

Caregivers' attitudes toward promoting exercise among patients with late-stage lung cancer

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Background The benefits of exercise, even at low intensity levels, in improving overall health, psychological well-being, and quality of life in patients with cancer have been well documented. However, few patients are involved in formal exercise programs, and little is known about the factors that motivate those who do participate. Although it has not been well assessed, it stands to reason that spousal and family support is an important determinant of cancer patients' adoption of, and adherence to, an exercise program.

Objective To characterize attitudes among the family caregivers of patients with late-stage lung cancer about their role in promoting exercise.

Methods 20 adult family caregivers of patients with stage IIIB or IV non-small-cell lung cancer were asked during semistructured interviews about their views on the role of exercise in "fighting cancer," whether with respect to survival, health, psychological well-being, or overall quality of life; their ability to encourage patients to exercise; and their receptivity to getting exercise instructions from health care providers.

Findings Family caregivers viewed exercise as important in fighting cancer. Past exercise patterns and lifestyle were important considerations, with some family caregivers who had not previously exercised considering household activities sufficient for promoting fitness. Family caregivers emphasized the importance of knowing the established boundaries of their relationships and respecting patients' autonomy. Caregivers generally thought that direction from health care providers to exercise would more likely result in meaningful behavioral change for patients.

Limitations The participants were recruited from a quaternary medical center and restricted to those with lung cancer, which may limit the generalizability of the findings to other settings or cancers.

Conclusions and interpretation Family caregivers believe that exercise is important for patients, but feel constrained in their willingness and ability to promote exercise behaviors because of the established boundaries of their relationships. They have mixed opinions about the utility of exercise promotion by health care providers. Family caregivers are ambivalent about promoting exercise for patients with advanced cancer. Nonjudgmental assessment of patients' past exercise preferences and established relationship boundaries should inform clinical judgment about the utility of engaging family caregivers in the promotion of exercise.

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The benefits of exercise in improving cardiopulmonary health, psychological well-being, and overall quality of life are now well accepted. Less well recognized is the fact that these benefits extend to patients at the end stages of chronic disease and cancer.¹⁻⁴ Especially encouraging are findings showing that exercise, even at low intensity levels, can confer meaningful clinical benefit to patients with even the highest levels of symptom burden, functional decline, and morbidity.⁵⁻⁷ Lung cancer, a highly prevalent disease

in which more than half of all patients live longer than 1 year, may serve as an important case in point. Patients with lung cancer commonly report symptoms of dyspnea and fatigue. Evidence shows that exercise can alleviate those symptoms as well as improve patient quality of life.⁸ Unfortunately, few patients are involved in formal exercise programs, and little is known about the factors that motivate those who participate in exercise.

Because families and caregivers can influence social behavior, it stands to reason that spousal

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and family support is an important determinant of cancer patients' adoption of and adherence to exercise. This expectation is supported by evidence suggesting that family involvement increases exercise adherence regardless of an individual's health status.⁹⁻¹² Individuals with a variety of disease states, including stroke, arthritis, diabetes, and coronary artery disease, participate more consistently and gain significantly more benefit in exercise programs when family members are involved.^{13,14} In the cancer literature, however, family and caregiver interventions have not consistently benefited cancer patients' quality of life, symptom management, and mental health.¹⁵ Few interventions have included caregiver involvement in promoting exercise behaviors in patients with cancer, and consequently, its impact remains largely unknown. In addition, caregivers' views on the appropriateness of exercise in the context of cancer have also not been studied.

The development of effective interventions that leverage caregivers' influence over cancer patients' willingness to exercise would require a nuanced and comprehensive appreciation of caregivers' attitudes. This may be uniquely true of patients with late-stage disease, who are less likely to reap the long-term benefits of exercise, yet are disproportionately plagued by the adverse symptoms that exercise has been shown to ameliorate. To address the absence of knowledge in this regard, we conducted a qualitative study to explore the attitudes, beliefs, and experiences among caregivers of patients with late-stage lung cancer regarding their ability to have an impact on the patients' exercise behaviors.

