Editorial

Patient-centered care in lung cancer: exploring the next milestones

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Abstract: In this editorial, the authors comment on a recently published review paper by Molassiotis *et al.* on the developments made over the past 40 years in supportive care for patients with lung cancer. During this period, a paradigm shift promoting patient-centered care (PCC) has led to an important change in the approach of supportive cancer care, from a purely disease-centered approach, measuring survival-related outcomes, to recognizing the importance of quality of life outcomes as well. This change of understanding in supportive and palliative care for patients with lung cancer can be further advanced through the understanding that there is a need to address bio-psycho-spiritual concerns and health belief models, within the context of the family socio-cultural environment, for both patients and their caregivers. There is also a need to address the psycho-spiritual effects of cancer on those health care professionals treating patients with lung cancer, in order to reduce compassion fatigue and increase resilience. Future directions for supportive care for patients with lung cancer may include the development of a patient-tailored treatment approach, assisted by the integration of a multidisciplinary team of health care providers and evidence-based complementary medicine practices, within conventional supportive care practice.

Keywords: Lung cancer; supportive care; palliative care; complementary and alternative medicine; integrative oncology

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Case vignette

David, a 63-year-old high school math teacher, had been suffering for the previous 6 months from a chronic cough, atypical chest pain, dyspnea on exertion and a reduced appetite with weight loss. A right-sided infiltrate was found on chest X-ray, and after his symptoms and the infiltrate did no resolve with antibiotic treatment, he was sent for an in-depth evaluation, which revealed metastatic, non-small cell lung cancer (stage IV). David's medical oncologist recommended a 4-cycle regimen with cisplatin, pemetrexed (Alimta) and Bevacizumab (Avastin), along with pamidronate (Aredia). David and his wife, Martha, decided that he needed to change his lifestyle, and he immediately quit smoking and began a "healthy" diet, consuming only organically grown vegetables and fruits, as well as taking herbal medicines which claimed to "boost the immune system during chemotherapy".

David's oncologist works at an outpatient medical center which provides patients with an integrative supportive care program. The integrative program provides patients with complementary and integrative medicine (CIM) therapies, helping reduce the symptom load and improve quality of life (QOL) and function. The integrative service is staffed by a multidisciplinary team of medical and complementary medicine practitioners. Integrative physicians who are board-certified family physicians with extensive training in complementary medicine and supportive care first evaluate patients. David's oncologist referred him to the

integrative medicine service with two main goals: the first, to help David and his wife reach an informed decision on their choice of lifestyle and to provide evidence-based information regarding the effectiveness and safety of the herbal supplements which he had begun to take. The oncologist was especially worried that some of these products could negatively interact with the conventional anti-cancer agents he was receiving. Such interactions could increase toxicity and reduce efficacy of the treatment, preventing the achievement of optimal outcomes. The second goal of the referral was to see whether the CIM therapies being offered by the service could help reduce David's symptoms, primarily his persistent cough, as well as his symptoms of depression, insomnia and fatigue.

Patient-center care for patients with lung cancer

The special article recently published by Molassiotis *et al*. presents an important in-depth and comprehensive review of the past 40 years of supportive care for patients with lung cancer (1). This is an important paper, which should be read by any health care provider treating this patient population. It is of interest to note that five of the six authors are registered nurses (RNs), reflecting the central role of oncology and palliative care nurses as well as other medical professionals from a wide range of disciplines in creating a patient-centered care (PCC) approach in supportive cancer care. The PCC approach contrasts greatly with the prevalent conventional, disease-centered perspective, which focuses more on the tumor and less on the individual patient's needs and concerns. The paradigm shift to PCC views the patient as more than the "sum of the parts" (i.e., biological organs and markers), and tries to understand illness within the context of their health belief model. As a result, the accepted term being used today is "a patient with lung cancer", as opposed to "a lung cancer patient".

