 6 months on medical leave of absence. They are paying for his insurance out of pocket on COBRA using their disability income and some financial assistance from her sister.

Mrs. M. manages Mr. M.'s care. She comes to his appointments with him and maintains a detailed calendar with notes regarding his treatments, test results, and questions. During visits to the oncology clinic she gathers information about diet and the amount of activity that is best for her husband's health during his treatment.

Discussion 2—In assessing Mrs. M's goals as FCG, the oncology nurse would note that Mrs. M wishes to learn her husband's treatment and to provide support for her husband's health, while managing home and finances. Mrs. M recognizes that she needs a level of stamina and functional ability to meet the demands of the caregiver role. She has a significant amount of emotional distress regarding her physical health and her ability to continue her caregiving responsibilities. The oncology nurse may be instrumental in alleviating her worry and fear by identifying resources to assist with Mr. M's care when it is beyond what Mrs. M is physically able to fulfill. Figure 4 presents resources the oncology nurse might offer Mrs. M.

Assessment by the clinical social worker or psychologist of Mrs. M's history of alcoholism and depression may help in understanding her vulnerability to relapse. Early intervention to provide support and education may help her deal with distress, depression and uncertainty associated with her role. The importance of early intervention in areas of greatest vulnerability is apparent to support and maximize her QOL.

Identification of Mrs. M's strengths provides an opportunity to discuss how she has coped in the past and may effectively cope in the present. Mrs. M's prior experience as a caregiver for her mother is one area to explore with her to remind her of her strengths. She has indicated a strong connection to her faith and gains support and comfort in her spiritual activities. As Mrs. M deals with fears and frustrations, she may call upon her existing repertoire of strengths to cope.

Conclusion

The lung cancer experience from initial diagnosis through all phases of the disease can profoundly affect caregiver's well-being and ability to function. Two case studies of FCGs of lung cancer patients demonstrate the complexity of challenges faced by the FCG and how challenges in one area can compound challenges in another. The oncology nurse has the opportunity to be available and to listen to the FCG, to anticipate and assess each FCG's needs for support and education, and to convey that FCG well-being is a priority of care. After assessment and identification of priority needs, the oncology nurse may team with other disciplines to intervene with the best available resources (Table 2). The QOL of the patient with lung cancer and the QOL of the FCG affect each other. Palliation of symptom concerns for both must be addressed in comprehensive oncology care

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Implications for Practice

- * Family caregivers of lung cancer patients are an essential part of the healthcare team and have a significant impact on the health and well being of patients.
- * Family caregivers of lung cancer patients have multidimensional needs which impact their overall quality of life and must be recognized and addressed by oncology nurses to support optimal function in their role as caregivers.
- * To effectively address the needs of the family caregiver, collaborative practice and intervention within the oncology treatment center as well as the family caregiver's community should be mobilized.

