Palliative and Supportive Care (2008), **6**, 281–287. Printed in the USA.

doi:10.1017/S1478951508000424

REVIEW ARTICLE

Lung cancer: Challenges and solutions for supportive care intervention research

PENELOPE SCHOFIELD, B.SC.(HONS.), PH.D.,[1,2] ANNA UGALDE, B.A.(HONS.),[1]
MARIKO CAREY, D.PSYCH.,[4] LINDA MILESHKIN, M.B.B.S., F.R.A.C.P., M.BIOETH.(MON.),[1,2]
MARY DUFFY, R.N.,[1] DAVID BALL, M.B.B.S., M.D., F.R.A.N.Z.C.R.,[1] AND
SANCHIA ARANDA, R.N., PH.D.[1,3]

[1]Peter MacCallum Cancer Centre, East Melbourne, Victoria, Australia
[2]Faculty of Medicine, Dentistry, and Health Sciences, University of Melbourne, Parkville, Victoria, Australia
[3]Department of Nursing and Social Work, University of Melbourne, Parkville, Victoria, Australia
[4]The Cancer Council Victoria, Victoria, Australia

(RECEIVED May 29, 2007; ACCEPTED August 20, 2007)

ABSTRACT

Lung cancer is the leading cause of cancer death. It is associated with a high level of morbidity, particularly fatigue, pain, breathlessness, and coughing. These symptoms can have a substantial impact on psychosocial functioning. It is critical to have effective interventions demonstrated to improve quality of life particularly for those with advanced disease. However there is a paucity of high quality intervention research to guide practice in this area. This article discusses the challenges in conducting supportive care research in this group, including the patient's level of literacy in English, poor performance status, rapidly fluctuating health status, and familial or professional "gate-keeping." Many of these challenges can be overcome by broadening eligibility criteria, permitting some flexibility in relation to recruitment and data collection procedures, working closely with the treatment team, involving the patient's family, minimizing practical difficulties associated with intervention delivery, and reducing study burden in other ways, such as limiting the amount of data collected from the patient and shortening follow-up time intervals. We explore these potential solutions drawing on the experience of conducting a randomized controlled trial of a support intervention for people with lung cancer and their family.

KEYWORDS: Lung cancer, Supportive care, Intervention, Recruitment

INTRODUCTION

Lung cancer is now the biggest cause of death due to cancer in the world, accounting for 1.35 million new cases and 1.18 million deaths worldwide (Parkin et al., 2005). To date, the long-term results of lung cancer treatments are poor. Even with best available treatment, the proportion of people alive 5 years post-diagnosis is approximately 15% (Australian Institute of Health and Welfare and Australasian Association of Cancer Registries, 2001; Ries et al., 2006). Unfortunately, the nature of lung cancer is that there are very few early warning signs or symptoms of the disease; hence, presentation usually occurs when the disease is advanced. In addition to the poor prognosis, advanced lung cancer is often a physically burdensome disease. Symptoms arising from the disease or treatments can also have a considerable impact on psychological functioning.

Pain, both neuropathic and nociceptive, is common particularly among people with advanced cancer (Roth & Breitbart, 1996). Pain is critical to control, not only because of its debilitating effects, but also because of its contribution to fear, depression, and

Address correspondence and reprint requests to: Penelope Schofield, Peter MacCallum Cancer Centre, Locked Bag 1, A'Beckett Street, Victoria, 8006, Australia. E-mail: penelope.schofield@petermac.org

