

IASLC 15th World Conference on Lung Cancer

International Thoracic Oncology Nursing Forum Lung Cancer Satellite Workshop

Workshop in Review

Making Education Easy

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Abbreviations used in this issue:

ALK = Anaplastic lymphoma kinase
EGFR = Epidermal growth factor
MDT = Multi-Disciplinary Team
NSCLC = Non-small-cell lung carcinoma
QOL = Quality of life

Lilly

Answers That Matter.

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Welcome to this Workshop in Review for Sunday 27th October of the Satellite Meeting of the International Thoracic Oncology Nursing Forum (ITONF) at the 15th World Conference on Lung Cancer (WCLC), proudly supported by the International Association for the Study of Lung Cancer (IASLC) and the WCLC conference presidents.

This review has been created to provide summaries of selected presentations from the workshop for nurses, palliative care and allied health professionals.

We hope you enjoy this Workshop in Review, and we look forward to your comments and feedback.

Kind Regards,

Dr Janette Tenne

Medical Research Advisor

janette.tenne@researchreview.com.au

<http://itonf.com>



Preparing nurses for the next generation of mdt lung cancer care

Speaker: Professor Mei Krishnasamy

Summary: Keynote speaker Prof Krishnasamy challenged the audience to consider the complexities of nursing lung cancer patients - Where are we at? Where do we want to go? What is complex about caring for lung cancer patients? What is the role of nurses in multi-disciplinary teams (MDTs)? And what strengths can we draw on to assist the patients who will come into our care? In developing, implementing and evaluating best practice approaches to lung cancer care in Australia, she discussed four key areas of particular relevance to nursing in the context of MDT care.

1. *Personalised medicine:* Rapid DNA sequencing methods have been instrumental in the sequencing of the human genome and have greatly accelerated biological and medical research. Treatments which once took 30 years to develop, now take 18 months from lab to bedside - resulting in "new targeted agents and the development of personalised strategies for subsets of non-small-cell lung carcinoma (NSCLC)" such as monoclonal antibodies, EGFR blockers and ALK protein blockers,¹ however to-date there are no molecular targeted therapies available with demonstrated efficacy against SCLC. These rapid advances in biological research now translate into real treatments for people with NSCLC.
2. *Development and evaluation of interventions targeted at improving physical symptoms, social and psychological functioning.* Data from the Surveillance, Epidemiology and End Results (SEER) program shows us that patients with lung cancer are more likely to die from their cancer than a non-cancer related illness when compared with breast- and prostate-cancer patients, and have a worse comorbidity status than other cancer patients.² In addition, people living with lung cancer experience greater distress;³ greater nihilism and stigma;^{4, 5} and greater decrements in functional capacity than other groups.⁶ They also report and demonstrate poor levels of health literacy.⁷

The next generation of lung cancer nurses will be working in an arena where patients will be on multiple new-targeted therapies and will see increasing levels of survivorship as a realistic treatment outcome. The challenge for nurses will be acquiring the skills, knowledge and breadth of capacity to care from pre-diagnosis, through potential multiple treatments, to end of life or hopefully on into survivorship.

3. *Ageing population:* A further challenge that demands new knowledge will be the growing cohort of lung cancer patients reaching old age, representing a tsunami of potential comorbidities to go alongside a lung cancer diagnosis. Rapidly changing treatment options and the demand for greater capacity for self-management will come at a stage in life where patients are less able to do so, resulting in a significant impact on older peoples' function, cognitive capacity and prognostic outcomes. Approximately 57% of all new cancer diagnoses and 73% of cancer deaths in Australia occur in people aged 65 years or older, and the ratio of Australians in this age group is set to double to one quarter of the population over the next 35 years.* The priority for medical and nursing education is to integrate geriatric oncology knowledge and skill in advanced practice of specialist nursing care, and the ability to apply knowledge beyond the average patient group studied in clinical trials.
4. *A patient centred approach:* A major barrier to the implementation of MDT plans has been a lack of consideration of patient choices and comorbidities.⁸ The focus of MDTs needs to move away from the optimisation of clinical decision-making, quality of teamwork and resource burden⁹ and towards patient-centred models of care that deliver demonstrated patient benefits. In a MDT model it is often the nurse who brings the "voice of the patient" to the discussion table assisting patients in taking an integrated, informed and engaged role in treatment decisions and helping to relieve fear and anxiety. Delivering patient-centred care can only be done in the context of MDT - "care providers that respond to their consumers with personalised care, high quality care and service excellence are poised to thrive... They differentiate themselves by building a brand identity around a patient-centred approach to care."*