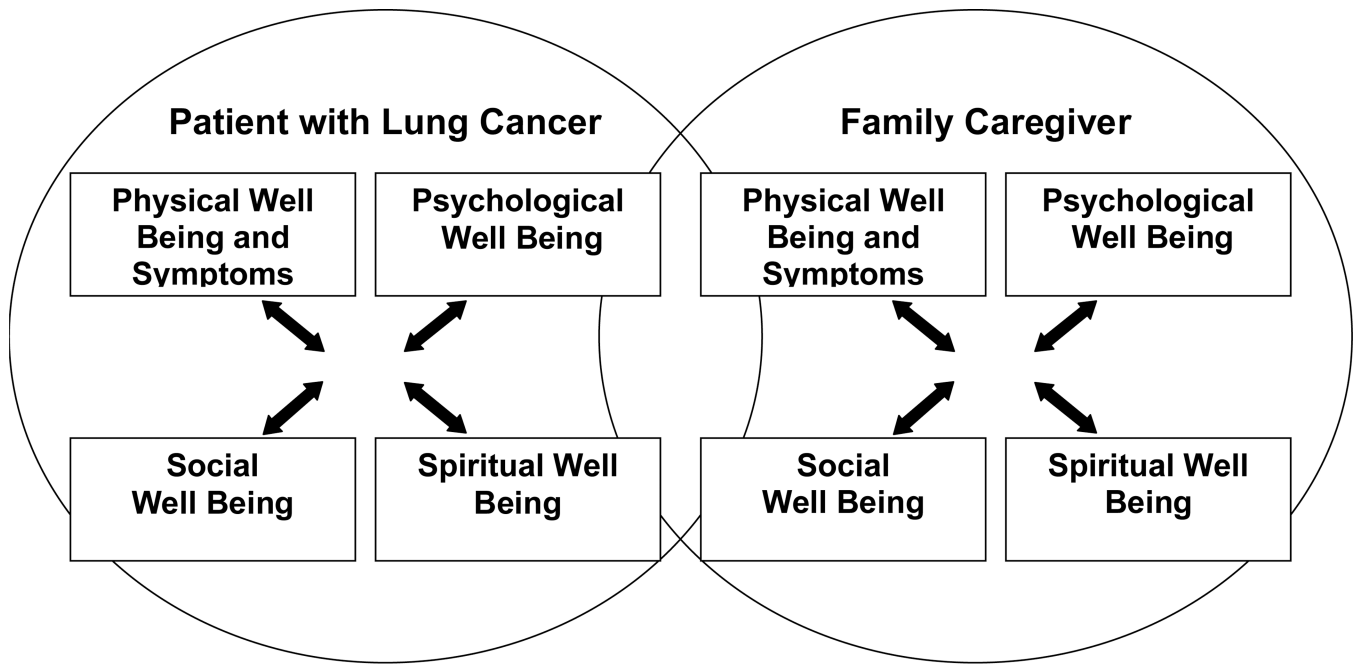


Figure 1.
 Quality-of-Life Model Applied to Lung Cancer
 Ferrell B, Primary investigator (2009) 5 P01 CA136396-02: Palliative Care for Quality of Life and Symptom Concerns in Lung Cancer. National Cancer Institute. City of Hope National Medical Center.

