A Qualitative Study of the Experiences During Radiotherapy of Swedish Patients Suffering From Lung Cancer

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Purpose/Objectives: To describe experiences during radiotherapy of patients suffering from lung cancer.

Design: Inductive, qualitative.

Setting: A radiotherapy department in the south of Sweden.

Sample: 15 patients with lung cancer undergoing their second week of radiotherapy.

Methodologic Approach: Interviews were conducted in a hospital setting, transcribed, and content analyzed.

Main Research Variables: Experiences during radiotherapy.

Findings: The patients' experiences fall into four categories: fatigue, physical distress, managing disease- and treatment-related issues, and obstacles to managing. Fatigue was a major experience expressed in terms of low energy levels and low fitness, sometimes leading to social isolation.

Conclusions: Nurses need to implement interventions to minimize side effects of radiotherapy and maximize patients' abilities to manage the disease and the treatment.

Interpretation: Informing and educating patients about pretreatment and assessing fatigue as well as implementing interventions (e.g., nurse-patient interaction, support, information, encouragement, focus on the patients' own resources) may lead to improved comprehensive care during radiation therapy.

Key Points . . .

- ➤ In this study, all patients with lung cancer experienced some kind of physical distress during radiation therapy (RT).
- ➤ Fatigue was expressed as a major experience during RT.
- ➤ Nurses need to implement interventions to maximize the side effects of RT and patients' strategies for managing the disease and its treatment.

The literature covers a range of distress experienced by patients with cancer undergoing radiation therapy (RT). Several factors are significant for the distress that occurs and how painfully it is experienced (e.g., the localization of the tumor, the size of the treatment area, the total radiation dose, the sensitivity of normal tissues) (Swedish Council on Technology Assessment in Health Care, 1998). In 2001, the Swedish incidence of lung cancer was 3,044 cases, and the overall five-year survival rate was less than 10% for non-small cell lung cancer and 2%–5% for small cell lung cancer (National Board of Health and Welfare, 2003). RT can be delivered as single modality or in combination with chemotherapy or surgery. The typical dosage is 3,000–4,400 cGy, five times a week, 180–300 cGy per day, depending on whether treatment is aimed at the lung tissue or bone metastasis (Regional Oncological Centre, 2001). Nursing care for patients with lung cancer and their families involves education, symptom management, and emotional support as they face significant emotional challenges. Patients and families often experience anxiety and fear after diagnosis and about the unknown effects of RT. Individual nursing interventions are prescribed to provide support, ensure the continuity of care, and improve quality of life (Swedish Council on Technology Assessment in Health Care). A study of 434 newly diagnosed patients with lung cancer showed that despite an increased risk of dying within two years after diagnosis compared to other diagnoses, patients demonstrated an ability to live with the fact that they have cancer (Degner & Sloan, 1995). Houston and Kendall (1992) determined that patients with lung cancer are confronted with continuing stressors rather than a single, limited situational crisis. Most patients' self-perception and future orientation change dramatically during the disease process. Lung cancer challenges lifelong values and beliefs and may result in changes in cognition, affect, and behavior (Houston & Kendall). Faller, Bulzebruck, Drings, and Lang (1999) found that coping and emotional distress may have affected survival among 103 patients with lung cancer. A study of 55 patients before and after RT showed that real or false expectations affect patients' response to illness (Koller et al., 2000). Therapy-related expectations such as pain and emotional control, healing, and tumor or symptom control have to be considered by professionals.

The quality of life of patients with lung cancer changes over time because of increasing physical complaints related to disease progress, whereas psychological complaints remain stable over time (De Valck & Vinck, 1996). A review of studies conducted from 1970–1995 revealed that patients with lower levels of quality of life at baseline showed more anxiety and depression after receiving treatment (Montazeri, Milroy, Hole, McEwen,

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& Gillis, 1998). Female patients tended to experience more psychological distress than males (Bredart et al., 1999), and patients with advanced lung cancer had more problems than those with early-stage disease (Degner & Sloan, 1995).

The most problematic symptom experienced during RT is fatigue (Cleeland et al., 2000; Cooley, 2000; Degner & Sloan, 1995; Sarna, 1998a; Winningham & Barton-Burke, 2000). Along with coughing, breathlessness is the most commonly reported symptom in patients with lung cancer (O'Driscoll, Corner, & Bailey, 1999). Sarna (1998a) determined that greater depression was a predictor of higher levels of physical symptom distress. Distress experienced by patients with lung cancer during RT has been studied in quantitative research concerning prevalence and correlation symptoms. Patients' verbal accounts of experiences and distress have not been described sufficiently but are of great importance to the development of individualized nursing interventions and to fully understand patients' situations. The purpose of the current study was to describe the experiences of patients with lung cancer during RT.