In the context of personalised medicine, nurse-led interventions and care for older people, Prof Krishnasamy considered the challenge of resource allocation to deliver on the challenges of specialist lung cancer care now and into the future - for example, what will it mean to deliver end of life care to a patient who has been on 8 biological therapies? How do we put our services where they are needed most to deliver excellence in patient care at every stage, not 2 months into a 6 month prognosis. The continuing challenge is timely, knowledgeable and multi-disciplinary planning to deliver measurable excellence in patient-centred care.

Out of the shadows into the clinic - stigma impacting on late presentations

Speaker: Dr Janine Cataldo

Summary: Lung cancer survivors experience more physical and psychosocial problems for longer periods of time than survivors of other cancers. They feel stigmatised because their disease is strongly associated with smoking, regardless of whether they are a previous smoker, current smoker or have never smoked. This perceived stigma - including fear of discrimination - is a significant predictor of increased depression and decreased quality of life (QOL). In addition, it can lead to late presentations and influences patient-clinical communication, case finding and treatment. Stigma contributes to the symptom burden of patients but is amenable to intervention and when we do intervene there are measureable positive health outcomes.

An interesting comparison exists between HIV and lung cancer - both diseases are perceived as being caused by a controllable behaviour, i.e. unsafe sex and smoking. With both conditions patients assign a level of responsibility to their disease - many feel that their lung cancer is their fault. With this in mind, the Cataldo Lung Cancer Stigma Scale (CLCSS) has been developed to measure the stigma perceived by people with lung cancer based on the HIV stigma scale.¹⁰

The CLCSS is based on four factors, which are then assigned a factor-loading, and are reflected in the four subscales:

- *Stigma shame* - relates to the patient's personal sense of stigma and shame and the perceived consequences of people knowing they have lung cancer such as trying to keep the disease a secret
- *Social isolation* - addresses losing social supports and a feeling of isolation because they feel they deserve their disease
- *Discrimination* - refers to feeling judged, discriminated against or "treated like outcasts"
- *Smoking* - relates to lung cancer being considered a smoking-caused disease, even if the patient has never smoked or stopped smoking years ago.

In conjunction with other instruments - e.g. to measure self-esteem (RSES, Rosenberg Self-Esteem Scale); depression (CES-D, Center for Epidemiological Studies - Depression Scale); social support and social conflict (Social Support Indices); and quality of life (Quality of Life Inventory) - the CLCSS can be used to identify the presence and impact of lung cancer stigma and allow for the development of effective stigma interventions for patients with lung cancer.

Lung cancer stigma has been shown to be a predictor of poor patient outcomes; a hindrance to help-seeking behaviour and a barrier to early detection and treatment of lung cancer and may keep patients from reporting distressing symptoms. Many factors contribute to stigmatisation including the perception of smoking as a choice rather than an addiction, the fear that second hand smoke harms children and the de-normalisation of smoking over the past 20 years - resulting in the transformation of smokers from "cool" to "social pariah".

Early presentation is important. For as many as 80% of patients with lung cancer, the disease is inoperable because diagnosis is too late.* Dr Cataldo commented that there is insufficient research to explain the delay in diagnosis, but it is clear that people often do not develop obvious symptoms until the cancer is in an advanced state. Therefore, screening and education for patient's at risk, such as current smokers or those who have quit within the last 15 years, provides an opportunity to identify and treat this disease earlier. In addition it is becoming increasingly important to eliminate the stigma associated with lung cancer so that we can focus on prevention, treatment and patient care. Dr Cataldo concluded with the statement "If you have lungs, you can get lung cancer".