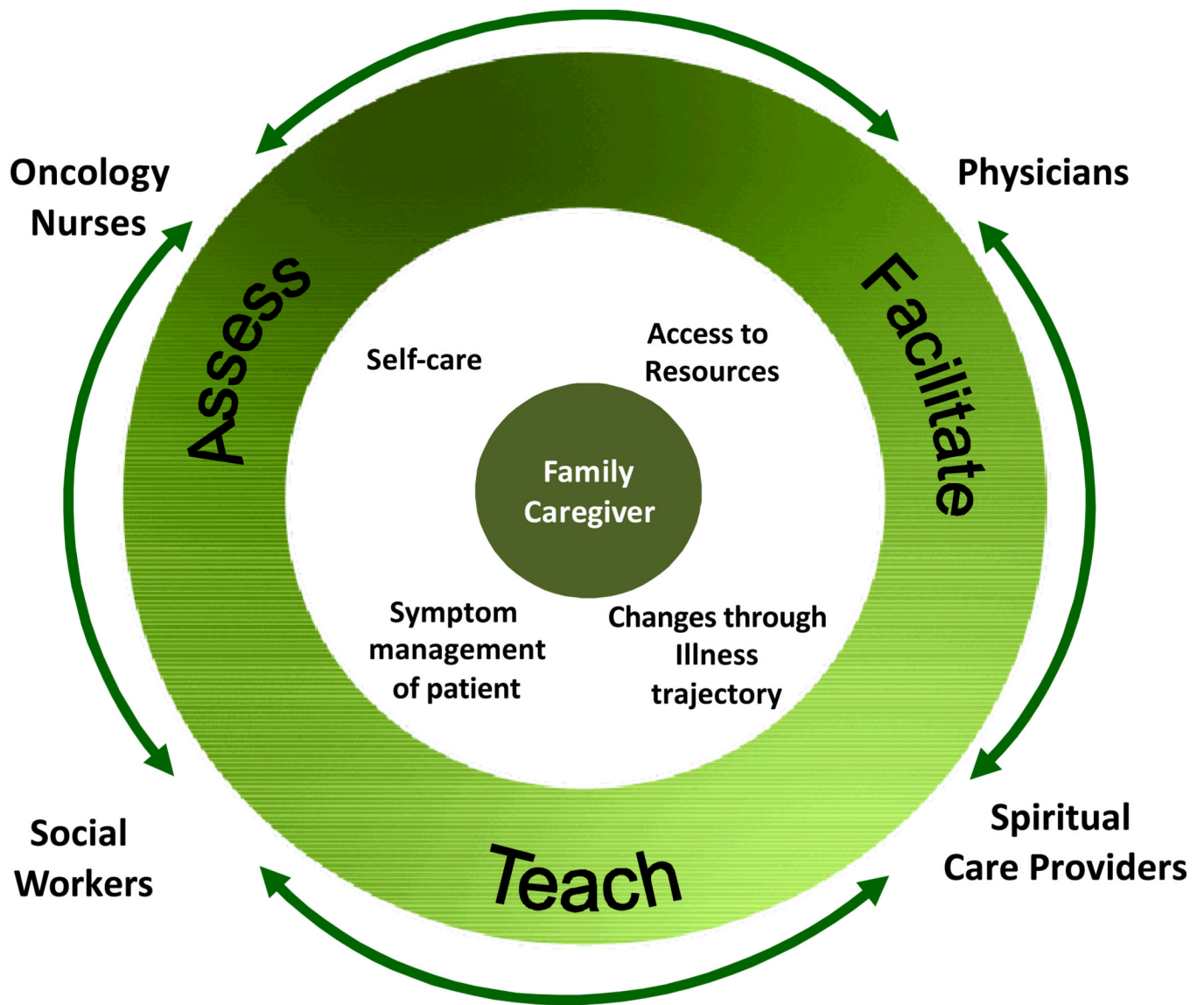


Figure 2.
Roles of Interdisciplinary Team in Care of the FCG.