Methods

Design

Using a qualitative descriptive design, we conducted semistructured interviews to understand caregiver attitudes, beliefs, and experiences. This protocol was reviewed and approved by Mayo Clinic's institutional review board.

Participants

A purposive sample of 20 adults (10 men, 10 women) was used. The participants included individuals who lived within 30 miles (48 km) of our institution and who were caregivers of participants in a larger study cohort of 311 patients with stage IIIB and IV non-small-cell lung carcinoma (NSCLC) or extensive stage small-cell lung cancer (SCLC) that included monitoring their physical function and who were participating in an ancillary qualitative study to characterize patients' attitudes toward exercise.^{16,17}

Data collection

The semistructured interviews were conducted by an experienced qualitative nurse researcher (AMD or LMR) after we had received participant consent. All of the interviews

were audiorecorded, transcribed, and accompanied by detailed field notes. The interviews were about 45 minutes long. The patient was not present during the caregiver interviews to allow a fuller expression of the caregiver viewpoints. The interview guide was developed based on the existing limited research, findings from our prior studies, and clinical observations.^{13,14}

Each interview began by asking caregivers what "exercise" meant to them. After they had given their responses, the interviewer shared the definition of exercise that was being used for this study: "a systematic way of stressing the body to increase flexibility, stamina, and strength," and proceeded with the rest of the interview. This definition derives from Caspersen and colleagues' broadly accepted distinction between physical activity and exercise:¹⁸ physical activity is defined as any bodily movement produced by skeletal muscles that results in energy expenditure, whereas exercise is defined as physical activity that is planned, structured, repetitive, and purposive. Examples of questions in the interview guide are provided in Table 1. Caregivers were recruited for interviews until data saturation was achieved, that is, when no new themes emerged from the interviews.

Analysis

The transcripts were verified by the interviewers for accuracy then reviewed in their entirety to gain an overall impression of their content. Content analysis was used in an iterative process for coding data,^{19,20} then the text from each interview was assigned a category code. These codes included categories of unique concepts or ideas. Data were then further grouped into subthemes and assigned second-level codes. The transcripts were coded separately by 2 researchers to identify differences.^{19,20} Discrepancies were resolved by consensus of the coders and research team.

Attention to measures of trustworthiness including credibility, dependability, and transferability was maintained throughout the analytic process. Credibility of the study data and processes was assured through: the systematic use of an interview guide; biweekly meetings to review field notes, category codes, and exemplars for category fit, and to discuss any new findings or observations; coding in small units to capture unique concepts; review of transcript codes by a second investigator; and final verification of the coding scheme through the evaluation of the exemplar quotations associated with each category or subcategory. Dependability was a limited concern because of the single interview per subject design and the completion of data collection within a 6-month period. However, potential clinical practice changes that might have influenced study findings were monitored. According to Graneheim and Lundman, decisions about the transferability or generalizability of the study findings are ultimately up to the reader.^{19,20} Caregiver

TABLE 1 Interview guide

Do you believe [patient name] exercises enough?

Thinking about [patient name], when he/she exercises, do you notice a change in the severity of the symptoms he/she has?

How do you feel about exercise as part of fighting cancer?

What are some of the barriers to helping [patient name] begin or continue with an exercise program?

What are some things that would make it easier to support [patient name] to begin an exercise program?

How difficult or easy would it be for you to support your loved one in an exercise program?

What are your concerns about the safety of [patient name] participating in an exercise program?

What would be your response if a nurse or therapist were to make a periodic phone call to provide education or encouragement for [patient name] to continue in an exercise program?

and patient demographic data, and a description of the participant flow through the selection process are offered to aid readers in evaluating transferability.

Results

Participants

Of the 20 participating caregivers, 18 were spouses and 2 were sons who were serving as caregivers for their mothers (Table 2). The mean age of the caregivers was 63 years (range, 35-80), and half of them were men. The average age of the caregivers' patients was 65 years (range, 52-83), with all but 2 of them having metastatic disease. Patient survival after the interview, a reflection of disease status and caregiver burden, ranged from 2 to more than 20 months.

