



CANCERcare®

Improving the Quality of Life for Lung Cancer Patients



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Improving the Quality of Life for Lung Cancer Patients

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Improving the Quality of Life for Lung Cancer Patients

Introduction

In New York City on October 20-21, 2015, CancerCare sponsored a group of executives from lung cancer advocacy organizations and key opinion leaders in lung cancer at a roundtable discussion and gave presentations reviewing the significance of patient reported outcomes related to lung cancer patients' quality of life. The ultimate goal of this meeting was to elevate the importance of patient reported outcomes and quality of life in lung cancer, not only within the context of clinical trial outcome measures, but also within the practices of every healthcare professional charged with the care of cancer patients.

This whitepaper reviews these experts' presentations and the discussion concerning cancer-related weight changes, dietary recommendations, the role of exercise in rehabilitative medicine, and the use of social media in mounting a call to action in support of these causes. Distribution of the whitepaper will include CancerCare's lung cancer website (www.lungcancer.org), related websites, healthcare political action groups, select key opinion leaders, psychosocial oncology professionals, and Capitol Hill leaders.

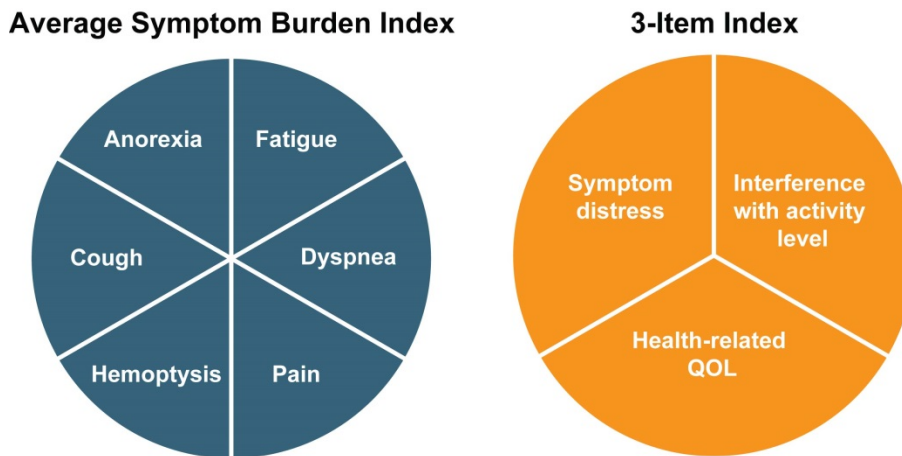
Quality of Life and Patient Reported Outcomes: Relation to Major Clinical Outcomes

Definitions of quality of life (QOL) and the individual components of which it consists for lung cancer patients may always be variable to an extent. We do, however, typically identify 5 dimensions of QOL. The *physical* dimension includes symptoms, such as fatigue. The *functional* dimension describes patients' abilities to care for themselves on a daily basis, which becomes more important as patients grow sicker. *Psychological* and *social* dimensions include anxiety and depression, sexual relationships, and friendship, all of which impact relatively healthy patients the most. A *spiritual* dimension is also important to most patients and is individually determined.

The three QOL measures used most for lung cancer patients are the Lung Cancer Symptom Scale (LCSS), the European Organization for Research and Treatment of Cancer (EORTC) QLQ-C15-PAL, and the Functional Assessment of Cancer Therapy-Lung (FACT-L). The LCSS was developed for patient management and use in clinical trials. The EORTC and FACT-L are general use modules. There are some differences among these 3 measures but they are all reasonable and validated in more than 50 languages. The LCSS is also available electronically for use in clinical trials or daily practice.¹ These assessment tools can be used to develop symptom burden indexes as they would apply to lung cancer-specific patient reported outcomes (PROs).

An average lung cancer-specific symptom burden index consists of 6 symptoms including anorexia, fatigue, dyspnea (shortness of breath), pain, coughing, and hemoptysis (coughing up blood) (Figure 1).

