Who cares? The impact on caregivers of suspected mining-related lung cancer

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ABSTRACT

Background In the present study, we investigated the emotional, physical, financial, occupational, practical, and quality-of-life impacts on caregivers of patients with mining-related lung cancer.

Methods This concurrent, embedded, mixed-methods study used individual in-depth qualitative interviews and the 36-item Short Form Health Survey (version 2; RAND Corporation, Santa Monica, CA, U.S.A.) quality-of-life measure with 8 caregivers of patients with suspected mining-related lung cancer who had worked in Sudbury or Elliot Lake (or both), and sometimes elsewhere. Individuals who assist workers in filing compensation claims were also interviewed in Sudbury and Elliot Lake. Interviews (n = 11) were transcribed and analyzed thematically.

Results Caregiver themes focused on the long time to, and the shock of, diagnosis and dealing with lung cancer; not much of a life for caregivers; strong views about potential cancer causes; concerns about financial impacts; compensation experiences and long time to compensation; and suggestions for additional support. Quality-of-life scores were below the norm for most measures.

Individuals who assist workers in preparing claims were passionate about challenges in the compensation journey; the requirement for more and better family support; the need to focus on compensation compared with cost control; the need for better exposure monitoring, controls, resources, and research; and job challenges, barriers, and satisfaction.

Conclusions Caregivers expressed a need for more education about the compensation process and for greater support. Worker representatives required persistence, additional workplace monitoring and controls, additional research, and a focus on compensation compared with cost control. They also emphasized the need for more family support.

Key Words Lung cancer, caregivers, cancer impacts, mixed-methods research

INTRODUCTION

Lung cancer is the leading cause of cancer death in men and women, and small-cell lung cancer is less common than non-small-cell lung cancer. In 2017, it was expected that about 28,600 Canadians would be diagnosed with lung cancer and that 21,100 would die. Symptoms are usually not experienced until the disease is advanced. The average 5-year survival rate for lung cancer in Canada is only 17%. Smoking, particularly cigarettes, is the predominant cause of lung cancer, making the demonstration of an occupational cause in smokers challenging. Other possible causes of lung cancer include a variety of occupational and environmental exposures.

Hard rock metal mining contributes substantially to the Canadian economy and has occurred in Canada for more than a century, with nickel, gold, uranium, and copper mining figuring prominently in northern Ontario. Some aspects of nickel, uranium, gold, and copper production have been associated with lung cancer development and are of occupational health interest.

To receive compensation for lung cancer in Ontario, work exposure does not have to be the only potential cause, but it must be a significant cause. Rejected claims can be
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 appealed in the 6 months after rejection. Between 1990 and 2003 in Ontario, about 25% of successful lung cancer compensation claims were related to mining and quarrying.11

Lung cancer patients often receive care from close family members, and those family caregivers also provide most of the care for family members who are palliative, making such care delivery essential to the Canadian health care system.12 Informal caregiving for cancer patients is associated with significant occupational impacts, financial impacts, distress, and other negative health impacts13–15. The highest rates of emotional distress for cancer patients are reported by lung cancer patients, with partners reporting similar rates.16 A significant proportion of caregivers also report little time to look after themselves, high rates of depression and anxiety, and low mental health-related quality of life (qol).17

Although published studies have reported on the emotional, physical, financial, psychosocial, and qol life impacts of cancer on caregivers18–22, few mixed-methods studies have been conducted in the minerals industry. One Australian study examined patients who were asbestos workers and their caregivers23. Significant tolls on caregivers were observed, with the caregivers reporting devastating social impacts and suspension of normal life as they provided constant care and support at the expense of their physical and mental health. Those individuals were at great risk of psychological distress and in need of support services. Support was particularly important at the time of diagnosis and after the death of the person for whom they had been caring. Suggestions from that study included providing caregivers and their families with tailored information; simplifying the process for claiming benefits; and providing access to an advocate for advice and support. The need for initiatives designed to increase levels of social connection within and across the caregiver community was emphasized, as was the potential for an online support community to be helpful.