Methods

Context and Setting

This study was conducted in an RT department in the south of Sweden. The patients who were interviewed stayed in an oncology ward or a patients' hotel during the treatment period or commuted from home. The patients were treated by linear accelerator five days a week, and the length of the course varied from 10–22 treatments. The radiation varied from 180–300 cGy per day. A group of three or four specially trained oncology nurses at every accelerator administered the treatment and was responsible for the nursing care of 25–30 patients per day. Each treatment lasted about 15 minutes, including approximately five minutes of individual nursing care. Each patient had his or her own responsible primary nurse, who provided individual patient information and education and coordinated any consultations required with other personnel. The patients met with an oncologist once a week at the ambulatory clinic to medically manage problems.

Design and Sample

An inductive, qualitative design was chosen to study each patient in a natural setting. The focus of the interviews was the meaning of having lung cancer and undergoing RT (Denzin & Lincoln, 2000). All nurses at the department were informed verbally and in writing about the study and were asked to identify patients who met inclusion criteria. Patients were not eligible if they were participating in any other study or were considered unable to communicate verbally. Primary nurses responsible for patients during treatment distributed informed consent letters consecutively to 20 patients with lung cancer during their first week of RT. Sixteen patients gave verbal consent to take part, but one died shortly before the interview. Therefore, 15 patients, 4 women and 11 men who were 54–81 years of age, participated.

Procedure

The interviews served as a discourse between the patient and interviewer where the overall meaning rather than the words was important. The respondent had an opportunity to narrate various situations and endeavored to arrive at meanings that he or she and the interviewer could understand (Mishler, 1986). All interviews were conducted by the first author during the second week of RT and took place in a hospital setting. The interviews began with getting acquainted with the respondent and recording subsidiary data, including age, gender, family, profession, and hobbies, which served as a warm-up session. The respondents spontaneously spoke about the importance of their participation in the study. The first author began the taped portion of the interview by asking the respondent to speak openly about experiences in daily life during RT treatment. An interview guide was used to ensure that experiences during RT and the schedule of a normal day were discussed in all interviews. When the respondents faltered or began to speak about areas not covered by the study, the interviewer reiterated relevant questions to redirect the respondent. The taped portion of the interviews lasted 40 minutes and was regarded as a conversation between the parties (Mishler). This session gave the respondents an opportunity to speak openly about various situations. When the respondent felt satisfied with his or her statements, the interview was ended.

Credibility was increased in testing the biases and perceptions through peer debriefing and analysis by the authors. The steps of content analysis created observation of pervasive qualities and atypical characteristics to ensure that characterization was justified throughout the analysis. Descriptions of the patients' experiences agreed with the authors' experiences of research conducted in the area of RT. The authors facilitated a thorough, in-depth, and intensive examination of the data. A dependability audit was achieved when the coauthor examined the interviews and analysis. An independent oncology nurse assessed the questions of the interview guide to achieve transferability. A potential for biases existed because the first author worked as an oncology nurse in the treatment department at the time of the study. By maintaining a neutral stance and not presenting her own perceptions of the care given or the experience of the subjects interviewed, biases were eliminated. Neither of the authors was involved in the care of the respondents.

Data Analysis

The tapes were transcribed verbatim by the first author, and linguistic and paralinguistic features such as pauses, nonlexical expressions, and utterances of feelings such as laughter or crying were documented. Transcribing was complex, tedious, and time-consuming work that demanded careful listening and relistening and resulted in a reasonably adequate transcription to enhance the understanding of what the respondents said. The transcribed material, a total of 118 pages, was interpreted using content analysis techniques (Burnard, 1991). Interpretation was assumed to be an intellectual process whereby the authors gained knowledge about the respondents. The only essential requirement of the authors engaged in the process of understanding and questioning was to have insight, imagination, openness, and patience to interpret (Denzin & Lincoln, 2000).

Ethical Considerations

The study was considered and approved by the chief physician of the department where the interviews were conducted and by the research ethics committee of Lund University. The eligible respondents received information and a request for verbal informed consent to participate in the study. After each interview, the audiotape that was used was marked with a code number. When the tapes were transcribed, each transcript was given a false name to make the discussions between the authors easier and to mark the verbal citations of the findings. When a respondent started to cry because of psychological or emotional distress, the tape recorder was paused until the patient said that it was all right to proceed. The patients understood that professional intervention by the first author was not always possible.