Figure 1. Average and 3-Item Symptom Burden Indexes



Gralla RJ, et al. *J Thorac Oncol.* 2014;9:1243-1248.
Hollen PJ, et al. *Cancer.* 1994;73:2087-2098.

Lung cancer patients typically do not have all of these symptoms but approximately 80% have 3 or more. Now consider the specially designed 3-item index, which includes symptom distress, interference with activity level, and health-related QOL (also in Figure 1). The components of the 3-item index measure how the 6 components of the symptom index actually impact the patient. All lung cancer patients have meaningful scores for all measures on the 3-item index, and these measures are more meaningful to patients than experiencing the symptoms themselves. Results of the 3-item index, therefore, are more impactful than symptoms.^{2,3}

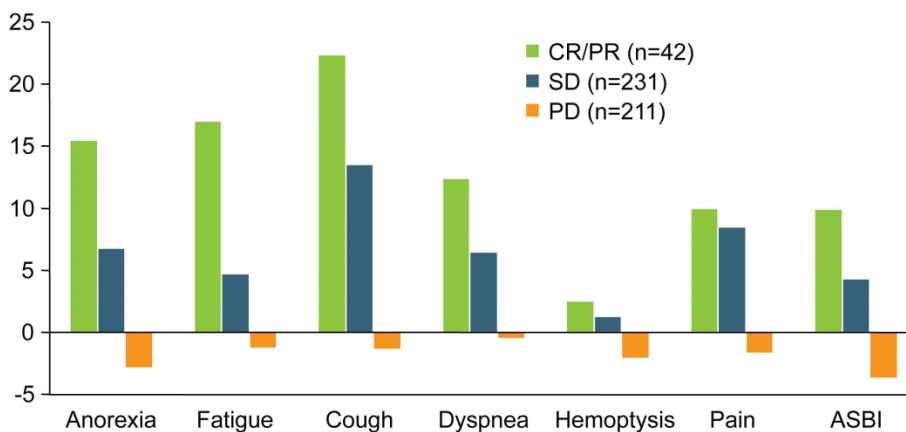
This was further demonstrated in an electronic web-based survey of 660 lung cancer patients who were asked to rank 20 issues of concern on a 5-point scale ranging from “not important at all” to “very important.” The top 5 ranked issues were QOL, maintaining independence, burdening others, performing normal activities, and ability to sleep. None of these issues are symptoms, such as pain, fatigue, and being depressed, all of which were of less importance to respondents than the top 5 issues.³

Clinical trial data demonstrate that QOL and PRO data can reflect degrees of response to treatments even when standard results of the effectiveness of the tested

drugs (such as survival, response rate, and progression-free survival) are comparable.⁴

In a major study of 2 chemotherapeutic agents in 488 advanced non-small cell lung cancer patients, the 3 typical subgroups (complete and partial response, stable disease, and progressive disease) were examined for improvements in PROs to see if they related to outcomes, regardless of treatment. Improvements in PROs did correspond, demonstrating that QOL and PRO data are sensitive to outcomes. Researchers in this study concluded that QOL and PRO information provides complementary efficacy information that can guide routine clinical practice (Figure 2).⁴

Figure 2. Symptom Improvement From Baseline Reflected in Response to Therapy



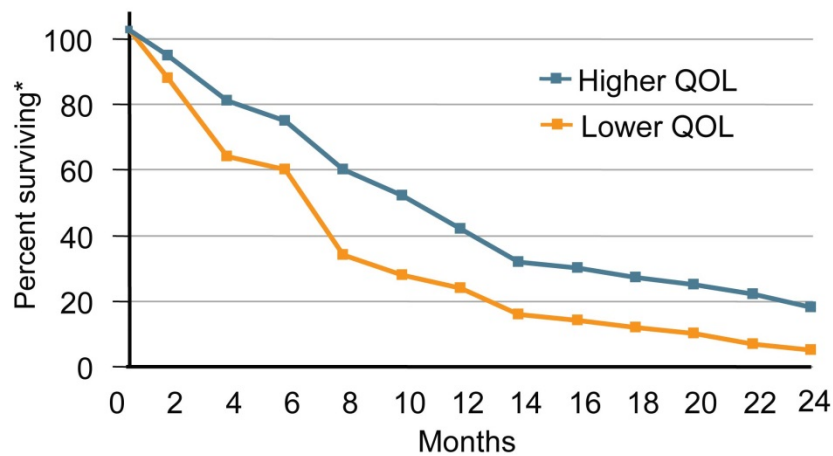
1. De Marinis F, et al. *J Thorac Oncol.* 2008;3:30-36.