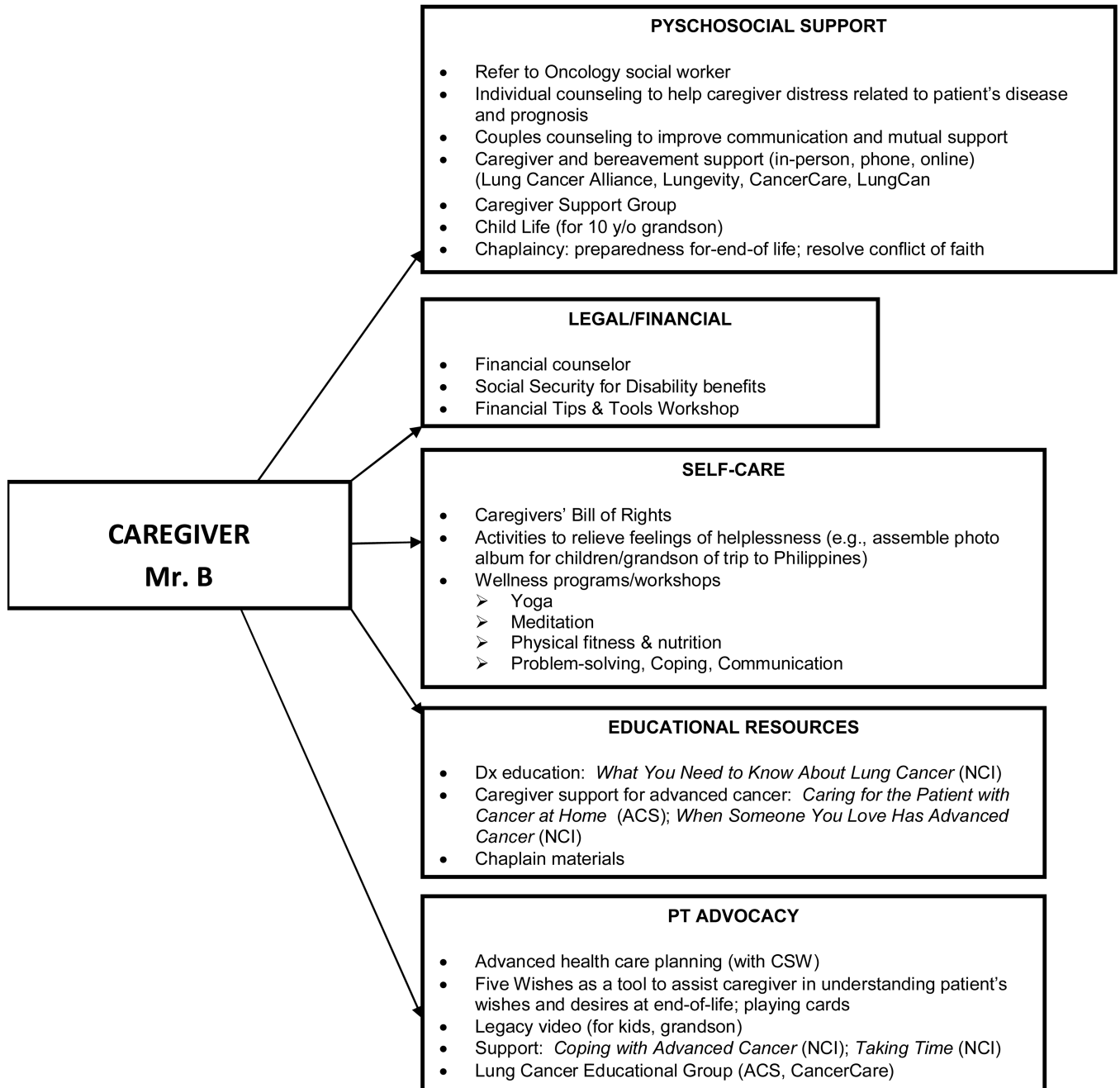


Figure 3.
Family Caregiver-Mr. B

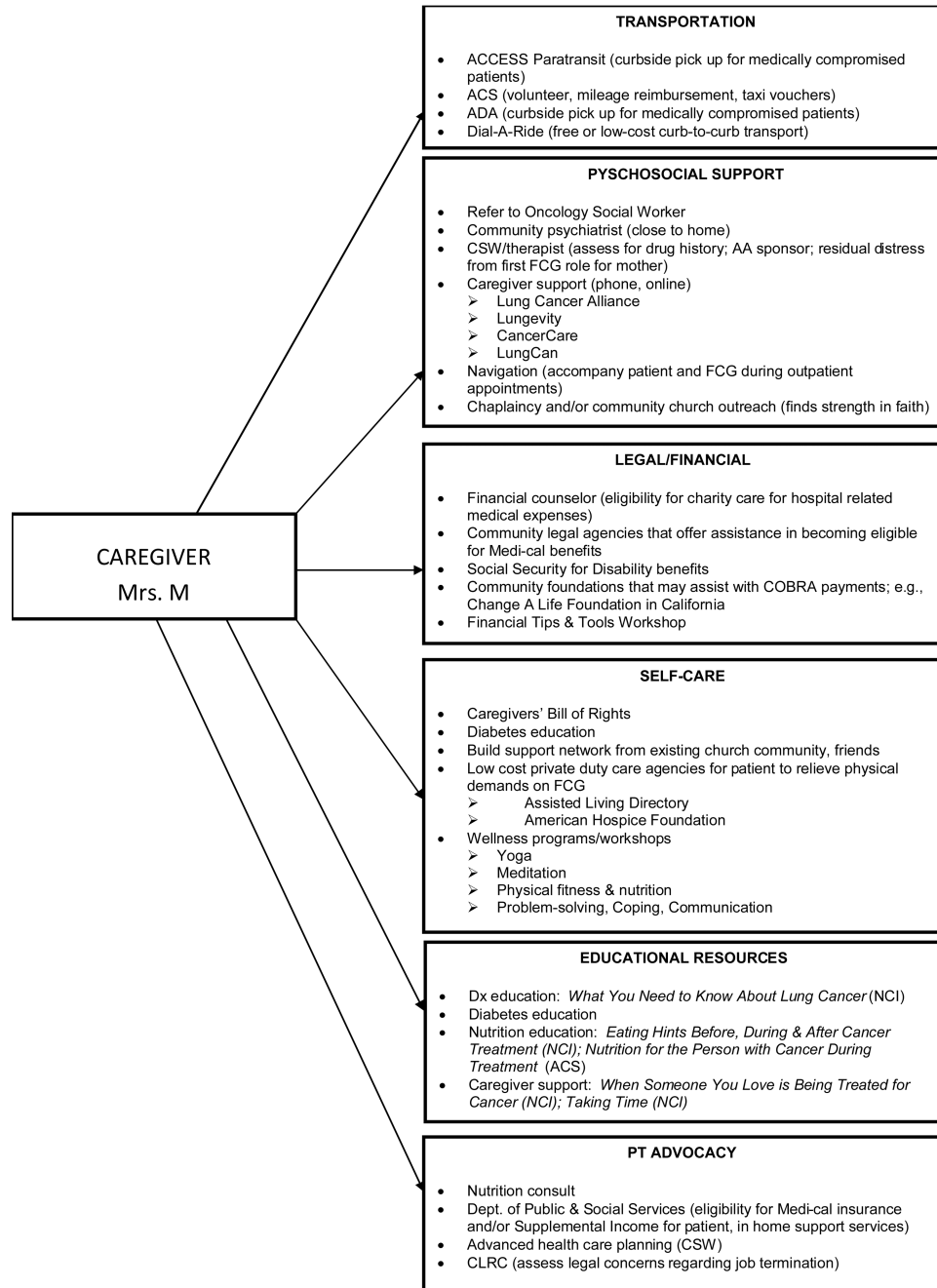


Figure 4.
Resources for Family Caregiver-Mrs. M

Table 1

Assessment of a Family Caregiver

<p>KEY THINGS TO REMEMBER</p> <ul style="list-style-type: none"> • The oncology nurse has limited time with the FCG to assess and intervene. • Be available for the FCG and listen. Convey: <ul style="list-style-type: none"> – FCG’s well-being is important. – FCG’s role is essential to care of the patient and often requires support. – Support the FCGs in fulfillment of their goals of care for the patient. – Support and education will be geared to what the FCG finds useful and acceptable. – There will be follow-up to check for unmet needs. • Be willing and able to take a few minutes away from patient to let the FCG articulate his/her needs (they may feel they do not want to share in the patient’s presence). • With knowledge of patient status and needs: <ul style="list-style-type: none"> – Anticipate potential FCG needs for education, assistance with physical care, emotional support. – Anticipate future needs of FCG per illness trajectory of patient; with an uncertain future the FCG may be concerned about what they will be required to help with in the future. • With assessment of FCG status such as physical health, functional status, cognitive status, culture, language, religious preferences, and living situation or proximity to patient: <ul style="list-style-type: none"> – Anticipate need to have others assist with care. – Anticipate need for tools to assist with care management (medication diary, treatment instructions and schedule, appointment calendar, symptom diary, list of essential resources with phone numbers). – Anticipate best types of support based on preference, culture, religion, and accessibility. <p>CAREGIVER ASSESSMENT TOOLS AND LINKS</p> <p>American Medical Association’s Caregiver Self Assessment Questionnaire (http://www.ama-assn.org/ama1/pub/upload/mm/433/caregiver_english.pdf)</p> <p>NPCRC Caregiver Strain Index (http://www.npcrc.org/usr_doc/adhoc/caregiver/Caregiver%20Strain%20Index.pdf)</p> <p>Modified Caregiver Strain Index (http://consultgerim.org/uploads/File/trythis/try_this_14.pdf)</p>