Few studies24,25 have examined the long-term qol among caregivers of cancer patients. Kim et al.24 studied caregiver qol from 3 to 5 years after diagnosis. Caregivers who remained in an active caregiver role for a long time had low qol. Caregiver age and the stress associated with caregiving were significant predictors of qol. Caregivers who look after patients with advanced cancer can display compromised qol and mental health, potentially negatively affecting the physical and emotional well-being of the patient. Other research suggests that early palliative care interventions focusing on patient symptoms and caregiver support might improve caregiver qol.26

The present study arose from an interest in work-related cancers and the associated challenges of mining-related lung cancer for families. In the study, we investigated

- the emotional, physical, occupational, practical, and qol impacts on individuals caring for patients who worked in Sudbury and Elliot Lake, Ontario, and who had possible mining-related lung cancer; and
- how to better assist those caregivers.

The investigations took the perspective of the family caregiver and, for the first time, the perspective of worker representatives who assist families in filing compensation claims for individuals who have worked in the minerals industry. It is important to situate the perspectives of worker representatives in relation to caregiver views and experience.

METHODS

Ethics and Participants

The study received ethics approval from the Laurentian University Research Ethics Board.

So as not to disrupt families during the initial period of diagnosis adjustment, the included caregivers were those whose family members had received a diagnosis of lung cancer at least 6 months before recruitment.

Recruitment

Sudbury and Elliot Lake were selected for the study, given their associations with nickel and uranium mining respectively and a desire to have geographic and resource variation in caregiver experiences. Potential caregiver participants were recruited in a variety of ways:

- Letters sent from worker representatives or advisers (working at either a mining-related union in Sudbury or at a government office in Elliot Lake, Ontario) who assist minerals industry workers in filing for compensation
- Investigator contact information provided by reporters who had written articles for local newspapers in Sudbury and Elliot Lake
- Study recruitment posters displayed at the Sudbury and Sault Ste. Marie offices of the Canadian Cancer Society and distributed by some of the Society’s drivers, and also displayed in some Sudbury and Elliot Lake grocery stores
- Requests made to participants to suggest other potential participants

Caregivers were not recruited through local lung cancer specialists, given that the focus for those specialists is the patient, and not the caregiver. Also, we did not want to add to caregiver stress during active patient treatment. Furthermore, given that the compensation experience was of much interest, the worker representatives or advisers were more likely to be in most recent contact with family caregivers and to be aware of the compensation efforts for particular cases.

Interviews

Caregiver participants provided written informed consent. Individual in-depth and in-person qualitative interviews of 1–2.5 hours’ duration were conducted with 8 caregivers (6 spouses, 1 daughter, 1 son) at their residences in Sudbury or Elliot Lake by a trained interviewer. Qualitative interviews with caregivers inquired about the impact of the lung cancer diagnosis; caregiver experiences; the patient’s work history; caregiver views about the potential causes of the worker’s lung cancer; impact on family finances; impact on the caregiver’s occupation; family experiences with the compensation process; suggestions for other caregivers; and demographic information (Table 1). At the end of the qualitative interview, caregivers self-completed the 36-item
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TABLE I  Qualitative questions for caregivers

For the consent you just signed, I’ll be asking you questions about your family member’s diagnosis of lung cancer. There are no right or wrong answers. Feel free to ask me to repeat the question or to ask for clarification if you do not understand the question. You may also choose not to answer any question. If you need a pause or to take a break, we can stop the interview at any time.

May I ask your first name? Gender?

Okay, let’s start with a few questions about where you live and your relationship to the person who is or was ill.
- What is/was the name of the person who is/was ill?
- What relation are you to the person who had lung cancer?
- Where do you live now? Is that the same place as when you cared for the person with lung cancer? If no, where did you live then?

Can you tell me in your own words when the person with lung cancer first noticed symptoms of lung cancer?
- What were the symptoms?

When was the person diagnosed with cancer by a doctor?
- What treatments were recommended?
- Where did the person receive treatment?
- Did the person have to travel for lung cancer care, and if so, what was that like for you?
- Where did the person live at that time?
- Who was the main caregiver for the person with lung cancer?
- What supports were in place at home to help with the care?
- What was your role in the care?
- How long did you care for the person? (Or if ongoing, how long have you cared for the person?)

Can you tell me more about the work history of the person with lung cancer?
- Where did the person work, and where, when [were they] diagnosed with lung cancer? About how long did [the person] work there?
- What did [they] do there?
- Did [the person] continue to work for a while or stop work directly after the diagnosis?
- Where else did [the person] work before the lung cancer diagnosis, and what did [they] do there?