ASBI, average symptom burden index; CR, complete response; PR, partial response; SD, stable disease; PD, progressive disease.

From diagnosis on, the importance of sustained QOL in lung cancer has been demonstrated in a study of 673 lung cancer patients (Figure 3).

Figure 3. Impact of QOL at Baseline

Prospective Analysis of 673 Patients at 30 Centers



*P = 0.0001, using the LCSS QOL measurement.
Hollen PJ, et al. *Lung Cancer*. 1997;18:119-136.

The influence of QOL at baseline or the start of the study on survival was examined. Results demonstrated that if QOL scores were higher at baseline, survival times were longer in these same patients. Other factors such as cancer stage or overall health of the patient are often used as predictors of survival, but in this study QOL at baseline was a better predictor of survival than these two more traditional criteria. These results suggest that QOL warrants consideration as a primary endpoint separate from survival.⁵

Baseline PRO factors can also be correlated with survival. In a recent trial, 622 stage IV lung cancer patients receiving chemotherapy were evaluated every 3 weeks for PRO factors, which were correlated with survival. An index was created using the number of negative PRO factors, demonstrating how they correlated with survival in these patients (Table 1).

Table 1. Relationship Between Baseline PRO Factors and Survival

Number of Negative PRO Factors	Median Survival	1-Year Survival	2-Year Survival
0	16 months	64%	36%
1 or 2	13 months	54%	30%
3	9 months	38%	13%

This index identified more accurate survival differences than performance status, a standard measure of patients' ability to function. It can be used to improve clinical trial design and analysis, and contribute to more personalized patient care.⁶

A recent Canadian study provided insights into physicians' and nurses' appreciation for QOL evaluations and their utilization. Doctors more than nurses appreciated time saved in patient consultation through performing a QOL evaluation, and 93% of doctors felt these evaluations enhanced the quality of patients' visits. Almost half of surveyed physicians felt QOL evaluations reduced X-rays and other scans, 91% believed they identified patients not benefiting from chemotherapy earlier, and 100% felt they identified pain and related issues faster with QOL evaluations.¹

A number of common clinical issues impact QOL and survival in cancer patients including diminished appetite, frailty, fatigue and diminished activity, weakness, and nausea. From its onset these issues start working in complicated and interrelated ways to contribute toward "cancer cachexia," a syndrome of skeletal muscle mass loss that cannot be fully reversed by conventional nutritional support and leads to progressive functional impairment.⁷

In the Asia-Pacific study of QOL in lung cancer, baseline appetite was studied to determine if it affected survival.⁶ PROs determined a median appetite score of 75 at baseline, and those above and below this median were tracked throughout the study. Those with appetite scores at or above the median at baseline lived 5 months longer than those with scores below. The same study also examined the relationship between pretreatment activity levels and survival in a similar way. These researchers concluded that patients with pretreatment activity levels above the median at baseline also lived longer.

To cancer patients, progressive frailty means loss of independence, and dependence on caregivers. It is also associated with impaired mental and emotional status, loss of strength and weight, and chronic disease.^{8,9} Loss of skeletal muscle mass (sarcopenia) contributes to frailty and plays a major role in cancer cachexia. Nearly half (47%) of all cancer patients either have it at diagnosis or develop it through their disease course.¹⁰ Sarcopenia is associated with reduced tolerance and poor responsiveness to treatment, susceptibility to infection, and poor quality of life.^{11,12}