anxiety (Roth & Breitbart, 1996). Breathlessness is another highly distressing symptom, common among lung cancer patients, particularly those with advanced disease. This can restrict all activity and cause anxiety, panic attacks, depression, and fear of impending death (O'Driscoll et al., 1999; Tanaka et al., 2002). This symptom is particularly associated with reduced quality of life (Smith et al., 2001). Another common symptom in lung cancer patients is a persistent cough, which can lead to sleep disturbances and physical exhaustion and, in turn, to reduced quality of life (Vena et al., 2006). Finally, quality of life may also be reduced due to chemotherapy and radiotherapy treatment-related side effects (Chau et al., 2005; Monk et al., 2005). Anticancer treatments offered can exacerbate existing symptoms, especially fatigue. Fatigue can have an impact on social, physical, and psychological functioning and can also cause patients to experience feelings of disempowerment and loss of control and can change their views of themselves (Pawlikowska et al., 1994; Krishnasamy, 1996). Symptom severity is a strong predictor of depressive symptoms (Kurtz et al., 2002). Hence, with the array of debilitating physical symptoms, it is not surprising that psychological distress is highly prevalent among people with lung cancer (Akechi et al., 2001; Zabora et al., 2001) and persists after treatment commencement (Hopwood & Stephens, 2000). Distress is heightened among lung cancer patients by perceptions that they are stigmatized because others associate their disease with smoking (Chapple et al., 2004).

To address the array of interconnected symptoms and emotional and practical concerns expressed by people with advanced lung cancer, high quality intervention research aimed at improving quality of life is required. Therefore, in addition to clinical interventions to manage distressing symptoms associated with lung cancer and its treatment, there is increasing recognition that supportive care interventions confer additional quality-of-life benefits (Rehse & Pukrop, 2003; Carlsen et al., 2005; Schofield et al., 2006).

Improving Research Output on the Unmet Supportive Care Needs for People with Advanced Lung Cancer

Despite clear evidence of the physical, psychosocial, and psychological needs experienced by people with lung cancer, there is little high quality research available to guide practice. In comparison with three other major cancer types in developed countries, breast, prostate, and colorectal, the number of research publications related to quality of life is second lowest in lung cancer, with only colorectal cancer recording fewer publications (Sanson-Fisher, 2006). Approximately 64% of the papers were data-based papers, and of those, only 20% reported on the outcomes of an intervention (Sanson-Fisher, 2006). The reasons for this are not clear, but it is likely due, at least in part, to the perceived difficulties of conducting intervention research with this population because of patients' poor performance status and the often short duration of survival, making recruitment difficult and attrition rates high. To develop the evidence base to inform practice the difficulties associated with testing supportive care interventions need to be clearly understood and possible solutions explored. In this article, the issues related to sample selection, recruitment, attrition, and engagement with the intervention are explored and possible solutions offered.

SAMPLE SELECTION

Eligibility Criteria

Difficulties can arise in establishing suitable eligibility criteria for supportive care research studies. Patients often have poor performance status, a poor prognosis, or may have burdensome symptoms, making them less likely to complete study requirements. Cognitive dysfunction, due to brain metastasis, may cause cognitive or psychological problems that may render patients unsuitable for these studies, particularly if outcome measures are questionnaire based. A randomized trial for treating patients with brain metastases closed early due to poor accrual, with only 17 of the 43 participants recruited evaluable after treatment, mostly due to death (Guerrieri et al., 2004). People with lung cancer can often be too sick to participate in supportive care trials. This was the major reason for nonparticipation in a trial of home nursing care, which screened over 900 participants to enroll 166 (McCorkle et al., 1989). It is hard to overcome the difficulties arising from the morbidity and poor prognosis associated with advanced lung cancer. These issues are compounded by an often rapidly changing clinical situation as disease advances and new issues arise, all of which might alter a patient's eligibility in a relatively short period of time. It is therefore necessary for researchers to work closely with the medical team to determine the suitability of potentially eligible participants.