The last four decades have seen the spread of a holistic and humanistic approach in the field of bio-medical oncology. This has led to the integration of additional therapeutic approaches which can enrich the concept of well-being and QOL. The emergence of PCC-oriented supportive and palliative care, which is taking place within the "fortress walls" of conventional oncology, parallels the evolution of additional models of patient-centered care. These models reflect Engel's bio-psycho-social model in family medicine (2); Antonovsky's concept of a sense of coherence and salutogenesis (as opposed to pathogenesis) (3); and the emergence of the field of psycho-oncology, which focuses not only on patients' concerns but also on the caregiver and the health-care provider (4,5). Finally, the PCC approach has advanced significantly as a result of an increased awareness by health care providers of the dimension of spiritual care. Concepts of spiritual well-being, quality of dying (and not just living) and the role of post-traumatic growth in ameliorating compassion fatigue among health care providers have contributed significantly to the advancement of PCC in cancer care (6,7).

The emerging field of psycho-oncology has also helped to advance a PCC approach, by examining the psycho-social-cultural backgrounds of patients with cancer (8). PCC requires a multi-layered approach in order to understand patients' concerns, needs, and expectations, all of which can change during the many stages and cycles of treatment. This is true for a number of aspects of cancer care: the individual patient's view of his or her disease, as well as the treatment process; the interaction with spouses, parents/children, and other caregivers; the relationship with the surrounding society and culture, primarily in societies with strong collectivistic traits; and finally, the barriers of communication with the health care provider, especially with respect to unmatched health belief models and the understanding of treatment goals (9).

In their review of supportive cancer care, Molassiotis *et al*. present an extensive analysis of the transformation which has been taking place within the medical community. The gradual increase in awareness of the need for a PCC-oriented approach has advanced significantly during the past 40 years, including for patients with lung cancer. This paradigm change is being evaluated using reliable and validated assessment tools of patient reported outcomes (PROs). The authors present a number of these PRO measures, which have also been used for examining supportive care practice in patients with lung cancer. Other measures are being used for qualitative research of PROs, such as short patient narratives like those addressed by open-ended questions appearing at the end of Measure Yourself Concerns and Wellbeing (MYCAW) questionnaire (10,11). The use of narratives is especially helpful in exploring the impact of supportive intervention such as CIM, and is becoming more prevalent in the scientific literature, especially the narrative-based medical and sociological-anthropological literature.

Goals of supportive care in lung cancer

In their well-researched review, Molassiotis *et al*. suggest

that the main objectives of supportive care in LC, especially in patients with advanced and metastatic disease, are "stabilization of the disease and symptom management". They present the eight domains which need to be addressed by supportive cancer care, as suggested by Maguire *et al*.: physical, daily living, emotional, spiritual, informational, communication, social, and cognitive (12). While these domains are all central for both patients and their health care providers, there may be other issues which may also need to be addressed. For example, the impact of psycho-familial-social factors on smoking cessation may include not only bio-medical but also emotional elements such as self-guilt and shame, which can often lead to depression ("it's my fault"). Blame may be placed on the patient, sometimes unconsciously, by family members or health care practitioners, who may agree with the stigma that follows smokers, attributing them responsibility for their present illness.

The approach of the review on support cancer care is that of an epidemiologic analysis of tertiary prevention. The authors present the evidence available on the role of smoking prevention in improving patient's health outcomes, as well as reducing LC recurrence among survivors. While this is an important goal, the diagnosis of LC can also be used to advance the primary and secondary prevention of smoking among the patient's family and caregivers. However, while the supportive care environment provides an opportunity to improve patient well-being, it can also make use of the psycho-familial crisis which follows the diagnosis of LC for the achievement of similar outcomes and goals for those involved in the patient's care. Such an intervention would need to be carefully monitored by the psycho-oncology team, in order to ensure an optimal dynamic which presents the patient's journey as an opportunity for lifestyle change and growth for others affected by the diagnosis.