In lung cancer, sarcopenia is associated with poor outcomes and affects approximately 60% of patients.¹³ Sarcopenia and associated functional loss may even precede cachexia, which is significant, because data show that patients without muscle depletion survive more than 3 times longer than those with muscle mass depletion.¹⁴ Weight loss alone, however, is not sufficient to monitor sarcopenia because such changes explain only 35% of variation in area of muscle mass.¹³ Other measures such as handgrip strength and walking muscle strength have also been used to determine the impact of cachexia/sarcopenia. Data from such studies have indicated that there was no difference in these measures between patients with cachexia/sarcopenia and those without these issues, but these patient groups had significantly different survival rates favoring the non-cachexia/sarcopenia group.¹⁵ At least 4 skeletal muscle mass assessment tools exist, each with its advantages and disadvantages. Magnetic resonance imaging (MRI) remains the gold standard but is considered costly, time consuming, and is not routinely used.^{16,17}

Appetite stimulation has been considered a key mechanism in promoting weight gain and counteracting the anorexia that characterizes cancer patients. Cannabinoids and hormones (megesterol) have both been studied.¹⁸ Both agents demonstrated positive effects regarding appetite stimulation and weight gain, with results favoring megesterol; however, neither of these agents demonstrated any impact on lean body

mass.¹⁸ Another class of agents known as ghrelin agonists stimulates both hunger and release of growth hormone.¹⁹ Two recent clinical trials compared anamorelin, a ghrelin agonist, with placebo in lung cancer patients. Anamorelin-treated patients demonstrated significant advantages in lean body mass and weight gain. There were no hand grip strength differences between the two groups. Other agents including selective androgen receptor modulators are also being investigated, but so far results in later phase clinical trials have shown mixed results.

We have seen that QOL and PRO measures are more important to cancer patients than symptoms experienced through the course of their disease. We have also seen that these measures can contribute to improved understanding of cachexia, sarcopenia, and related issues that compromise QOL in lung cancer patients. As such, QOL or PROs are as important as survival when evaluating individual treatments and overall management of lung cancer patients.

Eating Hints, Dietary Changes, and Recommendations

In advanced lung cancer, malnourishment is a frequent cause of death. Nearly 60% of lung cancer patients have lost significant weight by the time they are diagnosed, often due to late-stage diagnosis, and 25% to 50% of these patients are considered malnourished.^{20,21} Cancer patients often do not realize that weight loss due to the disease is unhealthy and should be encouraged to maintain a healthy diet and to avoid weight loss.

Patients who have weight loss at their initial diagnosis are more likely to have delayed treatment and to develop anemia. They are also less likely to receive full chemotherapy dosing. They are at greater risk of increased toxicity to cancer drugs and reduced absorption of them, and more likely to have slower post-operative recovery. They typically have poorer responses to treatment and less progression-free and overall

survival, and are more likely to suffer other symptoms of poor nutrition including nausea, vomiting, and diarrhea. A mere 5% weight loss can lead to reduced functional status and lower QOL.²² Weight stabilization can improve all of these issues.

Identifying patients in need of nutritional intervention at diagnosis is important. The Commission on Cancer requires their accredited cancer centers to use a Distress Screening tool that often has nutrition oriented components such as eating, diarrhea, constipation, and nausea, but because these tools are so broadly designed, patients in need of nutritional support can go undetected.²³ It is possible, for example, for a patient who had scored “zero” on a distress test to be brought to the attention of a dietitian a month later, even though that patient had noted nutritional problems on the initial distress screening.

Once identified, however, patients rated as malnourished receive a thorough nutritionally focused assessment. Nutritional screenings consist of multiple steps and consider criteria such as height/weight ratios, unplanned weight loss, severity of illness, and likelihood of nutritional intake to develop risk-based management guidelines individualized to the patient. Specialized oncology nutrition screening tools are also available; however, several barriers including lack of staff and support services hinder their adoption in spite of their potential benefit to cancer patients.

Registered dietitians recognize the cancer anorexia cachexia syndrome (CACS) as weight loss greater than 5%, or 2% in patients showing depletion of skeletal muscle mass or body weight as determined through weight/height ratios. Solid tumor patients are at risk of CACS.