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Adapted from reference (Levine, 2011)

Table 2

Resources for Family Caregivers

Resource	Source	Description
Advance Health Care Planning		
Caring Connections	www.caringinfo.org	State specific advance directive
Five Wishes	www.agingwithdignity.org	Living will that expresses personal needs: medical, personal, emotional, and spiritual
Bereavement		
American Hospice Foundation	www.americanhospice.org	Care and support for grieving people of all ages; includes publications to purchase
Center for Loss & Life Transition	www.centerforloss.com/bookstore/	Books for child, teen, and adult mourners written by Alan D. Wolfelt, PhD
Grief Recovery Online for All Bereaved	www.groww.org	Online grief support
Grief Net	www.griefnet.org	Online community, resources and support for people dealing with grief, death, and major loss
Growth House	www.growthhouse.org	Educational material about the end-of-life with books for caregivers and health care workers
Kids Konected	www.kidskonected.org	Education and support for children and teens who have a parent with cancer
Legacy Videos	www.alovinglegacy.org www.zarpz.com	Provides the seriously ill of all ages an opportunity to share their legacy on video
MD Junction	www.mdjunction.org	Bereavement support groups
Moyer Foundation's National Bereavement Resource Guide	www.moyerfoundation.org/pdf/NationalBereavementResourceGuide_2010Update.pdf	Bereavement resources for children and adults
The Arnold C. Yoder Survivors Foundation	www.theacy.org	Grief support and education for children and adults
Education		
American Cancer Society	www.cancer.gov 1-800-227-2345	<ul style="list-style-type: none"> ◆ Caregiving: How to Care for a Loved One With Cancer -- And Yourself ◆ Caring for the Patient With Cancer at Home: A Guide for Patients and Families <p>(see website for more)</p>