Findings

Four categories with six subcategories were found in the analysis. Fatigue had process and affecting factors; physical distress; managing disease- and treatment-related issues including general issues and specific symptoms, specific issues, self-perception, and daily routines; and obstacles to managing.

Fatigue

All of the respondents except one described fatigue as a general experience that was not connected to specific parts of the body. Some of the respondents spoke of what they believed was the "art of fatigue." Mental fatigue meant being tired without physical signs, and general fatigue was a feeling of weakness in the whole body. Fatigue was referred to as a physical experience or as a combination of physical and emotional experiences. According to one respondent,

> If you say you've been working for a whole day and still think you haven't achieved anything . . . feel you haven't been doing as much as you wanted—so, it's like a mental fatigue.

The respondents described fatigue in their own words, which are summarized in Figure 1.

> My energy levels are taxed; why, I don't know. I have to rest in between. You have to shave . . . you have to shop and get your hair cut, but, no, I haven't been able to do that, and I don't care that much.

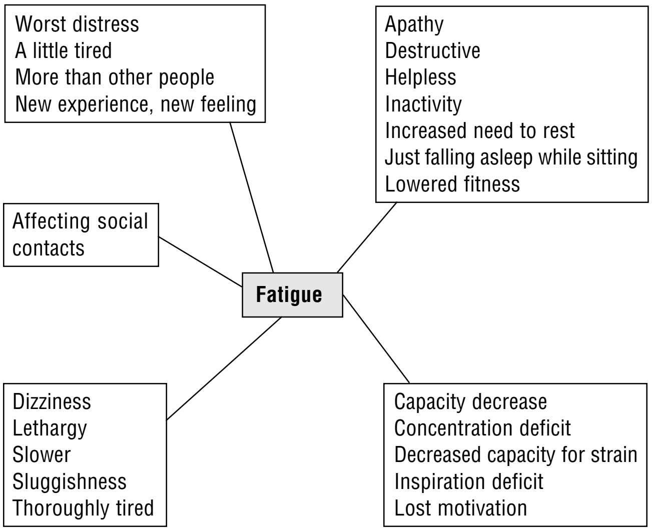

Figure 1. Components of Fatigue

Process: Fatigue was divided into escalating, varying, and longitudinal processes. An escalating process describes an increasing amount of fatigue for each treatment day: "The nearer you get to the end of a session, the more worn out you are." Fatigue also was described as varying for each day in treatment; that is, patients experienced intermittent periods with fatigue. "There are periods when you get really tired but . . . when it's over, then you feel fit again." Longitudinal fatigue refers to fatigue that remains at a constant level during the entire treatment. One patient said, "Some general sluggishness, a little tired, you get from this."

Affecting factors: Respondents believed their fatigue was caused by different treatments, painkillers, uneven blood glucose, or low red blood cell counts. Some respondents suspected that fatigue might cause the physical distress they experienced.

> They also say it's common that you feel a little tired from this. . . . Now, it's not like I'm down on my knees because of this anyhow, but you get a little sluggish from it.

Physical Distress

All respondents experienced some kind of physical distress during RT. The most common physical distress was pain, which was felt as pain from an actual body zone treated with RT or as a general tension. For some patients, pain appeared only briefly when they sneezed or coughed. The pain could keep patients awake at night or flare when they laid down on the treatment couch. Two respondents had a stomachache of a temporary nature, but only one found it troublesome. Most of the respondents said that they had sleep disturbances. They spoke about the reasons for the disturbances, pattern, and need for sleep during their treatment: "Now I have had some pain, so I, in principle, have been awake all day and night."

Breathlessness was experienced by two-thirds of the patients and usually was connected to difficulties in getting enough air during stressful physical activities. Some patients reported feeling a breathlessness that existed since their diagnosis or even prior to it. Breathlessness could affect respondents when they arose from bed in the morning.

> I know what breathlessness is now. . . . You used to laugh at people not being able to walk upstairs before . . . then, I could run up. . . . Now, you are the same. Now, I have to grasp the banisters when walking upstairs.

Distress related to appetite was a common problem, and eating habits were altered. According to one participant, "I don't want to bring people home and show how badly I eat."

Managing Disease- and Treatment-Related Issues

General issues and specific symptoms: To manage the situation during a course of RT, support in the form of assistance from family or friends was described as essential to all patients but one. Patients identified other helpful strategies, including accepting the situation as it is, trying to live as usual, talking and laughing, asking questions, taking one day at a time, and organizing the treatment situation, so that life can proceed as smoothly as possible. Capable nurses and doctors were identified as important for handling the treatment situation. Half of the respondents talked about home as a refuge and a way of distracting themselves from the hospital environment and their role as patients under treatment for cancer.