Have you ever thought about what might have caused [the] lung cancer?
- (If work is mentioned) What exposures do you think might have contributed, and why do you think those exposures are important?
- What do you think should be done about those exposures, if applicable?
- Did [the] employer at the time of the cancer diagnosis assist the family? If so, how?
- Were they helpful and understanding, if applicable?

What impact did the diagnosis have on you and your family?
- Can you talk about how you felt when you heard this diagnosis?
- Did anybody help you deal with [the person’s] illness?
- What was the impact on household finances, and how did you cope?
- How did the lung cancer diagnosis affect your life?

What was the financial impact on the family? Examples are travel-related costs for care or visiting the family member in care, costs for home care or lost income for the family.
- What were the financial impacts on you and the household?
- Did you have travel-related costs for care or visiting the person in care, costs for home care, or lost income for the household?
- Do you have any suggestions about how to help others cope?

How did dealing with the person’s illness impact your job, if applicable?
- How supportive was your employer?
- Did the person apply for compensation for their lung cancer?
- If applicable, where, and was it granted?

What do you think would help people and their caregivers who experience mining-related lung cancer?
- What more could be done to help them?
- What resources could be helpful?

Is there anything else that you would like to share?

Is there anything that I haven’t asked you that I should have?

We are going to shift now into a different kind of questions. These will be questions about you. Before we do that, do you want to take a little break?

What is your age group?
- Under 20
- 20–29
- 30–39
- 40–49
- 50–59
- 60–69
- 70–79
- 80 and over

We have almost finished the interview. If you could complete these questions, we would be most grateful. (Adinister SF-36 Quality of Life Scale; )

a Version 2: RAND Corporation, Santa Monica, CA, U.S.A.
Short Form Health Survey [SF-36 (version 2; RAND Corporation, Santa Monica, CA, U.S.A.]) qol scale27 in relation to the preceding 4 weeks. Responses were analyzed as directed28. Thus, the study design was a qualitative concurrent embedded study, wherein qualitative and quantitative data are collected at the same time, but the emphasis is placed on one type of data—in this case, the qualitative data, so that the quantitative data are considered embedded.

Individual in-person and in-depth qualitative interviews of up to 2 hours’ duration were also conducted with 3 worker representatives, 2 from a mining-related union and 1 from a government office (a worker adviser), who assist workers and their families in filing compensation claims. Written informed consent was obtained from those participants. These qualitative interviews inquired about the duration of the contact that the representatives had with workers having possible mining-related lung cancer and with their caregivers; the emotional, physical, financial, occupational, practical, and qol impacts of a lung cancer diagnosis on mining-related workers and their caregivers; the compensation process, experiences, and outcomes; suggestions for additional company, union, health care provider, and compensation assistance for workers and their caregivers; and suggestions to help worker representatives and advisers better assist workers and their caregivers (Table II).

All qualitative interviews occurred over a period of 6 months, were digitally recorded using 2 digital recorders, and were transcribed verbatim by a professional transcription service.

Analysis

Before data analysis began, all transcripts were read by 2 research team members to obtain an overall impression of the content. Thematic analysis to identify patterns or themes in the qualitative interviews was undertaken by 2 research team members following the steps outlined by Braun and Clarke29:

- Familiarizing oneself with the data
- Generating initial codes
- Searching for themes
- Reviewing potential themes
- Defining and naming themes

Thematic analyses were separately undertaken for the caregiver and the worker representative or adviser interviews. Two research team members achieved consensus in stages throughout the study as the codes and themes evolved. Qualitative data quality was enhanced by ensuring that caregivers spoke freely, that attention was devoted to context to ensure the capture of caregiver perspectives, that decisions made during the research process were discussed by the research team and noted, and that multiple researchers were involved in the various data steps. The qol analysis was performed as instructed for the SF-3628.