Themes

Three broad themes emerged from the interviews: caregivers viewed exercise as important for patients with advanced lung cancer; caregiver promotion of patients' exercise behaviors has boundaries; and exercise guidance from a health care provider or providers may influence patients' exercise behaviors. Exemplar quotations are provided for each theme and subtheme.

Caregivers' view of exercise as important. All of the caregivers viewed exercise as a part of "fighting cancer" whether with respect to survival, health, psychological well-being, or overall quality of life. Caregivers included physical activity, as defined per Caspersen and colleagues,¹⁸ in their con-

ceptualization of exercise. Engaging in exercise or physical activity was viewed as an action that could maintain health, improve the patient's sense of well-being, and provide an improved sense of control and hope:

Well, staying active, just by doing, you know, like your normal outside work, I mean, just being outside, it makes you feel better. Any time you feel better, I think you fight your cancer better.

Caregiver of a 61-year-old man

... exercise is a way of practicing being alive, even moving and doing something. It takes your mind off the disease.

Caregiver of a 64-year-old man

We are doing something positive and I think that is very important because it reinforces hope. And, I just do think exercise is very important for your health, just overall, and I do believe in cancer, as well.

Caregiver of a 52-year-old woman

Although caregivers generally viewed exercise as beneficial to patients, a subtheme – past preferences and patterns of exercise – also emerged. Caregivers tended to describe themselves and their loved ones as either "exercisers" or "not exercisers," suggesting that past preferences and lifestyle were important considerations in their attitudes about exercise. Caregiver participants who had not been previously involved in formal exercise programs were more likely to consider usual or household activities to be adequate exercise. In cases in which the caregiver engaged in formal exercise but the patient did not, the caregiver was more likely to encourage exercise in addition to engaging in other activity.

There are so many things that you can do that are productive, you know, people tend to think that exercise is just some regimen, but you can do all kinds of things and get great exercise.

Caregiver of a 71-year-old woman

If you eliminate some of that work [around the house] that would give you more time to exercise – exercise properly. Because when you are working, it is exercise in a sense, but then whether it is proper or not – probably not!

Caregiver of a 64-year-old man

Caregivers gave varied responses when they were asked if their family member exercised enough. Comparisons were often drawn between the patient's previous level of activity/exercise and present ability. When caregivers compared current and previous levels of exercise or activity, they often identified themselves or their patients as formal exercisers or nonexercisers.

TABLE 2 Demographic characteristics of caregivers and patients

Caregiver gender	Characteristic			Metastatic site	
	Caregiver age, y	Patient age, y	Caregiver relationship to patient	Brain	Bone
M	35	58	Son		X
M	74	71	Spouse		
M	62	83	Son		
F	69	72	Spouse	X	
F	80	79	Spouse		
M	67	60	Spouse		
M	70	67	Spouse	X	X
M	54	52	Spouse		
F	58	56	Spouse	X	X
F	61	64	Spouse	X	
M	68	66	Spouse		
M	79	73	Spouse	X	X
F	62	66	Spouse	X	
M	57	54	Spouse		X
F	56	57	Spouse		
F	69	73	Spouse		
F	70	69	Spouse		X
F	57	65	Spouse		
M	64	56	Spouse	X	X
F	57	61	Spouse		

He never felt the need to exercise, although he was fishing, golfing, you know, coached the kids, so he was an active person, but not an exerciser.

Caregiver of a 57-year-old man

The way that she has always been, like I said, she has never been an avid person that would involve in any type of exercise program and even when she is involved in an exercise program it's nothing in comparison to other people.

Caregiver of a 58-year-old woman

Caregivers' support of patients' exercise behaviors has boundaries. Caregivers commonly identified that their relationships had boundaries that constrained their role in supporting patient exercise. The caregiver's role in supporting the cancer patient in exercise was influenced by the subthemes

supporting patient autonomy and knowing the limits.

