Lessons Learned From Being a Lung Cancer Nurse Researcher

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Lung cancer is the world’s most common cause of cancer death (1.3 million deaths per year). In the UK context, public views lung cancer quite negatively. The disease attracts little attention from the media, the public, and, until very recently, from research funders. The UK National Cancer Research Institute document, Lung Cancer Research in the UK, highlighted the relative lack of funding in the United Kingdom for lung cancer research. There is a perception that research with lung cancer patients is difficult to undertake because of patients’ poor prognosis and high symptom burden. Because lung cancer patients are statistically more likely to come from educationally, socially, and economically disadvantaged backgrounds, some researchers have assumed that these patients do not want to participate in research, particularly qualitative (talking) research. Despite notable exceptions, little nursing research focuses specifically on lung cancer. Interventions to support cancer patients tend to be developed and evaluated in patients who have a good prognosis. Acceptability, relevance, and efficacy are rarely tested in patients including those with lung cancer, whose prognosis is poor. We must change this.

For the last 5 years, I have worked exclusively with lung cancer patients in conducting research, recruiting nearly 200 lung cancer patients in the northwest of England into health services research projects. I have learned some valuable lessons (the hard way) for designing and planning research with people affected by the disease.

Relevance. People affected by lung cancer are willing to be involved in developing research questions. Patients are eager to participate in research that they view as relevant and that can contribute to the care of others in the future. I am often asked, “How will this research help other people?” a question that highlights their desire to make a positive difference for others, which tends to be their primary motivating factor for enrolling in a study. I have learned that patients generally understand research for an intervention study that may result in some personal benefit for themselves and for future treatments. However, in qualitative or descriptive research studies, patients are less sure how their personal views and experiences will contribute to change or benefit others. It is important for the researcher to communicate how data could contribute to new practices or understandings.

Participant burden. Patients are extremely good at helping the researcher determine the burden of a research method; I have learned that my visiting at the patient’s home to complete an interview or questionnaire is preferable to an extra hospital visit for the patient. I have learned that lung cancer patients have limited access to their own transport or may not be well enough to travel. The traditional planning of studies needs to carefully reflect patient needs and preferences.

Recruitment. A patient’s condition may change very quickly. Participant well-being must always override the pressures of recruitment. It is important to “seize the day” with recruitment and be as flexible as possible with participants, understanding that a good number of patients who want to participate may have to withdraw later because of their health.

Technology-based research. In my experience, many lung cancer patients do not have easy access to the Internet or e-technologies, but this does not mean they cannot use them. In contrast, many caregivers use the Internet for information and resources. There is a shift to using e-technologies in research, and ongoing careful consideration of these in the future should be made.

Support for the researcher. Interviews and questionnaires may deal with very difficult and sensitive issues; even seemingly pragmatic questions can elicit emotionally charged answers from patients. I have learned that it is essential to ensure that researchers have adequate mentoring, supervision, support, and time to debrief.

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Disseminating findings to participants at the end of the study. Most lung cancer patients will not be alive to see the results of our research studies. Patient continuity of representation on steering groups can be problematic. It may be useful to start a patient-caregiver reference group for the research (rather than having one user representative) and to report findings to local/national patient groups and charities. In my experience, patients do want to participate in research studies of all types and derive benefit from participation. The potential for nurses to contribute to the current research agenda on survivorship and supporting individuals affected by lung cancer is significant. In the last 2 years, a number of studies have been funded in the United Kingdom, specifically to develop interventions for lung cancer patients; this increase in research funding is welcome, and I hope that this ongoing research has an impact on practice and outcomes for patients and their caregivers in the future.

References