RESULTS

Caregiver Characteristics

The 8 caregivers included 6 wives (1 in the 60–69 age group, 4 in the 70–79 age group, and 1 in the 80–89 age group), 1 daughter in the 50–59 age group, and 1 son in the 60–69 age group. Interviews occurred in the homes of the caregivers in Sudbury (n = 7) and Elliot Lake (n = 1). The family members diagnosed with lung cancer worked in the mining industry, primarily in Sudbury, Elliot Lake, Timmins, and occasionally also elsewhere in northern Ontario and Canada. Although time of death was not always identified, some of the diagnosed family members had recently passed away, others had died several years earlier, and one was at end stage, but still living.

Caregiver Results

Five themes emerged from caregiver interviews:

- Long time to, and the shock of, diagnosis, and dealing with a loved one’s lung cancer
- Not much of a life for caregivers
- Strong views about potential lung cancer causes
- Concerns about financial impacts, compensation experiences, and long time to compensation
- Suggestions for additional support

TABLE II  Representative qualitative questions for workers

|   | Question                                                                 |
|---|-------------------------------------------------------------------------|
|1  | Can you provide your job title and what your job involves?              |
|2  | For how long have you been working with/involved with people with possibly mining-related lung cancer and their caregivers? |
|3  | What types of impact (such as emotional, physical, financial, occupational, practical, quality of life, other) does a possibly work-related lung cancer have on the patient? Can you describe the impact? Similarly, what types of impact does a possibly work-related lung cancer have on the caregivers? Can you describe the impact? |
|4  | Do most people apply for compensation? What are the barriers and facilitators to filing a claim for the patient and caregiver? What percentage of claims for potentially mining-related lung cancer are successful, and what is the average wait time that a compensation claim takes to resolve (and what is the range from shortest to longest, in your experience)? How do patients and caregivers find the compensation process? What is challenging, what could be done better? |
|5  | What do you think companies, unions, health care providers, the Workplace Safety and Insurance Board, and anybody else could do to help people and their caregivers who experience mining-related lung cancer? |
|6  | Could anything more be done to help you assist patients with a possibly-mining related lung cancer and their caregivers? |
|7  | Is there anything else that you would like to add?                        |
Long Time to, and the Shock of, Diagnosis, and Dealing with Lung Cancer

A predominant theme was the lung cancer diagnosis in the family member. One participant (daughter, interview 4) commented on the lengthy period from the appearance of symptoms until final diagnosis, saying, “It took us a long time to get him diagnosed.” Participants also described the shock and emotional impact of the diagnosis of lung cancer in their family member. One participant (wife, interview 1) shared that “It hit us like a ton of bricks.” That sentiment was echoed by another participant (son, interview 9) who said, “It forever changes you.” Some participants also reflected on the progression of the lung cancer and the likelihood of death. One participant (wife, interview 1) said, “He was just fading away before my eyes.” Another (wife, interview 3) noted that “You have to find a way to live with it.”

Not Much of a Life for Caregivers

During the treatment process, numerous participants reflected on the all-consuming process of caregiving for their family member, while their own lives receded into the background. One participant (wife, interview 3) said, “Well, you really don’t have much of a life.” Another participant (wife, interview 6) explained that “I was with him 24/7. Never left him.” The totality of the caregiving experience was shared by a third participant (wife, interview 5) who said, “I did it all by myself—24 hours.”

Strong Views About Potential Lung Cancer Causes

During the interviews, participants had strong views about the potential causes of the lung cancer in their family member, including asbestos; dust; radiation; working in the sintering plant, mines, or acid plant; dampness in the mines; and the lack of protective equipment. One participant (son, interview 9) explained that “We knew that it was the result of the radiation ... from working in the mines, from exposure to radioactive material, radioactive ore.”

Concerns About Financial Impact, Compensation Experiences, and Long Time to Compensation

After the diagnosis, participants expressed concern about the financial impact on their families. One participant (wife, interview 3) said, “We were short of money, first of all.” Another (wife, interview 5) said,

At first there was very little money ... got a hard time with groceries and that type of thing ... and, uh, later on we got compensation. It was better. But when he died, all I had was $2,000 left in the bank.

Participants commented about the length of time it took to receive compensation in addition to the experience of being denied compensation. One participant (wife, interview 7) said, “Got workman’s compensation. So, uh, I’m ... I’m really well off.” Another with a different outcome (wife, interview 3) said, “We didn’t get nowhere.”