Caregivers described that knowing the boundaries of the relationship was a factor in the amount and type of encouragement they offered. Many mentioned that, based on prior experience, encouragement to increase activity would not likely result in action by the patient. Caregivers' expectations of the patient's response to being encouraged to exercise shaped caregiver attitudes about their role in exercise promotion, with some seeing the topic of exercise as "off limits" because its promotion would be perceived by the patient as a criticism.

... I try and not say too much because if I do bring it up, she takes offense to it ... that I'm insinuating that she needs to lose weight or something. So it's pretty hard for me to bring up the exercise thing.

Caregiver of a 52-year-old woman

I encourage the walking, post-walk [for example], you have got a great blush in your face, the dogs sure seem happy, you sure got a lot of energy today ... I don't push her hot buttons. And that would be one of her hot buttons, because she'd think I was saying she was fat.

Caregiver of a 54-year-old woman

All of the caregivers described their care recipients as self-motivated and wanted to support their autonomy in making decisions about exercise/activity.

He pretty much is self-sufficient and self – what is the word that I want? – driven ... No, he has enough people around him that push him when he needs to be pushed but he really doesn't need that. He has always been self-motivated, and the cancer hasn't changed that at all.

Caregiver of a 56-year-old man

Absolutely, he motivates himself. He's got a lot of reasons to stay healthy and to be feeling good. And he's doing amazing and it's just awesome to be part of that. But I don't have to say, hey, get your bootie going or anything like that. He does it because he knows he needs to.

Caregiver of a 66-year-old man

Knowing the limits involved and knowing that the probable outcome of pushing would not yield the desired outcome influenced the approach taken by several caregivers. "Nagging" was a common term used to describe caregivers' attempts at support.

He doesn't like a naggy person, you know? ... Well, we have been married for 47 years, so I know the way to say it.

Caregiver of a 65-year-old man

Others described how their support and encouragement was dependent on the patient's willingness or desire to engage in activity.

No, just the only barrier would be if he's not interested in doing it, and he is not going to be doing it. Yup! I'm not crossing it! It doesn't make any sense to.

Caregiver of a 56-year-old man

But you don't tell him what to do! It's got to be his idea and his way.

Caregiver of a 72-year-old man

Exercise guidance from a health care provider or providers. Some caregivers suggested that a direct prescription by a health care provider or providers might increase the likelihood that they would be more active in encouraging exercise, although others believed that the provision of thera-

pist or nursing support for an exercise intervention would not be helpful.

At this point, I would let her be because of the fact that I have done other pushing before in the areas of exercise prior to her diagnosis. So I already kind of know. I mean, I would still give it a try if that's what the professional ordered ...

Caregiver of a 58-year-old woman

In direct response to whether suggestions coming from someone besides themselves as the caregiver were anticipated to be better received by the patient, caregiver views were mixed.

I think that would be helpful to her. No, if I do it it's nagging. [If somebody else says it] It is 'suggestions' then.

Caregiver of a 71-year-old woman

Yes, he is better if coming from somebody else. It really is, even his daughter. [Laughs] Like I said, he doesn't like criticism, so, and I don't criticize him.

Caregiver of a 72-year-old man

No, bring it on! It would be very helpful, yes. It is a form of encouragement, the more the better.

Caregiver of a 60-year-old woman

Others, however, were more hesitant because they did not perceive additional help or therapy was needed. Caregivers believed the patient was active enough or able to manage their own exercise program.

I would say at this time not necessary because he is very capable of handling his own exercise so he doesn't really need the encouragement.

Caregiver of a 66-year-old man

One spouse suggested support from a nurse or therapist might be beneficial to him, but he felt his wife (the lung cancer patient) would feel that support was an added burden to her,

I think maybe a burden. Not necessarily to me, but to her. If she was asked that question she'd say, 'oh, I'm sure that would be wonderful,' but when it comes to actually ... talking to people ... she doesn't.