Almost all of the patients used some kind of mental pastime: reading, watching television, knitting, and shopping. Half of the patient group discussed hope in terms of having a positive feeling or hoping for an improvement: "I am very optimistic and I have decided this will turn out well and that is the way it is going to be."

Specific issues: Respondents had their own strategies for successfully reducing or eliminating their feelings of fatigue. Patients overcame fatigue mentally in several ways; for example, they decided that they did not have to get out of bed, learned how to endure fatigue, or seized an opportunity to do something they would miss otherwise. Fatigue was conquered by deliberately resisting or eliminating the feeling, having fun, completing a project, concentrating on something else, relaxing, or being active. All of the respondents who had strategies that reduced or eliminated fatigue used rest as a relieving technique. One respondent said, "I try to concentrate on something and relax." According to another, "I've had to slow down things, well, after a while, and I've been taking a break. I have to do that now as well."

Self-perception: The respondents talked about the altered perception of themselves. Either they learned to accept their sick role or altered body or they would not accept their new image as patients with cancer. Some respondents still were deciding whether to accept their new perception. Others viewed the sick role as self-inflicted.

Daily routines: Activities routinely performed were used to manage daily life. Eight of the patients woke up early and completed activities such as household tasks, going for treatment, taking short walks, showering, or paying social calls. The other seven patients woke up late and started the day slowly, doing almost the same things as the early risers. Afternoons were filled with a rich variety of activities, from resting and reading to social contacts, shopping, household tasks, and hobbies. In the evenings, six of the patients described engaging in various social activities in or away from the home. Nine patients sometimes watched television but, instead, preferred other activities (e.g., reading, solving crossword puzzles). Nine respondents walked every day; they walked around the house once a day, walked their dog, or took two to three 20–30 minute walks.

Obstacles to Managing

Most of the respondents reported different kinds of fear that hindered their ability to manage their lives during RT. Fear of the unknown was expressed in terms of not knowing, being urged to learn things on their own, and experiencing new bodily symptoms. Thinking about the future, where the illness would take them, and whether the treatment might change the future was stressful. Many expressed a fear of sudden encounters in different kinds of uncontrollable situations. These encounters might be repeated questions from former colleagues, unexpected visitors to the ward, meeting people with an altered body, an unknown length of waiting time, what other people say about patients with cancer, or being avoided by friends at social events. Some respondents openly expressed a fear of impairment or getting worse from the disease or its side effects. According to one respondent, "It's trying when you get the same question from everybody. . . . They all ask how I'm doing, what's wrong with you, how do you feel . . . I get the same question from twenty persons an hour. Now, I avoid it."

Discussion and Implications

Most patients' experiences included fatigue, physical distress, and possibilities for and obstacles to managing the disease and treatment experiences. When asked to speak openly about their experiences, half of the respondent group said that they did not experience distress or experienced much less distress during RT than they expected from what they had been told or read. All patients except one mentioned fatigue or issues interpreted as fatigue, which has been described as the most common symptom for patients with lung cancer (Degner & Sloan, 1995; Sarna, 1993; Swain, 2000; Winningham & Barton-Burke, 2000). Although fatigue is a frequently reported symptom of people with cancer, it is poorly understood (Winningham & Barton-Burke; Wu & McSweeney, 2001). Patients expressed fatigue in a variety of ways; some used simple words to describe it, whereas others used metaphors or compared the feeling with earlier experiences during chemotherapy. These experiences are consistent with findings from previous studies (Beach, Siebeneck, Budener, & Ferner, 2001) that reported that patients undergoing RT may have significant levels of pretreatment fatigue (e.g., after chemotherapy). Many patients experienced breathlessness, a symptom that usually is unreported by patients and unnoticed by healthcare professionals, with fatigue (Roberts, Thorne, & Pearson, 1993). Two-thirds of the patients in this study spoke of lowered fitness and energy levels or described trying to be active, maintain fitness, and relax. As a possible way to manage the situation, respondents compared their current fitness and energy levels with those before their illness. The same techniques as before illness, such as going for a walk, were used for feeling better while undergoing RT. The patients were not always aware of the positive effect that exercise has on fatigue, as reported by Sarna and Conde (2001). This is significant because the problems posed by cancer-related fatigue previously have been described as adverse effects on individuals' adherence to cancer treatments and their capacity to work, psychological and physical functioning, and quality of life (Wu & McSweeney). Fatigue has led to social isolation because patients do not have enough energy to meet people or they are avoided as a result of the illness or altered body appearance (Curt et al., 2000). Patients felt secure spending many hours at home, and the isolation enhanced the need for being supported by the family caregivers. This, in turn, puts additional stress on family caregivers. Previous studies have shown that emotional support is considered time-consuming and difficult for family caregivers in home settings (Bakas, Lewis, & Parsons, 2001; Sarna & McCorkle, 1996).