Suggestions for Additional Support

In elucidating the needs of others in similar situations, participants described the need for more in-home and emotional support. One participant (daughter, interview 4) explained:

More help in the home for the ... like, you know, if it’s an older person, like, it’s hard on the family to continuously look after these people, because they don’t leave them in the hospital very long. They send them home and it’s up to you, right? So yeah, more help. There’s not enough help.

Another participant (wife, interview 6) outlined the need for workplace support by noting, “Our union helped.... We couldn’t have done anything without them. They were—our union rep was—so good.” One participant (son, interview 9) emphasized the depth of the need:

So provide whatever’s necessary for a family to deal with it.... And rather than do all the research, [coming] up with a cure for cancer. That’s not the biggest problem. The biggest problem is having to deal with it.

QOL Results

Results from the SF-36 qol instrument revealed that, for all measures except bodily pain, general health, and vitality, caregivers fell below the U.S. 2009 norm. Emotional role and overall mental health were 75% below norm, and physical functioning, physical role, and social functioning were each 62% below norm. The use of the SF-36 and the most recently available automated scoring system were provided free of charge on a one-time educational license. Data for Canadian norms were not available under that arrangement and are undergoing additional verification.

Worker Representative Results

The 3 experienced (male) worker representatives or advisers who were interviewed about their experiences of being present with, and advising, workers with possible work-related lung cancer included 2 union representatives and 1 government worker-adviser who assisted with filing compensation claims. Five themes emerged from their interviews:

- Compensation journey challenges
- Requirement for more, and better, family support
- Focus on compensation compared with cost control
- Requirement for better exposure monitoring, controls, resources, and more research
- Job challenges, barriers, and satisfaction

Compensation Journey Challenges

Participants described a lung cancer diagnosis and compensation system process that is fraught with challenges and barriers, including lack of knowledge about the claims process, frustration with the process, and more claims failures than successes. One participant (worker representative, interview 10) described his experience of the barriers:

There is a lack of knowledge that they actually have a valid claim. And that usually comes from
the first time you see the doctor, he gives you the bad news. He says, “Oh, by the way, you smoked, you know, bad luck for you.” They [The workers] almost always just stop there until they talk to somebody. So that’s the first barrier.

The second barrier, the adjudicator process, is a dog’s breakfast. I mean, from the time you file, to the time you actually get a claim allowed or denied, can be anywhere from three to twelve months, sometimes longer. I’ve had some that have been over a year.

Now, I don’t blame the board. The board’s trying to do an exhaustive re— you know— research and doing those kinds of things. But it really causes the client problems because, at the end of the day, their disease is progressing and the decisions are outstanding.

Another (worker representative, interview 8) referred to the rarity of compensation success:

We focus on getting the widow compensation for that lung cancer. Uh, but reality is there’s a very small percentage of widows that do get compensation. So the journey to get compensation, for some, it’s very quick and successful. For other widows, the journey is very long, ex— excessively long. And at the end of the journey, there’s the likelihood of the claim not being allowed.

The length of time for acceptance of a valid claim is coupled with what the worker representative participants perceive to be a high rate of claims denial. One participant (worker representative, interview 10) who strongly agreed with that situation said that “in a lot of cases, the compensation board denies claims; that seems to be pretty common to deny claims, especially for initial entitlement.” Another participant (worker representative, interview 11) agreed with the high numbers of claim denials saying, “If I took it all in all, from coming through the door to denials, I’d say about 80% are denied.” One participant (worker representative, interview 10) acknowledged that, for some, the process was successful and resolved quickly. He described two difficult challenges that could be a reason for the length of the process: “[The insurance board] supports the company more than they support the worker,” and “Most doctors seem to be hesitant even to get involved.”

Requirement for More, and Better, Family Support
Through all stages of a cancer diagnosis, including a Workplace Safety and Insurance Board claim, participants focused on the people diagnosed with lung cancer and their families. The families needed myriad resources for care and emotional support, far more than community services provided. They also needed help to access those support services. Participants explained that this help must come early in the cancer diagnosis journey. One participant (worker representative, interview 11) spoke about the need for supportive health care services to be available immediately, describing “a laundry basket of services you have to qualify for, each with different criteria for entitlement,” and

It shouldn’t matter if it’s work related or not yet. If the person’s afflicted with a disease, worked in the industry where that disease is known to come from, all of those services I talked about should be given to them by the board without question to help them through that critical time.... So there should be some way that either the companies, the unions ... the board has the ultimate responsibility to make sure those supportive health care services are available in their time of need, regardless if the claim is allowed or not.