Numerous clinical characteristics differentiate CACS from simple starvation. Compared to starvation, liver size and metabolism, skeletal muscle loss, and the quantity of energy spent just to maintain self are all increased in CACS.²⁴ These and other elements of CACS decrease patients’ performance status, social interactions,

ability to perform activities of daily living, and erode their capacity to maintain independence. The dietitian's goal is getting the patient to appreciate that this is not simple weight loss. CACS threatens their independence and challenges their QOL, and patients must come to this realization early in their disease for nutritional intervention to succeed.

Stopping weight loss in the "pre-cachectic" state (prior to 10% weight loss) is essential. The chance of success decreases with increased percent of weight loss. A comprehensive nutritional assessment is required. These are highly detailed assessments conducted by a registered dietitian (Table 2).

Table 2. Components of a Comprehensive Nutritional Assessment

• Medical history and diagnosis
• Body size, weight, and proportional data
• Biochemical data
• Clinical assessment
• Diet and current intake
• Functional status and QOL
• Weight loss quantity and velocity
• Treatment factors
• Socioeconomic factors and literacy

Often the symptoms of malnourishment are hidden and may include dry, flakey skin at the corners of the mouth indicating dehydration, or red tongue, which is symptomatic of thrush. Missing, rotten, or broken teeth may also be signs of an underlying nutritional risk. Many of these features may show in a patient's face, for example, but not be revealed by weight alone.

Successful interventions begin with the patient's current nutritional status and build upon small realistically achievable goals. If the patient is eating once a day, build slowly toward 2 meals per day based on what the patient enjoys without overwhelming the patient. Adding a glass of milk to a meal is a significant accomplishment. Small, frequent meals tend to work for patients with symptoms. Protein consumption should be encouraged with a goal of at least 3 significant servings per day. Food supplements are

a good source of calories but “real” food is a better nutritional source. Importantly, patients whose eating habits have been radically altered may want to adopt radical “healthy eating” programs but these should be discouraged until weight is stabilized and calorie and protein intake are adequate. Wholesome nutritional consumption should be emphasized.

Patients should eat whenever the body signals hunger because, if they fail to respond, the body may stop sending nutritional prompts. Snacks and foods of all varieties can be purchased, prepackaged for travel, and should always be available in the event of hunger. Caregivers must be included in nutritional planning and must learn about patient serving sizes and the preparation of personalized food “kits” that contain drinks, snack foods, and small sandwiches. Reliable online resources include “Nutrition for the Person With Cancer During Treatment” and “Eating Hints: Before, During, and After Cancer Treatment,” which can be found at <http://www.cancer.org> and <http://www.cancer.gov>, respectively.

Registered dietitians must also work with doctors, nurses, and physicians’ assistants because design of the nutritional plan must address all causes of the patient’s symptoms, some of which may result from therapy. These may include opioid-induced constipation and chemotherapy-induced nausea and vomiting, among others. Chemotherapy drugs are also known to cause electrolyte imbalances and may require additional nutritional attention.

Often the best approach to nutritional intervention is multidisciplinary; addressing not only physical but psychosocial needs, and the resources available to the patient. If the patient lacks the resources to participate in the plan, it will not work regardless of how good it may be. Numerous resources exist and routinely work with nutritionists, including nurse navigators, physical and occupational therapists, social workers, and financial counselors.

Treatments such as nutritional intervention do not cure cancer but research has shown that intervening early to relieve symptoms, especially pain, leads to increased QOL and an overall better mood in patients. Compared with patients receiving standard of care, cancer patients who received early interventions to relieve symptoms required less aggressive care at end of life and also lived longer.²⁵ Integrating the sense that it takes a multifaceted approach early in treatment with practitioners will build trust from patients.

The Role of Exercise, Rehabilitative Medicine, and Strength Exercises

From diagnosis throughout the cancer care continuum, it is important to sustain physical fitness not only because it contributes to good QOL, but because it directly counteracts many of the side effects of both the disease and its treatments (Table 3).