Resource	Source	Description
		booklets for FCGs)
CancerCare Fact Sheets	www.cancer.org ; 1-800-813-HOPE (4673)	<ul style="list-style-type: none"> ◆ Finding Resources in Your Community ◆ Relaxation Techniques and Mind/ Body Practices: How They Can Help You Cope with Cancer ◆ Caring Advice for Caregivers: How Can You Help Yourself? <p>(see website for more booklets for FCGs)</p>
Cancer Support Community	www.Cancersupportcommunity.org	Information, resources and support community for all impacted by cancer
National Alliance for Caregiving	www.caregiving.org	Education, resources and advocacy for family caregivers
National Cancer Institute	www.cancer.gov	<ul style="list-style-type: none"> ◆ Caring for the Caregiver ◆ When Someone You Love Is Being Treated for Cancer <p>(see website for more booklets for FCG)</p>
National Family Caregiving Association	www.nfcacares.org	Education, resources, and advocacy for FCG
UCSF Caregivers Project Orientation to Caregiving: A Handbook for Family Caregivers of Patients with Serious Illness	www.cancer.ucsf.edu	Handbook developed to provide easily accessible and accurate information to family caregivers caring for loved ones with serious illness.
Housing, Assisted Living, Home Health & Hospice Care		
AARP Caregiving Help & Advice	https://caregiving.genworth.com	Nationwide home health care resources
Assisted Living Directory	www.assisted-living-directory.com	Senior care experts help locate the best assisted living facility for you and your loved one, nationwide

Resource	Source	Description
Cleaning For A Reason	www.cleaningforareason.org	Free professional house cleanings for women undergoing cancer treatment
Hospice Foundation of America	www.hospicefoundation.org	End-of-life care resources for patients, families and professionals
Joe's House	www.joeshouse.org	Assists cancer patients and their families find lodging near treatment centers nationwide
New Life Styles	www.newlifestyles.com	National directory and resources for senior care, assisted living, home health, and hospice care
Individual and Family Counseling		
Caregiver Health Insurance and Mental Health Benefits	Medical Insurance Card	Determine if caregiver carries medical insurance and is eligible for mental health services. Link caregiver to marriage and family therapist, licensed clinical social worker, psychologist and/or psychiatrist in their coverage plan.
LiveStrong	www.livestrong.org	Free, confidential counseling referrals for patients and caregivers.
National Alliance on Mental Illness	www.nami.org	Nation's largest grassroots mental health organization
National Substance Abuse and Mental Health Service Administration	www.samhsa.gov	Substance abuse and mental health services
Legal/ Financial Assistance		
Brenda Mehling Cancer Fund	www.bmcf.net	Provides financial assistance for medical and legal services, housing, home healthcare, travel, phone bills, for cancer patients ages 18 to 40.
Cancer Legal Resource Center	www.disabilityrightslegalcenter.org	Free, confidential information on cancer-related legal issues
Chronic Disease Fund	www.cdfund.org	Financial assistance for expediting therapy
Employment Development Department (State of California)	www.edd.ca.gov	Apply for State Disability Insurance (SDI) and unemployment.
Family Medical Leave Act	www.dol.gov	Entitles eligible employees to take unpaid, job-protected leave
Feeding America	www.feedingamerica.org	Nation's leading domestic hunger-relief charity
Financial Counselors	On-staff	Refer to the financial counselor at your facility
Give Forward	www.giveforward.org	Online tool that enables friends and family to send financial support to patients