Caregiver of a 54-year-old woman

Another spouse described involvement from a physical therapist as both a potential negative and positive outcome,

I don't know, sometimes when people call people when you're not doing so good and you know you can't do

much more and they say, 'well, what more can we do' ...
they can kind of sometimes put a downer on ...

Caregiver of a 56-year-old woman

Discussion

Caregivers of patients with late-stage lung cancer in this study viewed exercise as an important health promotion activity, yet they described their role in encouraging the patient to exercise as limited, given their need to support the patient's autonomy and the patient's likelihood of following through on encouragement to exercise. Caregivers tend to conflate exercise and physical activity and spoke, despite being provided with definitions of both, much more about "being active" than doing exercise. Even for those who did not perceive that the patient was active enough, the negative consequences of "nagging" were barriers to adopting the role of an external motivator. Instead, they chose more passive forms of support, such as congratulating good efforts to exercise or engage in physical activity. These findings mirror those of Beverly and Wray²¹ in a sample of patients with type 2 diabetes and their spouses, in which spouses reported that there was a fine line between encouraging exercise and nagging.

Although family caregivers are often co-opted for interventions with patients, especially when patients are at the end of life or have conditions that affect cognitive capacity, findings from our study suggest that they perceive themselves as being limited in their ability to promote exercise and, therefore, were not likely to push the issue. This reflects, in large part, their familiarity with boundaries within the relationship. Caregivers indicated that past experience enabled them to anticipate patients' responses. In general, they expected negative and defensive reactions to suggestions regarding initiating or increasing exercise behaviors. Notably, even though a third of the patients had brain metastases and a third bone metastases, this was not a source of concern or reluctance among caregivers to endorse exercise. Interpersonal, rather than medical, issues seem to inform caregivers' attitudes. An important finding is that caregivers attempted to work around those potentially negative consequences by lauding the patients' attempts to exercise or engage in physical activity after the fact.

Caregivers varied in their receptivity to education, support, or guidance from a nurse or physical therapist. However, at least half of them were receptive to that possibility, suggesting that health care providers may need to take a more active role in having conversations with caregivers about exercise and providing them with direction. This need is highlighted by caregivers' consistent assertion that they expected negative reactions from patients to their suggestions and encouragement for initiating or increasing exercise. Our results suggest that clinicians need to sup-

port caregivers who may not be comfortable in suggesting exercise options to their family member. Encouraging routine behaviors that involve more intense physical activity (eg, walking the dog, taking steps, and so on) and offering ways to emotionally connect through these routines may increase family caregivers' ability to encourage exercise. This would allow the caregiver to focus on supporting the patient's efforts rather than being perceived as introducing and perseverating on a challenging topic. Others have commented on this issue. Hong and colleagues, for example, suggest that fostering a shared commitment to exercise in patient-caregiver dyads may minimize misinterpretation of spousal exercise encouragement as nagging.¹³

This study has both strengths and weaknesses. The fact that participants were recruited from a quaternary medical center may limit the generalizability of our findings because the study population may differ systematically from the caregivers of patients who are treated in community and rural settings. The collection of more granular information regarding caregivers' demographic and socioeconomic characteristics would have permitted readers to better assess the applicability of the results to other lung cancer populations. A strength of the study is the consistency of the themes articulated by caregivers despite their differences in age, gender, and relationship to the patient.

Further research is needed to better understand the impact of caregiver or family support and styles on a patient's willingness to exercise. In addition to understanding caregivers' role expectations in promoting exercise, research in patients' perspectives on the value of spousal support in exercise is needed. Once these points of views have been elucidated, informed interventions may be developed. Near-term practice implications from these findings include the need for health care providers to appreciate and fulfill their role in promoting exercise among patients with advanced lung cancer.

Conclusion

Caregivers endorse exercise as an important part of fighting cancer; however, they feel constrained in their willingness and capacity to promote exercise in patients because of established relationship boundaries. They have mixed opinions about the utility of exercise promotion by health care providers, but many endorsed the benefits of health care providers becoming allies in encouraging more consistent exercise and physical activity for those with advanced cancer.

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