The patients in this study experienced a great deal of emotional distress; in fact, Sarna (1998b) revealed that people with lung cancer have more emotional distress than those with other types of cancer. Patients' thoughts about the future are described in the literature as sometimes leading to vulnerability or sleeping disorders, may be expressed as uncertainty, and are associated consistently with emotional distress, reduced quality of life, and compromised psychosocial adjustment (Houldin, 2000). Some patients described how the unknown future kept them awake at night. For some patients in the current study, sleep was disturbed by thoughts of uncertainty, pain, dry coughing, or coughing caused by mucus, which is similar to reports from previous studies (Engstrom, Strohl, Rose, Lewandowski, & Stefanek, 1999; Sheely, 1996).

Managing their daily lives seemed to be to related to managing the situation, which is described as inner control or control by a spouse, friends, or colleagues who patients can depend on and trust (Antonovsky, 1987). Patients' ability to manage their daily life during treatment is an important aspect. RT nurses must assess this ability during the course of treatment. In this study, managing daily life during a course of RT is solved by routinizing everyday life, previously described as problem- and emotion-focused strategies to cope with the treatment (Wengstrom, Haggmark, & Forsberg, 2001). Individuals create their own "common sense" interpretations of symptoms to guide their coping efforts (Barsevick, Whitmer, & Walker, 2001).

At the start of RT, most patients have lived with cancer for quite some time and accepted being ill or concentrated on the healthy part of themselves, which Houldin (2000) described as struggling with issues related to forgiving themselves for the cancer diagnosis. Many respondents took the opportunity to speak about issues of importance from the entire span of their illness. The meaning of having cancer, being treated for cancer, and suffering from subsequent psychological distress converges with patients' feelings of vulnerability. Patients may question the efficacy of their own coping abilities and judgments because of self-doubt; this was similar to other research findings that described how patients need support and validation of their feelings and that unreasonable demands, self-imposed or otherwise, may affect adaptive coping (Houldin). Patients with lung cancer have higher overall prevalence rates of psychological distress and higher levels of depression, anxiety, and hostility than patients with other cancer diagnoses (Zabora, Brintzenhofeszoc, Curbow, Hooker, & Piantadosi, 2001). A thorough assessment of patients' personal resources by a responsible nurse makes it possible to carry out individual interventions aimed at improving patients' well-being (Wengstrom, 2000).

Study Limitations

Qualitative designs never ensure that the same symbol or symbolic message means the same thing every time the words emerge in text or speech. The data gathering was affected by the level of knowledge, experiences, and biases and the authors' own perspectives.

The sample size of 15 patients was chosen because the amount of verbal data was expected to be large and qualitative research tends to emphasize intensive contacts with the subjects. On one hand, the sample cannot be representative in the quantitative sense; on the other, in qualitative research, any subject belonging to a specified group is considered to represent that group and the descriptive interpretation that results also is applicable to other groups of patients with cancer.

Conclusions

Further research is needed to determine how the fatigue of patients with lung cancer is affected specifically by fear, patients' ability to self-care, and correlation to other distress experienced pretreatment or during the course of RT. Previous research has measured fatigue on a few occasions during RT, but longitudinal assessment in the context of quantitative data is needed to obtain a clear understanding of the pattern during the entire treatment series. Suggested future studies should focus on energy levels, fitness and fatigue, patients' own resources for managing daily life during RT, and a comparison and evaluation of patients' strategies for overcoming fatigue. Nursing assessment of patients' resources before RT and information about presumptive distress enhance the possibility of discovering patients at risk for noneffective fatigue management. Through individual nurse-patient interaction aimed at assessing patients' resources and fatigue, support and information may lead to improved comprehensive nursing care during RT. Nurses also need to implement interventions to minimize the side effects of treatment and maximize patients' own management strategies.

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For more information . . .

- ➤ Lung Cancer Online
  www.lungcanceronline.org
- ➤ American Lung Association
  www.lungusa.org/diseases/lungcanc.html
- ➤ Lung Cancer.org
  www.lungcancer.org

Links can be found at www.ons.org.