Survivorship - how do we define in lung cancer

Speaker: Caitlin Broderick

Summary: The concept of a survivor has been around for centuries, but the debate over a precise definition and terminology continues and differs depending on the disease state or situation. For cancer patients, the National Coalition for Cancer Survivorship (NCCS) has defined a survivor as an individual "from the time of its discovery and for the balance of life". The NCCS recognised that having a cancer diagnosis was not only about the quantity of life in months or years but also about the impact of the diagnosis and treatment on the quality of an individual's life, including physical, emotional, legal and financial aspects. In more recent years the National Cancer Institute (NCI) has broadened this definition to include family, friends and caregivers.¹¹ By contrast, the biomedical definition can be phrased as "individuals who have had a life threatening disease but have remained disease free for a minimum of 5 years".¹²

Various groups have described the phases of survivorship for cancer patients, in order to provide a structure to planning for health systems and patients alike. NCCS founder, Dr Fitzhugh Mullan describes the three phases as:¹³

- *Acute survival:* beginning at diagnosis, and surviving treatment and its immediate effects;
- *Extended survival:* begins at the completion of treatment and encompassing the period of follow-up; this phase is dominated by anxiety and fear of recurrence;
- *Permanent survival:* when the risk of recurrence is unlikely; this phase is about surviving in the longer term including psychological and physical effects alongside the risk of secondary cancers.

But why does the definition matter? In lung cancer, the 3rd phase of permanent survival is only applicable to about 10% of patients, so the acute and extended phases are much more relevant to the concept of survivorship. Caitlin highlighted that if we as healthcare professionals perceive the concept of survivorship as being only about long-term survivors, then we risk ignoring the majority of our patients. It is recommended that all cancer patients are provided with a survivorship care plan or continuum on completion of primary treatment. The Institute of Medicine (IOM) in its report entitled "From cancer patient to cancer survivor" recommended implementing individual survivorship care plans which encompass:¹⁴

- *Prevention* of recurrent and new cancers and health promotion (e.g. smoking cessation)
- *Surveillance* for metastasis, recurrence or secondary cancers as well as assessing medical and psychological late effects
- *Interventions* for consequences of cancer and its treatment as well as the physical, psychological, financial impacts for the patient and their family
- *Coordination* between the patient, specialists and primary care providers to identify treatments, follow-up care and ensure that survivors' health needs are met.

In current practice, nurses have a high degree of contact with the patient during the acute care phase. However as patients move along the continuum and complete treatment, then entering the survivorship phase, patients describe "feelings of abandonment" as contact with nursing staff declines, due to stretched resources and shorter visits, resulting in less opportunity to voice concerns.

A survivorship care plan begins with a holistic assessment of the patient at diagnosis, offers interventions through an individualised care plan and directs patients towards appropriate resources to access. It also provides a summary of treatment received and follow-up planned. For some, such as surgical and radiotherapy patients, this is clearly defined, but it is not so easy to define in longer term targeted therapies when it is not clear when treatment ends and many patients may be lost to survivorship follow-up. With improved treatments, there are growing numbers of cancer survivors, although lung cancer is still underrepresented in the literature as only about 3% of survivors are lung cancer patients.

For NSCLC, the majority of recurrence occurs within 2 years and reduced to 5% at 5 years. Patients are at increased risk of second primary lung/aero digestive tract cancers especially if lifestyle risks such as smoking continue.¹⁵ Smoking cessation intervention, patient education and screening for secondary cancers can be included in care plans to influence behaviours, reduce and identify risks. Unfortunately at present, there are no agreed guidelines for the surveillance of lung cancers among professional groups.

Caitlin concluded by summarising that every patient will benefit from a comprehensive assessment from diagnosis to survival, with planning for the future, offering interventions to the patient and their family to reduce the negative impacts of the diagnosis and treatment, while enhancing the positive aspects. We need to offer evidence-based care to support patients through all phases of acute, extended and permanent survival.

Positive impact of specialist lung cancer nurses on better patient outcomes

Speaker: Professor Angela Mary Tod

Summary: The impact of the lung cancer nurse specialists (LCNSs) on patient's lives and outcomes is widely recognised. As important is how to capture this impact - in the world of evidence-based medicine and constrained resources, it is key to demonstrate this impact on patient's lives to the budget holders that fund the services.

When considering the positive impact that lung cancer nurse specialists have on patient outcomes, it is useful to reflect back on the development of the advanced practice roles such as the Clinical Nurse Specialists and Nurse Practitioners. The factors that influenced success, for example patient focus and a shared vision amongst stakeholders, as well as how success was defined, whether it be patient education or quality of life, are equally as important and relevant today. The quality of care and support that specialist nurses offer has been instrumental in reducing unnecessary hospital admissions and re-admissions, reducing waiting times, improving access to care, educating health and social care professionals and supporting patients in the community.