Table 3. Common Side Effects of Cancer and Its Treatments

• Fatigue
• Pain
• Poor flexibility – stiffness – chest tightness
• Muscle weakness
• Body weight issues
• Poor body image
• Anxiety, stress, and/or depression

Studies have shown that exercise throughout cancer treatment is safe and improves physical functioning, QOL, and cancer-related fatigue. According to the American College of Sports Medicine (ACSM) roundtable on exercise guidelines for cancer survivors, cancer patients should avoid inactivity and should exercise at least 2.5 hours per week.²⁶

In the past, clinicians advised cancer patients to rest and avoid activity but emerging evidence concerning the benefits of exercise have led to a reversal of these outdated recommendations. Current data suggest that regular exercise and attention to

fitness should begin at the time of diagnosis and continue through pretreatment, surgery, chemotherapy, radiation, and post-surgery rehabilitation. Post-treatment studies have shown that with less exercise, more post-treatment problems occur. According to ACSM guidelines, exercise prescriptions should be individualized to the patient's pretreatment aerobic fitness, related medical problems, response to treatment, and the negative effects of treatment that the patient is experiencing.²⁶

Animal studies have been conducted to determine if exercise affects cancer development and growth. These studies have, for example, tested groups that were sedentary, had exercised, had chemotherapy plus exercise, and just chemotherapy. The results of such studies have shown that the tumors in animals that had chemotherapy plus exercise shrunk more than in animals that were sedentary. Now there are patient studies looking at the response to exercise with each patient's tumor biology. Exercise may be another treatment in the fight against cancer.²⁷

Regardless of cancer stage, drug treatment or therapy, and surgical status, the benefits of exercise extend across patient classification. Fitness level prior to surgery may play a role in the occurrence of post-surgery complications, and research has demonstrated that walking for just 1 hour 5 times weekly prolongs survival.

In lung cancer/pulmonary resection patients, the musculature of the respiratory system is of vital importance. The goal for these patients is strength maximization of the respiratory musculature. These muscles include the diaphragm, intercostal muscles, abdominal muscles, and other accessory breathing muscles. Inhalation through the nose can increase the depth of respiration to inflate the entire lung and this should be practiced through training exercises to build respiratory muscle. During exercise, which might include activity such as lifting, exhalation upon the stress of lifting builds the power of these muscles. Breathing exercises are essential to lung cancer patients. Routines are easily searchable on the Internet and contain detailed explanations of why and how we breathe: <http://www.youtube.com/user/lungexercise>.

Breathing patterns can be improved, increasing body muscular strength, which decreases the level of breathlessness and fatigue. Weight training exercise should be coordinated with breathing so that upon exertion (lifting), the patient breathes out. Breath should not be held during exertion.

The first step to implementing an exercise program is establishing a baseline. On a scale of 1 to 10 for breathlessness, consider 1 as normal and 10 as breathless or exhausted. Use the same scale to measure exertion. An evaluation of recovery time is needed. After walking to point 10 (breathlessness), record how much time is required to regain a normal breathing pattern. The goal is to decrease the time required to regain a normal breathing pattern. Repeat this process with stair climbing and again with weight training to establish baselines. Baselines can be established with any exercise routine, and for the cancer patient who maintains an exercise program, the ability to track and validate progress is very positive. This provides patients an opportunity to objectively measure and see that they really are growing stronger.

Compound exercises are good because they engage large muscle groups. They include walking, stair climbing, biking, chair exercises, wall push-ups, knee lifts, and upper body weight training. Reasonable goals should be set from the beginning of the program. Especially important to the lung cancer patient, cardio fitness requires specific attention. The patient should include cardio exercise intervals of 30 minutes 2 to 5 times per week (bicycling, treadmill, walking). Cardio exercise improves oxygen to the working skeletal muscles. Strength and breathing training can be practiced simultaneously. These should incorporate routines that focus on improving muscle strength of the shoulders, chest and back muscles, and diaphragm.

Studies have shown that exercise itself decreases cancer risk. Encourage cancer patients to think of exercise as medicine. Cancer patients should incorporate regular exercise into their everyday lives so that it becomes as much a part of who they are as breathing, eating, and sleeping. Community exercise programs help people appreciate that exercise is normal for everyone while also providing an opportunity to become part of a new social group. Once exercise has become integrated into patients' personal lives, its benefits will continue for the remainder of their years.