Complementary and integrative treatment options

Another aspect of supportive cancer care for patients with LC, which needs to be explored, is the health belief model regarding the use of complementary integrative versus alternative medicine. Nearly half of patients diagnosed with LC will eventually turn to one or more CIM modalities, though less than half will disclose this practice to their health care practitioners (13,14). Bauml *et al*. surveyed patients with LC who were receiving active treatment, and found that the use of complementary medicine was associated with a greater level of self-perceived control over the cancer itself (12). The prevalent use of CIM reflects the gap in communication with health care providers, as well as a need by patients to find a better way to cope with their disease and treatments. Indeed, there is a large and growing body of research supporting the benefits of a number of CIM modalities for patients with LC undergoing treatment for QOL-related outcomes. These include the use of herbal products, acupuncture (15), reflexology (16), Yoga (17), and Qigong (18).

Herbal medicine is the most popular CIM treatment being used by patients with LC, and many herbal compounds have been found to augment the effects of some anti-cancer agents. Examples of this are extracts from the herb Mistletoe (*Viscum album*) given to patients with advanced NSCLC who were undergoing treatment with carboplatin-based regimens (19); injections of Astragalus polysaccharides in combination with vinorelbine and cisplatin in patients with advanced NSCLC (20); and other Chinese and Japanese herbal remedies which are widely used by this patient population (21,22). At the same time, the use of herbal supplements during LC treatment may result in significant toxic effects, such as thrombocytopenia resulting from the use of the herb *Echinacea* in a patient with NSCLC treated with cisplatin and etoposide (23). It is also important to be aware of the potential negative interactions between herbal products and anti-cancer agents, such as the inhibition of metabolism of the agent Gefitinib by the Chinese herb *Marsdenia tenacissima* through effects of the herb on cytochrome P450 activity (24).

The potential for CIM treatments to significantly improve supportive cancer care has led a number of the leading cancer centers to include integrative oncology services within their walls (25). A multidisciplinary panel of experts in integrative medicine was commissioned by the American College of Chest Physicians to provide evidence-based clinical practice guidelines for the use of CIM among patients with lung cancer (26). A conceptual model for integrative care was later designed at a leading lung cancer center (27). These developments reflect the direction of supportive care for patients with LC, and require the medical establishment to make important decisions regarding the use of available and future resources for the treatment of these patients.

Supportive care and lung cancer: future directions

What should be the next step in advancing supportive and

palliative care for patients with LC? Is there a need for additional paradigmal changes in order to bring about this change? Have the past 40 years of supportive cancer really achieved a wide-ranging consensus among clinicians who are treating patients with LC and their caregivers, or are we still focusing primarily on the survival curve? And finally, how can we help patients with advanced disease like David, as well as his wife and caregiver Martha, to experience better supportive care than what is currently provided? The article by Molassiotis *et al*., which presents the significant advances made in this field over the past four decades, should make us optimistic about what the future holds for us as providers of health care for patients with LC. At the same time, there is need to intensify a holistic, bio-psycho-social-spiritual approach, such as that of PCC, which is sensitive to the individual needs, concerns, health belief models and desires of patients and their caregivers.

In addition to the above, there is also a need to widen the focus of supportive care to the patient's family members and caregivers. They, too, can have health-related concerns, which have traditionally been considered secondary to those of the patient. We need to acknowledge that health care providers such as the patient's family physician, oncologist, nurse, social worker and others may themselves be "wounded healers". They, too, may need psycho-spiritual help in order to help them overcome compassion fatigue and gain resilience for the next encounter with suffering, death, and the struggle for well-being and healing (28). Finally, we need to integrate evidence-based complementary medicine practices within the daily weave of the supportive care cloth. Complementary medicine should be provided to patients with LC by a multi-disciplinary team of oncologists, surgeons, nurses, psycho-oncologists, integrative physicians and practitioners trained in complementary medicine, and spiritual care supporters. Conventional medical services, such as those provided by dietitians, physiotherapists, occupational therapists etc., need to incorporate empathy and compassion along with professionalism. We need to personalize LC care, within a context which goes beyond the high-tech search for receptors and genetic mutations. We need to not only personalize anti-cancer treatments but also to view the entire spectrum of health care providers, patients and their caregivers. After all, we are all in essence just real people with real needs and concerns. Such an approach may be a promising key to reaching a comprehensive patient-tailored approach, leading to a significant advancement in supportive care of the patient with lung cancer.

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