Nurses working in these advanced and specialist roles spend time in clinical activity (60%), education (17%), management activity (19%) and research (4%).¹⁶ Patient outcomes can be improved through all four of these areas of activity, and capturing the impact of the LCNS role involves looking at all four areas of activity. In the United Kingdom, the enormous impact of LCNSs is reflected in evidence-based guidance regarding LCNS involvement in care, including publications from NICE, the National Lung Cancer Audit, the Dream MDT and the NLCFN/Roy Castle Lung Cancer Foundation.

Prof Tod went on to discuss which outcomes are most important – the National Cancer Patient Experience Survey¹⁷ provides a useful illustration of the impact of LCNS on patient outcomes. The results demonstrate the difference for patients in centres where there is a LCNS vs. where there is not. For patients who see a nurse, outcomes are so much better across a variety of dimensions, including patients' understanding of treatment choices, access to support and self-help groups and patients' understanding of their disease.

Prof Tod presented a toolkit called "Capturing impact. A practical toolkit for nurse consultants"¹⁸ the content of which is equally applicable to other advanced nurse practice roles such as LCNSs. This toolkit provides a comprehensive framework for capturing the range, level and type of impact of the LCNS. Consider not only the direct impact but also the indirect impact of the LCNS role, as well as the different levels where this impact could be felt – the patient, staff and organisation. Also consider sources and types of evidence collected to demonstrate impact – use existing sources where appropriate, and consider quantitative as well as qualitative data.

Prof Tod focussed on the impact that LCNSs have on access to treatment. The UK National Lung Cancer Audit¹⁹ identified that in those units where patients were seen by a LCNS, patients were twice as likely to have access to anti-cancer treatment. Prof Tod discussed the results of a collaborative research project, which sought to understand how the LCNSs have this impact on access to treatment. The research showed that it was the nurses' patterns of working, as well as the roles and qualities that nurse specialists have that were just two of things that made the difference. The continual presence of the LCNS across the patient pathway, in contrast to the patient's more episodic contact with other members of the multidisciplinary team, was critical. This continuity is the key to better patient outcomes, and is unique to the LCNS in terms of the multi-disciplinary team.

Non-pharmacological management of breathlessness and cough

Speaker: Professor Alex Molassiosis

Summary: The everyday reality for lung cancer patients is that they live with a symptom burden that is often not well managed, and for which there is little evidence as to how to best manage. Two of these commonly experienced symptoms include breathlessness and cough.

In lung cancer, a great deal of variation exists between clinical sites in patient access to non-pharmacological symptom management approaches, and often patients with only the most severe symptoms are seen by a clinician. The evidence is minimal or inconsistent for most interventions. Additionally, patients tend not to complete treatments, and hence a major improvement is often not seen.

When it comes to the delivery of non-pharmacological interventions, there are a host of important considerations, including the timing and location of the interventions, as well as the requirement for a variety of interventions as patient's needs, preferences and symptomology vary markedly. Caregiver involvement is potentially important, and patients differ in whether they desire contact with other patients or not. The practicality of the intervention as well as patient comorbidities must be taken into account, and patient education is vital. Patients are often interested in techniques that would help with specific problems. For example, cough suppression techniques to help with eating, taking medication, or preventing vomiting. Finally, patients tend to discontinue interventions quickly if they see little immediate benefit.

There are a number of promising non-pharmacological interventions for the management of cough and breathlessness in lung cancer, including diaphragmatic breathing, anxiety management, relaxation techniques, sleep hygiene training, vocal hygiene training, cough suppression techniques and behavioural interventions. When a systematic review of non-pharmacological interventions for respiratory symptoms in lung cancer was conducted in 2012,²⁰ it was found that the majority of the trials had a primary focus on breathlessness with minimal work in cough management, many did not have robust designs (pilot studies, feasibility studies, small sample sizes, no power calculations) so no firm conclusions could be drawn from these data.

Prof Molassiosis went on to discuss a new non-pharmacological intervention for respiratory distress symptom cluster for which his group is conducting an ongoing pilot feasibility trial. The core components of this intervention include the delivery of symptom preparatory information plus diaphragmatic breathing (20-25 minutes), cough suppression techniques (20-25 minutes) as well as self-acupressure on chest points (20-25 minutes). These techniques are accompanied by supplementary information to be read at home, which provides practical advice about such things as symptom experiences, and vocal and sleep hygiene amongst others. Unpublished preliminary analyses of the data from this feasibility trial are encouraging.