Culturally and Linguistically Diverse Groups

Given the strong relationship between smoking and lung cancer, it is relevant to consider the characteristics of smokers. In some English-speaking countries, such as Australia, the United Kingdom, and the United States, smoking can be more common in those

from non-English-speaking backgrounds (e.g., Bertram et al., 1996). Some people from non-English-speaking backgrounds can have comparatively lower proficiency in reading and writing English, which can be a barrier for participating in questionnaire-based studies. Minor issues with English as a second language can be overcome by taking time to ensure the patient has full understanding of the research project and study requirements. However, in our randomized controlled trial (RCT), 10% of participants were excluded because they did not have sufficient English to complete questionnaires. Developing and testing interventions that specifically address the particular needs of various culturally and linguistically diverse groups is critically important. In general, these studies require multisite involvement to recruit sufficient numbers, substantial funding for high-quality translation services, and questionnaires to have been validated in the appropriate languages. Some questionnaires, such as the EORTC-QLQ C30 and the Hospital Anxiety and Depression Scale, have been validated for use in several different languages. Many other questionnaires that measure more specific dimensions, such as fatigue, have not been translated. Translation services can assist with several aspects of the research project, including ensuring the patient gives full informed consent, collection of data, and assistance with providing interventions.

Homogeneity

Having a homogenous sample enables the development of targeted interventions specific to each patient's disease characteristics and treatment regimen. A homogenous sample also assists in the clear interpretation of the results. Ideally, eligibility criteria should be clearly defined and focused to ensure that the intervention being tested is suitable for all participants. However, this must be balanced against the need for sufficient recruitment to achieve meaningful results. It may be argued that homogeneity of disease and treatment regimens may not be as important in supportive care research as in medical research. It may be more appropriate to ensure homogeneity in terms of levels of distress and other characteristics such as prognosis. For example, including patients who have newly diagnosed advanced disease with those who have lived with advanced disease for some time may lead to a higher recruitment rate; but it may be inappropriate to provide these groups with the same supportive care intervention, as their needs are likely to be quite different.

Difficulty in selecting a suitable sample needs to be acknowledged and accepted as a feature of this population. Although developing eligibility criteria with regard to the population is important, for many studies, patients that do not speak English or are too sick or cognitively impaired will need to be excluded as appropriate. Hence, developing suitable eligibility criteria for studies involving this group involves appreciating the nature of the disease and the characteristics of the population and evaluating the balance between having a sufficient sample size and ensuring the intervention is appropriate to the specific target group.

RECRUITMENT ISSUES

Point of Recruitment

From the perspective of results interpretation, it is optimal that patients are recruited into a trial at a similar point in the disease and treatment trajectory. However, it is frequently difficult to recruit people with advanced lung cancer into a trial at a consistent time point due to variations in the point of diagnosis, patients' physical and emotional state, and the competing activities occurring during their hospital visits. For example, recruiting after the initial appointment with the doctor seems a logical standard recruitment point, yet patients can receive bad news at this consult and may be too distressed to discuss participation in a trial. Moreover, at this point patients can be offered participation in a clinical trial of medical treatment. It can be confusing to offer a person who is trying to assimilate a wealth of new information entry into more than one trial at the same time. Another potentially suitable recruitment time is the planning and commencement of treatment. However, this too may be an overwhelming time, as patients are frequently given a lot of information by their treating team regarding treatment procedures and side effects. Access to patients may also be difficult, as the variety of physical symptoms, psychosocial issues, and comorbidities associated with lung cancer may mean the patients have several appointments with an array of medical, nursing, and allied health professionals. In our current RCT, we initially attempted to recruit at treatment planning; however, given access difficulties, we extended the recruitment window to the first few days of treatment. A flexible point of recruitment combined with a strong partnership with the treating team in the implementation of the research can help to identify the best opportunities for approaching the patient to maximize recruitment.