Another participant (worker representative, interview 10) also recognized the inadequacy of the present system and suggested that

in an industry like these people work in, it’s common knowledge that these people get sick from their work.... So if all these companies got together and said, you know what, let’s ... let’s make some kind of a fund to take care of these people.

Need to Focus on Compensation Compared with Cost Control
The worker representatives thought that the focus should be on providing people with financial assistance rather than on controlling costs. One participant (worker representative, interview 11) was distressed about that situation, which they saw as minimizing costs:

They need to get back to the workers compensation system that actually compensates people for workplace injury versus, you know, just trying to minimize their costs associated with those injuries and disease. That’s the part that really bugs me.

Need for Better Exposure Monitoring, Controls, Resources, and Research
The participants thought that there should be better exposure monitoring and controls to prevent workplace cancers and to prevent other occupational hazards and injuries. Specifically, one participant (worker representative, interview 10) said,

So there’s—there are—so many things, uh, that are exposure, uh, items that we don’t think are being monitored properly.... If they did better at controlling their poisons ... this worker would last for a long time.

Another participant (worker representative, interview 11) thought that evidence should be gathered at an early stage, saying, “More resources to gathering evidence at early stages when the person is still around would be very, very helpful.” Another (worker representative, interview 10) noted the requirement for more research studies about workplace injuries and the compensation system: “We do need these studies.... We do need evidence.”

All participants spoke of the importance of the medical profession and the role of clinicians in treating lung cancer.
Participants understood the importance of physicians in the compensation process: “We need doctors to get on board” (worker representative, interview 10), but they also understood the challenges (worker representative, interview 8):

I think the doctors, and I’m kind of defending them ... I wish they would do more. But they’re caught up in this awful work where they have endless clients as well, and their priority is treating the patient, not so much really understand his occupational exposure to get a claim allowed.

The other side of things, too. A lot of our claims are based on the doctor’s opinion. The doctors, especially the oncologist, they’re really not there to sit down with that worker and interview him for three, four, five hours to understand his occupational exposures, and if those occupational exposures contributed to their cancers. If you’re an oncologist, you’re thinking, “Okay, how do we cure this guy or make him comfortable.”

**Job Challenges, Barriers, and Satisfaction**

All participants said that, despite the challenges and barriers they experienced in their everyday work and the need for improvement of the process, they realized the importance of the work they do and felt good about the job that they do in helping workers and their families navigate a difficult process (worker representative, interview 8):

It’s great to kind of be part of the end-of-life process ... just to know that ... they’re being looked after.... So when there is, uh, claims that are allowed, that kind of carries over the next nine that are going to be denied.... So that’s the kind of up and down in our world.

One participant (worker representative, interview 11) described his perception of the job of worker representatives saying, “If you don’t have learned counsel or you’re not as smart as a whip yourself, you’ll get eaten up by the system.” Another (worker representative, interview 10) focused on the families of workers who had died: “If these widows didn’t have us, they would get nothing.”

Finally, the same participant (worker representative, interview 10) spoke of the distress that worker representatives experience in the face of the painful realities for affected workers and their families of a workplace illness that might or might not be compensable: “We get emotional about it. We get upset about it. Uh, but I wish the system was better for the workers. I wish it was.”

**DISCUSSION**

Fletcher *et al.*[^30] and Weitzner *et al.*[^31] developed a useful conceptual model of the cancer family caregiving experience. The model consists of

- the stress process (for example, patient illness experiences, caregiving demands, relationships, finances, emotional impact, fatigue, and sleep);
- contextual factors; and
- the cancer trajectory.

“Contextual factors” refers to the personal, situational, and social context in which the stress process is entrenched, including personal and social characteristics, personality features, social support, and relationship quality[^30]. The cancer trajectory is the course of the disease process and treatment over time, such as disease stage, duration of illness, and important moments in the cancer experience[^30,32,33].