Advancing Quality of Life as a Primary Outcome in Lung Cancer Management Through Social Media

When it comes to advancing a cause, it is difficult to measure the impact of social media or any of its individual venues. Most people, however, can probably agree that social media can have a tremendous impact on advancing a cause if there is a well-designed strategy behind it. Social media strategy design has become a specialized form of educating, communicating, influencing, and mobilizing causes all through electronic networks of personal connections and online communities. Ogilvy CommonHealth Worldwide in New York, has offered to donate its services in contributing to the design of social media to advance the significance of QOL and PROs among the criteria that define the quality of lung cancer care.

Healthcare conversations are not new to the Internet and social media. Thriving, specialized virtual communities have been created through social media and provide people with the capability of communicating globally on a 24/7 basis. A specific disease is an ideal focal point around which to build an online community. There is intense human interest to find additional connections when a patient or caregiver is faced with a medical challenge. All community members will want to learn about their disease and help fellow members of their community.

Other countries are ahead of the United States in developing online patient communities. Very credible online organizations already exist with the capability of connecting inquiring patients to websites and other organizations that cater to their specific disease. Online communities are currently performing greatly needed logistical services that help patients understand and cope with the daily problems and stresses of their disease. This has proven especially helpful to the small communities of patients

with rare diseases because there may be just a handful of patients in the world with the disease. It is important in lung cancer too, because of the social isolation that the stigma of both smoking and mortality can create.

The lung cancer community is already large. Patient interest in learning about the disease has grown to the extent that patients are known to attend the annual meeting of the American Society of Clinical Oncology (ASCO) to learn about new therapies and see results of the latest clinical trials. This is important because analytics indicate that some of these meeting attendees now have the ability to reach hundreds of millions of people with messages within minutes, all through coordinated social media.

Importantly, these are also people of some influence within their patient communities. The social media surrounding lung cancer as well as other forms of cancer have generated what are now known as Patient Opinion Leaders (POLs). These are individuals whose names have become known and respected because of their expertise and knowledge in the field. Their participation in relevant lung cancer events and social media communications over time in the field have brought them attention and garnered respect. Such status cannot be ignored because it is authentic, has a huge support network and following, and has the ability to gain the attention of influential oncologists and healthcare professionals.

Authenticity is key because it is central to the campaign of the social media message. Once identified, developed, and refined, the social media message should first be disseminated through Patient Opinion Leaders who have the ability to communicate the message clearly.

Amplification of the message is the next step. In building the campaign, care should be taken to select the appropriate social communities. They are not all equal. Carefully select the online communities that can have the greatest impact in support of your message. Initially, programming should educate and help people live with their

disease. Providing online support services can be augmented with offline support services. “Insight sessions” can be used not only to provide information but also gather feedback about how communications will be received.

Successful social media campaigns thrive on relevant personal emotion and knowing what resonates with your audience. Knowing what is important and inspiring to your audience matters because emotion – not analytical thinking – drives action. Centralizing these elements within the core of social media messaging drives perpetuation and keeps the message alive.

Conclusion

The “Improving the Quality of Life for Lung Cancer Patients” roundtable focused on promoting greater relevance of Quality of Life (QOL) and Patient Reported Outcomes (PRO) in the management of lung cancer patients. Evidence was presented demonstrating that patients value QOL with more regard than symptoms in lung cancer, and that treatment should be evaluated based on its effects on QOL or PROs as well as survival.

The roles of nutrition and physical fitness are vital to combating cancer cachexia and preserving skeletal muscle mass. These important QOL factors should be incorporated into the treatment plan at diagnosis and followed throughout the course of the disease.

Social media provides a powerful venue through which the cause of QOL and PROs as more highly valued lung cancer care criteria should be advanced. Strategically, focused groups can be developed within the lung cancer community that can impact medical practice and improve the quality of lung cancer care.

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