Refusal Rates

The rates of refusal are likely to be high in this population, although it is hard to know, as many supportive care trials do not report response rate data

(e.g., McCorkle et al., 1989; Wilkie et al., 1995; Corner et al., 1996; Sarna, 1998; Bredin et al., 1999; Stephenson et al., 2000; Wall, 2000). A randomized controlled trial assessing the effectiveness of a nurse-led follow-up against conventional medical follow-up for lung cancer patients (with any stage of disease, not restricted to advanced cancer) had a consent rate of 75%, with a variety of reasons for refusal, including "preferred to see a doctor," "confused by a new system or study," "used to current system," and simply "did not want to participate" (Moore et al., 2002). The high burden of the disease and the poor prognosis means that many patients can feel too tired or distressed to engage in the study or are just not interested. People may view involvement in research as just an additional burden, especially if extra appointments are required, particularly if the patient needs to travel long distances to the treatment center. The reasons for refusal in our RCT were as follows: 53% not interested in participating in the psychosocial sessions, 12% too tired, 12% from the country or interstate, 12% too distressed, and 10% other reasons. There is evidence of low uptake of psychosocial referrals among cancer patients (Curry et al., 2002). Therefore, high refusal rates may not simply be a consequence of poor health associated with lung cancer but may reflect upon the acceptability of the intervention, including the value of the benefits that patients perceive are associated with the intervention and how these weigh against other competing demands. When approaching a patient for recruitment, it is paramount to recognize that this is a distressing time for the patient and family. Allowing sufficient time to address any questions or concerns and outlining the potential beneficial outcomes either to the individual, family, or future patients may all assist in improving recruitment rates. Reinforcing the participants' right to withdraw from the study at any time without it affecting their treatment or relationship with their treatment center and providing them with a clear method for withdrawal can also increase the trust the patients have in the research process. Sensitive and timely approaches to potential participants will not only enhance consent rates but also will enhance the family's and treatment team's confidence and participation in the research.

Gate-Keeping

Familial and professional gate-keeping, defined as a request to not discuss a research project with a patient or advising the patient not to participate, can also be an issue. Due to the high burden of the disease, family members must deal with unfamiliar situations and demands, and many feel inadequately prepared for the caregiver role (Harrington et al., 1996; Hudson et al., 2002). Family members may see involvement in the research as an added and unnecessary burden for the patient or themselves and request that the patient not get involved. Treatment team members may ask that a patient not be approached if they believe the study is inappropriate for the patient or that it is an unsuitable time to talk to the patient. Working closely with the treatment team can also minimize professional gate-keeping. It should be recognized that gate-keeping may simply be good advice, as there will be times when it is inappropriate to approach a patient for physical or emotional reasons, and this should be respected by the research team. Flexibility with point of recruitment should permit another time to be arranged that is more suitable. Similarly, engaging the family in the research process by involving them in the explanation of the study, directly eliciting and responding to their questions and concerns, and emphasizing the patient's right to withdraw at any point should minimize family gate-keeping. It is also advisable to have more than one researcher trained in recruiting for any given study so that eligible patients are not missed because the appointed researcher is away or unavailable at the time that suits the patient, the family, and treatment team.

Recruitment problems, such as gate-keeping and high refusal rates, are critical to address not only because it will take longer to obtain a sufficient sample but also because there is a risk of sample bias, which can limit the generalizability of findings. Bias analyses should be conducted, particularly if the refusal rate is high. However, the best solution is to achieve a high recruitment rate by addressing these issues.

HIGH ATTRITION RATES

High attrition rates are not uncommon in supportive care intervention research with lung cancer. Of 34 patients with advanced cancer who participated in a breathlessness intervention, 14 had to withdraw due to deterioration before the 3 month completion of study (Corner et al., 1996). A study examining the effectiveness of a nursing assessment for symptom distress in advanced lung cancer recruited 48 into the study; however, researchers received 21 sets of completed data at a 7–8-month follow-up, with missing data due to death, emotional distress, or physical incapacity (Sarna, 1998).

Lamont and Christakis (2001) indicated that life expectancy estimates for individual palliative patients by their treating physicians are often wrong, on average by a factor of 5, generally overestimating survival time. Hence, people with lung cancer often become suddenly too sick to complete the study

requirements or die much sooner than expected, before study completion, leading to high attrition rates. In our RCT, the attrition rate at the 3 month follow-up is 19%, with 9% of patients dying before study completion and 10% withdrawing because they were close to death or too unwell to participate.