Resource	Source	Description
		as they navigate a medical crisis
HealthWell Foundation	www.healthwellfoundation.org	Financial assistance for eligible individuals to cover coinsurance, copayments, healthcare premiums and deductibles for certain treatments
Lazarex Cancer Foundation	www.lazarex.org	Financial assistance to defray the costs associated with patient participation in FDA clinical trials
LeafLit	www.leaflit.com	Medical debt reduction and management
Merck Patient Assistance Program	www.merck.com	Prescription coverage for those who cannot afford medications
National Organization of Rare Disorders	www.raredisorders.org	Prescription coverage for those who cannot afford life-sustaining medications
Partners in Care Foundation	www.picf.org	Financial resources for underserved children and families who face a catastrophic life event
Partnership for Prescription Assistance	www.pparx.com	Prescription coverage for those who cannot afford medications
Patient Access Network Foundation	www.panfoundation.org	Financial assistance to under-insured patients for medications
Patient Advocate Foundation (PAF)	www.patientadvocate.org	Mediation and arbitration services to assist patients with medical debt, insurance access and employment issues
Patient Services Incorporated	www.patientservicesinc.org	Provides premium or co-pay insurance assistance
Pharmaceutical Reimbursement Assistance Program	www.needymeds.com	Pharmaceutical sponsored non-profit program providing cancer drugs at reduced costs to patients in need.
Veterans Assistance	www.va.gov	Health and well-being services for veterans
Self-Care		
Caregiver Bill of Rights	http://www.co.delaware.ny.us/departments/ltc/docs/CG_Caregiver_Bill_of_Rights.pdf	Healthy reminder of caregivers' rights
CaringBridge	www.caringbridge.org	Free, personal and private websites that connect people experiencing a health challenge with family and friends
Lotsa Helping Hands	www.lotsahelpinghands.com	Free community web site on which to privately organize family and friends who volunteer help, matching with needed tasks on individualized calendar

Resource	Source	Description
Skype	www.skype.com	Free phone and video phone calls around the world
Touch, Caring & Cancer – Simple Instruction for Family and Friends	www.partnersinhealing.net	Instructional DVD on how to give comfort through touch and massage to a loved one with cancer
Yoga Bear	www.yogabear.org	Dedicated to promoting wellness and healing in the cancer community through the practice of yoga
Sexual Health & Intimacy		
Fertile Hope	www.fertilehope.org	Reproductive information to patients whose medical treatments present the risk of infertility
International Society for the Study of Women's Sexual Health	www.isswsh.org	Resources, including provider referrals, for women's sexual health
Sexuality and Cancer – For the Woman/Man Who Has Had Cancer and Her/His Partner	www.cancer.org	Education and resources on sexuality and cancer for men and women
Smoking Cessation		
National Cancer Institute Help Line	1-877-44U-QUIT (1-877-448-7848)	Smoking cessation counselors from the National Cancer Institute are available to answer smoking-related questions (English or Spanish)
Smokefree.gov	www.smokefree.gov	Counseling, support, tools and resources to quit smoking
Support Groups		
Cancer Hope Network	www.cancersupportnetwork.org	One-on-one support for cancer patients and families
CancerCare	www.cancercare.org	Online, telephone and in-person support groups for patients, caregivers and those who have lost a loved one.
Caregiver Support Groups	Local hospitals/facilities	Refer to caregiver support groups in the caregiver's community (offered by hospitals, churches, hospices)
HopeWell Cancer Support	www.hopewellcancersupport.org	Online community incorporating blogs and forums for patients and caregivers.
Imerman Angels	www.imermanangels.org	Personalized connections that enable 1-on-1 support among cancer patients and caregivers
LungCAN-Lung Cancer Action Network	www.lungcan.org/	Provides resources related to lung cancer including emotional and psychosocial support for caregivers and patients

Resource	Source	Description
Lungevity	www.lungevity.org	Provides community for those impacted by lung cancer
MetaCancer: A Community of Survivors & Caregivers	www.metacancer.org	Resources and online support for metastatic cancer survivors and their caregivers
Phone Buddy Program, Lung Cancer Alliance	www.lungcanceralliance.org	Peer-to-peer telephone support for lung cancer patients and caregivers
Transportation		
American Cancer Society	www.cancer.org	Transportation assistance for patients and caregivers to and from medical appointments (limited)
Angel Flight Network	www.aircharitynetwork.org	Air transportation for medically compromised patients and their families 1000 miles
CancerCare	www.cancercare.org	Transportation assistance for patients and caregivers to and from medical appointments
Corporate Angel Network	www.corpangelnetwork.org	Air transportation for medically compromised patients and their families 1000 miles
For Providers		
Cancer Patient Education Network	www.cancerpatienteducation.org	Network of healthcare professionals who share experiences and best practices in all aspects of cancer patient education.
Communication Tips - Cultural Sensitivities	www.eperc.mcw.edu/EPERC	Asking about cultural beliefs in palliative care
Pain & Palliative Resource Center	http://prc.coh.org/	Publications regarding family caregiving