Another technique that is currently being tested by Prof Molassiosis's group is inspiratory muscle training (IMT) which improves inspiratory muscle strength and endurance, and has to date not been studied in the lung cancer population. IMT uses a pressure threshold device, and the feasibility study has the patients' training beginning at low intensity for 30 minutes per day, with the intensity adjusting upwards monthly. The initial results from the feasibility study show that IMT improved breathlessness experience and decreased emotional distress amongst other positive benefits, and a fully powered trial is warranted.

References

1. Stahel R, et al. Strategies for improving outcomes in NSCLC: A look to the future. *Lung Cancer* 2013;82(3):375-82.
2. Cho H, et al. Assessing non-cancer-related health status of US cancer patients: other-cause survival and comorbidity prevalence. *Am J Epidemiol* 2013;178(3):339-49.
3. Zabora J, et al. A new psychosocial screening instrument for use with cancer patients. *Psychosomatics* 2001;42(3):241-6.
4. Chambers SK, et al. A systematic review of the impact of stigma and nihilism on lung cancer outcomes. *BMC Cancer* 2012;12:184.
5. Schofield P, et al. Optimism and survival in lung carcinoma patients. *Cancer* 2004;100(6):1276-82.
6. Granger CL, et al. Exercise intervention to improve exercise capacity and health related quality of life for patients with Non-small cell lung cancer: a systematic review. *Lung Cancer* 2011;72(2):139-53.
7. Koay K, et al. Suboptimal health literacy in patients with lung cancer or head and neck cancer. *Support Care Cancer* 2013;21(8):2237-45.
8. Jallil R, et al. Factors that can make an impact on decision-making and decision implementation in cancer multidisciplinary teams: an interview study of the provider perspective. *Int J Surg* 2013;11(5):389-94.
9. Lamb BW, et al. Improving decision making in multidisciplinary tumor boards: prospective longitudinal evaluation of a multicomponent intervention for 1,421 patients. *J Am Coll Surg* 2013;217(3):412-20.
10. Cataldo JK, et al. Measuring stigma in people with lung cancer: psychometric testing of the cataldo lung cancer stigma scale. *Oncol Nurs Forum* 2011;38(1):E46-54.
11. Leigh S. Cancer survivorship: A nursing perspective. In: Ganz P, editor. *Cancer survivorship: Today and tomorrow*. Springer. 2007. p. 8-13.
12. Bell K, et al. Cancer survivorship: why labels matter. *J Clin Oncol* 2013;31(4):409-11.
13. Mullian F. Seasons of survival: reflections of a physician with cancer. *N Engl J Med* 1985;313(4):270-3.
14. Institute of Medicine. From cancer patient to cancer survivor: Lost in transition. Washington, DC: The National Academies Press; 2013.
15. Johnson BE. Second lung cancers in patients after treatment for an initial lung cancer. *J Natl Cancer Inst* 1998;90(18):1335-45.
16. Royal College of Nursing. RCN factsheet: Specialist nursing in the UK. 2013. Available from: http://www.rcn.org.uk/_data/assets/pdf_file/0018/501921/4.13_RC_N_Factsheet_on_Specialist_nursing_in_UK_-_2013.pdf
17. Department of Health U. National Cancer Patient's Experience Survey Programme. 2012. Available from: <http://www.gov.uk/government/publications/national-cancer-patients-experience-survey-programme-2012-13>
18. 1Gerrish K, et al. Capturing impact: A practical toolkit for nurse consultants. 2011. Available from: http://www.wales.nhs.uk/sitesplus/documents/829/Capturing_Impact_-_A_practical_toolkit_for_nurse_consultants.pdf
19. 1NHS Information Centre. National Lung Cancer Audit Report. 2011. Available from: <http://www.hqip.org.uk/assets/NCAPOP-Library/Lung-Cancer-NHS-IC-AUDIT-2011.pdf>
20. Yorke J, et al. Nonpharmacological interventions for managing respiratory symptoms in lung cancer. *Chron Respir Dis* 2012;9(2):117-29.