Participant attrition can be minimized by reducing study burden. Long follow-up periods can be problematic in sick populations, so reducing the follow- up time is likely to be helpful. However, this can have implications for measures that assess participant responses over defined periods of time, such as "over the last month." Adopting flexible data collection techniques will reduce study burden when the patient is having difficulties, for example, gathering data over the phone or face to face while the patient is waiting for an appointment or receiving chemotherapy. Alternative methods of data collection can have little impact on responses (e.g., Allenby et al., 2002). When designing a study, consider the use of shorter questionnaires and surrogate measures from carers or medical team. Although surrogate measures may not be as accurate as obtaining information directly from the patient (Milne et al., 2006), this approach may result in lower rates of attrition. In addition, permitting data collection to occur over a window of time, such as 10 days, means that fewer patients are lost to follow-up due to fluctuations in health. The variations in time spacing between follow-ups should be recognized as a limitation of results. Finally, all members of the research team should strive to create conditions under which participants will enjoy their involvement in the study. This may mean booking a private room for them to complete a questionnaire, offering refreshments, or reducing other factors of burden such as parking.

Ultimately, a higher attrition rate needs to be accepted as a feature of this population, given the high morbidity and mortality, and considered in sample size calculations. If the patient dies while in the study, sending a personally written bereavement card to the family shows support and appreciation for the patient's participation in the study.

ENGAGEMENT IN INTERVENTION

Participant engagement in the intervention as specified by the protocol presents additional challenges. It is important that most participants complete all elements of the interventions. If not, this will dilute the impact of the intervention on outcome measures and make it difficult to estimate accurately the true effect size. For interventions that are long, complex, or involve significant participant effort, it may be difficult to achieve consistently high participant engagement. This has implications for the potential translation into standard clinical care: Difficulties that arise during a trial have important implications for the feasibility, acceptability, and appropriateness of an intervention strategy.

To maximize participant engagement, the practical issues of implementing the intervention must be carefully considered. The format must be appropriate for people with a fluctuating health status, such as those with advanced lung cancer. Group-based interventions may be impractical, as there is limited flexibility in session times, which is incongruent with any unexpected changes to a patient's health and treatment plans. The possibility of telephone, mailed, or internet interventions or home visits should be considered. Likewise, delivering interventions while patients are receiving treatment, such as chemotherapy, or are admitted as an inpatient may be appropriate if this does not add to patient burden. For face-to-face interventions, the provision of transport or parking and offering refreshments on arrival will also encourage engagement, and demonstrate appreciation for the patient's enrollment in the study. Also, scheduling face-to-face intervention sessions adjacent to treatment or clinic appointments may also limit the study burden. When analyzing intervention effects, intention-to-treat analyses should be adopted for randomized controlled trials to account for variations in intervention uptake (Higgins & Green, 2005).

CONCLUSIONS

The challenges associated with supportive care research in this group are considerable. This may well be the reason that there is a paucity of high quality rigorous randomized controlled trials in this area. As curative treatment is not an option for people with advanced lung cancer, this knowledge gap is critical to address if effective interventions to improve quality of life are to be routinely provided to this large and needy group. With careful planning, many of the challenges can be ameliorated if not overcome by careful consideration of the sample selection, permitting some flexibility in recruitment and data collection mechanisms and time frames, selecting an appropriate mode of delivery for the intervention, reducing length of follow-up, and using shorter questionnaires or surrogate measures.

Despite the high burden of symptoms and generally very poor prognosis, our experience is that people with advanced lung cancer have a strong desire to be involved in this type of research. Even if they may not personally derive any benefit from participation, satisfaction is derived from knowing that future patients are likely to profit. It is vital to embrace this work, despite the issues associated

with conducting rigorous research with this group. Collectively, we must rise to the challenge of working with this large group of people with such high needs.

ACKNOWLEDGMENTS

This work was funded by National Health and Medical Research Council Palliative Care Project Grant 310679.