The themes that emerged from our caregivers would be associated with all 3 elements of Fletcher *et al.*’s conceptual model, and apart from the information about compensation experiences, each has been well represented in the cancer caregiving literature. Choi and Kim[^34] wrote about the stages of shock, confusion, struggle, and acceptance (similar to the first caregiver theme). Lee *et al.*[^35] conducted a study of mesothelioma and asbestos-related lung cancer in a mining community, highlighting the fear and unpredictability of diagnosis and treatment for patients and families. Shilling *et al.*[^36] referred to “a life on hold,” resembling the second caregiver theme. As with the third caregiver theme, Mosher *et al.*[^37] described changing expectations, maintaining positivity, avoiding illness-related thoughts, and using religious approaches as coping strategies in patients with advanced lung cancer. Feliciano *et al.*[^38] reported various patient and family perceptions of lung cancer causation. Lee *et al.*[^35] described mixed patient feelings about employer loyalty and betrayal for cancer causation. The potential for adverse economic changes, including possible loss of the main source of family income is well documented[^39]. Although some authors have described the effort and time involved in seeking compensation[^35], additional study about the compensation experience for possible work-related lung cancer and its impact on caregivers and other family members is needed. Recommendations relating to needed improvements in support for lung cancer caregivers are abundant, including better communication with health professionals and the provision of volunteers who could offer relief and assistance[^35]. Various interventions to improve such support, using several modalities, have been evaluated; most focus on enhanced communication and increased access to professionals[^40]. The value of recognizing, enabling, and supporting the caregiver’s own resources and coping mechanisms and the value of peer support have been emphasized[^41]. Consistent with several other studies, the qoL results for caregivers in the present study unsurprisingly revealed effects on physical and mental health and social functioning[^24-26].

The first and second themes that arose from the worker representative interviews were consistent with the caregiver themes, as was underreporting and under-compensation of occupational lung cancer, such that some authors have recommended hospital-based systematic searches[^42], the use of a systematic self-administered questionnaire[^43], education both for workers at high risk for exposure and for health care providers[^44], and occupational cohort linkages to insurance claims[^45] to identify and enhance the identification of potential occupational cancer cases. Given the dearth of literature about individuals who assist in seeking...
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compensation for potential occupational-related lung cancer, the third, fourth, and fifth themes articulated by worker representatives appear to be recent findings that merit further future exploration. Given the lengthy and detailed compensation process and its impact on patients, families, and representatives, worker representative or adviser jobs are undoubtedly challenging, but potentially very rewarding when compensation for occupational lung cancer is successful and disheartening when it is not.

Our study has several limitations. To avoid leading caregivers and to focus on their views without adding to their distress, information about whether and how much a worker smoked was not collected in relation to possible lung cancer causes. The main challenge of the study was recruiting caregivers, despite the wide variety of recruitment methods used. Some combination of exhaustion from caregiving, a desire not to resurface very emotional feelings, and worry about how compensation or company benefits could be affected might have influenced participation and require further study. Caregiver participants might be considered selected participants. To determine the most effective method for improving recruitment, future efforts could try using the recruitment methods already used for the present study and could add the use of social media and lung cancer specialist contact if the specialists and caregivers are willing. Despite the small sample size for both caregivers and worker representatives, and hence the lack of transferability to similar settings elsewhere, this study has contributed to an understanding of the impact that possible occupational-related lung cancer imposes on caregivers and those who assist them with the compensation process. Future research should evaluate various supportive interventions for caregivers and explore the quality of work life for worker representatives and how to better support them.

CONCLUSIONS

Caregivers expressed strong opinions about potential mining-related causes of their family member’s lung cancer. They emphasized that the compensation process takes too long and can be frustrating. More education and assistance provided by compensation boards could be helpful. There is also a need for more support services, emotional support, and financial assistance for families, especially early on, whether compensation is provided or not. It would helpful if mining companies could assist with those needs to some extent. Worker representatives had very satisfying jobs, despite frequent claim denials. They identified the need for more resources and additional research to support claims, better exposure monitoring and workplace controls, greater financial support from the mining industry, and a more worker-friendly workers’ compensation system.

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CONFLICT OF INTEREST DISCLOSURES

We have read and understood Current Oncology’s policy on disclosing conflicts of interest, and we declare that we have none.

AUTHOR AFFILIATIONS

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