REFERENCES

Akechi, T., Okamura, H., Nishiwaki, Y., et al. (2001). Psychiatric disorders and associated and predictive factors in patients with unresectable nonsmall cell lung carcinoma: A longitudinal study. *Cancer*, *92*, 2609–2622.

Allenby, A., Matthews, J., Beresford, J., et al. (2002). The application of computer touch-screen technology in screening for psychosocial distress in an ambulatory oncology setting. *European Journal of Cancer Care*, *11*, 245–253.

Australian Institute of Health and Welfare and Australasian Association of Cancer Registries (2001). *Cancer Survival in Australia, 2001. Part 1: National Summary Statistics*. Canberra: Australian Institute of Health and Welfare.

Bertram, S., Flaherty, B., & Everingham, S. (1996). Knowledge and use of alcohol and other drugs among Vietnamese-speaking migrants. *Drug and Alcohol Review*, *15*, 121–126.

Bredin, M., Corner, J., Krishnasamy, M., et al. (1999). Multicentre randomised controlled trial of nursing intervention for breathlessness in patients with lung cancer. *British Medical Journal*, *318*, 901–904.

Carlsen, K., Jensen, A.B., Jacobsen, E., et al. (2005). Psychosocial aspects of lung cancer. *Lung Cancer*, *43*, 293–300.

Chapple, A., Ziebland, S., & McPherson, A. (2004). Stigma, shame and blame experienced by patients with lung cancer: Qualitative study. *British Journal of Medicine*, *328*, 1470–1475.

Chau, I., Norman, A.R., Cunningham, D., et al. (2005). Longitudinal quality of life and quality adjusted survival in a randomised controlled trial comparing six months of bolus fluorouracil/leucovorin vs. twelve weeks of protracted venous infusion fluorouracil as adjuvant chemotherapy for colorectal cancer. *European Journal of Cancer*, *41*, 1551–1559.

Corner, J., Plant, H., A'Hern, R., et al. (1996). Non-pharmacological intervention for breathlessness in lung cancer. *Palliative Medicine*, *10*, 299–305.

Curry, C., Cossich, T., Matthews, J.P., et al. (2002). Uptake of psychosocial referrals in an outpatient cancer setting: Improving service accessibility via the referral process. *Supportive Care in Cancer*, *10*, 549–555.

Guerrieri, M., Wong, K., Ryan, G., et al. (2004). A randomised phase III study of palliative radiation with concomitant carboplatin for brain metastases from non-small cell carcinoma of the lung. *Lung Cancer*, *46*, 107–111.

Harrington, V., Lackey, N.R., & Gates, M.F. (1996). Needs of caregivers of clinic and hospice cancer patients. *Cancer Nursing*, *19*, 118–125.

Higgins, J.P.T. & Green, S. (2005). *Cochrane Handbook for Systematic Reviews of Interventions 4.2.5*. Chichester, UK: John Wiley & Sons, Ltd.

Hopwood, P. & Stephens, R.J. (2000). Depression in patients with lung cancer: Prevalence and risk factors derived from quality-of-life data. *Journal of Clinical Oncology*, *18*, 893–903.

Hudson, P., Aranda, S., & McMurray, N. (2002). Intervention development for enhanced lay palliative caregiver support—The use of focus groups. *European Journal of Cancer Care*, *11*, 262–270.

Krishnasamy, M. (1996). *An Exploration of the Nature and Impact of Fatigue in Patients with Advanced Cancer*. London: The Institute of Cancer Research.

Kurtz, M.E., Kurtz, J.C., Stommel, M., et al. (2002). Predictors of depressive symptomatology of geriatric patients with lung cancer—A longitudinal analysis. *Psycho-Oncology*, *11*, 12–22.

Lamont, E.B. & Christakis, N.A. (2001). Prognostic disclosure to patients with cancer near the end of life. *Annals of Internal Medicine*, *134*, 1096–1105.

McCorkle, R., Benoliel, J.Q., Donaldson, G., et al. (1989). A randomized clinical trial of home nursing care for lung cancer patients. *Cancer*, *64*, 1375–1382.

Milne, D.J., Mulder, L.L., Beelen, H.C.M., et al. (2006). Patients' self-report and family caregivers' perception of quality of life in patients with advanced cancer: How do they compare? *European Journal of Cancer Care*, *15*, 125–132.

Monk, B.J., Huang, H.Q., Cella, D., et al. (2005). Quality of life outcomes from a randomized phase III trial of cisplatin with or without topotecan in advanced carcinoma of the cervix: A Gynecologic Oncology Group Study. *Journal of Clinical Oncology*, *23*, 4617–4625.

Moore, S., Corner, J., Haviland, J., et al. (2002). Nurse led follow up and conventional medical follow up in management of patients with lung cancer: Randomised trial. *British Medical Journal*, *325*, 1145.

O'Driscoll, M., Corner, J., & Bailey, C. (1999). The experience of breathlessness in lung cancer. *European Journal of Cancer Care*, *8*, 37–43.

Parkin, D.M., Bray, F., Ferlay, J., et al. (2005). Global cancer statistics, 2002. *CA: A Cancer Journal for Clinicians*, *55*, 74–108.

Pawlikowska, T., Chalder, T., Hirsch, S.R., et al. (1994). Population based study of fatigue and psychological distress. *British Medical Journal*, *308*, 763–766.

Rehse, B. & Pukrop, R. (2003). Effects of psychosocial interventions on quality of life in adult cancer patients: Meta analysis of 37 published controlled outcome studies. *Patient Education and Counseling*, *50*, 179–186.

Ries, L.A.G., Harkins, D., Krapcho, M., et al. (2006). *SEER Cancer Statistics Review, 1975–2003*. http://seer.cancer.gov/csr/1975_2003. Accessed December 20, 2006.

Roth, A.J. & Breitbart, W. (1996). Psychiatric emergencies in terminally ill cancer patients. *Hematology/Oncology Clinics of North America*, *10*, 235–259.

Sanson-Fisher, R. (2006). Challenges in quality-of-life research. Paper presented at the Clinical Oncology Society Australia (COSA), Melbourne.

Sarna, L. (1998). Effectiveness of structured nursing assessment of symptom distress in advanced lung cancer. *Oncology Nursing Forum*, *25*, 1041–1048.

Schofield, P., Carey, M., Bonevski, B., et al. (2006). Barriers to the provision of evidence-based psychosocial care in oncology. *Psycho-Oncology*, *15*, 863–872.

Smith, E.L., Hann, D.M., Ahles, T.A., et al. (2001). Dyspnea, anxiety, body consciousness, and quality of life

in patients with lung cancer. *Journal of Pain and Symptom Management*, *21*, 323–329.
Stephenson, N.L., Weinrich, S.P., & Tavakoli, A.S. (2000). The effects of foot reflexology on anxiety and pain in patients with breast and lung cancer. *Oncology Nursing Forum*, *27*, 67–72.
Tanaka, K., Akechi, T., Okuyama, T., et al. (2002). Factors correlated with dyspnea in advanced lung cancer patients: Organic causes and what else? *Journal of Pain and Symptom Management*, *23*, 490–500.
Vena, C., Parker, K.P., Allen, R., et al. (2006). Sleep-wake disturbances and quality of life in patients with advanced lung cancer. *Oncology Nursing Forum*, *33*, 761–769.
Wall, L.M. (2000). Changes in hope and power in lung cancer patients who exercise. *Nursing Science Quarterly*, *13*, 234–242.
Wilkie, D.J., Williams, A.R., Grevstad, P., et al. (1995). Coaching persons with lung cancer to report sensory pain. Literature review and pilot study findings. *Cancer Nursing*, *18*, 7–15.
Zabora, J., Brintzenhofeszoc, K., Curbow, B., et al. (2001). The prevalence of psychological distress by cancer site. *Psycho-Oncology*, *10*, 19–28.