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Causal Attributions for Fatigue by Older Adults with Advanced Cancer

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Abstract

Context—Fatigue is a prevalent, debilitating and often disruptive symptom for cancer patients. Yet, it remains inadequately understood and managed, especially among late middle- aged and older patients with advanced disease. Few studies have explored fatigue qualitatively and almost none have focused on patients' attributions for this subjective and multidimensional symptom.

Objectives—Our objectives were to: 1) examine the attributions patients 55 or older with advanced cancer made for their fatigue and how they arrived at these attributions; and 2) understand how patients' attributions affect how they contend with fatigue, including communication with health care providers.

Methods—We conducted qualitative in-depth interviews with 35 patients 55 years of age or older on their experiences with fatigue. Patients had a variety of cancers and were at stages IV or late III of the disease. Interviews were thematically coded and analyzed.

Results—Two main themes emerged: 1) Cancer-related treatment was the master and often the sole attribution patients made for their fatigue. Patients making this attribution expressed certainty about its accuracy and seemed less distressed about the symptom. 2) Multiple causes of fatigue, typically a combination of cancer, treatment and non-threatening causes (e.g., older age, overexertion, or anemia), were also offered by some. Patients seemed to resist identifying disease severity as a cause and appeared motivated to normalize and minimize the symptom, thus decreasing its threatening impact.

Conclusion—Patients' causal attributions for fatigue had a profound effect on their physical and psychological well-being, their communication with providers, and their integration of the symptom into their lives.

Keywords

Fatigue; causal attribution; cancer treatment; age; motivated reasoning; patient-provider communication

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Introduction

Fatigue is one of the most prevalent symptoms in cancer patients, reported by more than 50% of those with advanced disease,[1] and 70 -100% of patients undergoing any type of cancer treatment.[2] Late middle-aged and older adults with cancer seem more susceptible to fatigue because of age-related physical decline and comorbidities. Among cancer patients in this age group who are receiving chemotherapy, fatigue is almost universal,[3] and has been found to undermine patients' activity level, thus possibly creating a vicious cycle between inactivity and intensified fatigue.[3] Although research on the etiology, evaluation, and clinical and self-management of cancer-related fatigue is increasing,[4] it remains a "…poorly recognized, poorly understood, and poorly managed" symptom,[3] (p. E35) especially among late middle-aged and older patients and patients with advanced disease. The lack of qualitative studies on patients' interpretations and ways of contending with fatigue, we propose, further limits our knowledge of cancer-related fatigue (CRF) and its management.

The literature has substantiated that CRF is a multidimensional symptom that adversely impacts patients' physical, affective, and cognitive functioning.[5,6] In 2002, recognizing the diagnostic and management challenges intensified by the existence of multiple definitions and assessment tools for CRF, the National Institutes of Health convened a consensus conference to develop clinical practice guidelines for fatigue, pain and depression in cancer patients. The guidelines defined CRF as "a persistent, subjective sense of tiredness related to cancer treatment that interferes with usual functioning."[7] Despite this attempt to develop consensus, the field continues to employ a variety of measures for diagnosing, assessing and, eventually, managing CRF.[8] Some solely assess the presence and severity of the subjective experience of fatigue, whereas others evaluate how it influences the interrelated physical, emotional and cognitive domains of a patient's life.[9,10] In 2010, to better reflect the multidimensionality of the symptom, the National Comprehensive Cancer Network redefined CRF as "a distressing persistent subjective sense of physical, emotional and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning."[11]

The field's primary reliance on quantitative data on fatigue, and often on data provided by clinicians instead of patients, has limited our understanding of how cancer patients experience this "subjective sense of tiredness," how fatigue disrupts their "usual functioning," how they cope with the symptom, and what renders it distressing. The few qualitative studies of these issues, although based on very small samples, have revealed the significance of eliciting the meaning cancer patients assign to their experience of fatigue.[12–15] Specifically, two of these studies that compared the experience of fatigue among cancer patients and healthy individuals substantiated that only the patients described the symptom as distressing and debilitating whereas the healthy participants referred to it as a normal phenomenon they could manage.[12–13] In another qualitative study of patients with advanced cancer, fatigue was perceived as the body's experience of approaching death.[14] This association of the symptom with mortality, the authors suggested, explained the patients' attempts to overcome feeling fatigued by exercising, despite recognizing that these efforts were probably futile. Another qualitative study, also of patients with advanced disease, revealed that the experience of CRF consists of three distinct stages: the "prefatigue" state called tiredness, followed by fatigue, followed by a "postfatigue" stage called exhaustion.[15] In this study, many participants had not developed elaborate descriptions of their fatigue to share with their clinicians because they had anticipated and normalized the symptom. Finally, a qualitative study of mostly female breast cancer patients substantiated that the debilitating intensity of the symptom and the lack of effective coping strategies resulted in patients' feelings of distress and loss of controllability.[16] Moreover, patients did not expect their health care providers to be able to provide symptom relief.

These findings suggest that patients' perceptions of the symptom and how they influence communication with their providers might also account for the insufficient clinical management of CRF.[17]

Although cancer incidence and burden increase with age, a review of research on patients 55 years old and older indicated that they tend to be excluded from cancer-related symptom studies and clinical trials because of comorbidities and age-related health declines that complicate their medical profiles and, therefore, the interpretation of research results.[10] Despite a recent increase in research on CRF in older patients,[18-23] the extant literature still does not offer a clear understanding of the impact of advancing age on the symptom's etiology, expression, intensity, disruptiveness or its impact on cancer patients' mental health. Some research indicates that despite experiencing pronounced and persistent fatigue, late middle-aged and older adults with cancer have better emotional functioning[20] and quality of life[24] than their younger counterparts. This suggests an impact of age on how patients contend practically and mentally with CRF, which in turn might influence the symptom's disruptiveness and limit its distressing effect. However, other studies[19] discovered that CRF is strongly correlated with depression and anxiety among all, but particularly patients 65 years of age and older. Moreover, there is a lack of consistency in the definition of advanced age in the literature on cancer-related symptoms, because patients over 55, over 60, and 65 and older have all been conceptualized as older adults with cancer.[10] Therefore, the questions of how distressing CRF is among late middle-aged and older patients, what renders it distressing, and how patients cope with it remain unclear.

When we narrow our focus to advanced disease stage, our understanding of the experience of fatigue among late middle-aged and older adults with cancer is even more limited. Although studies on CRF in advanced cancer patients exist, they tend to include participants from across the age spectrum, making it difficult to disentangle the manifestation, severity and impact of CRF among patients 55 years of age and older.[25–27] The few studies that have examined the relationship between fatigue and age in patients with advanced cancer provide contradictory results. Some suggest that increasing age renders terminal patients more vulnerable to CRF,[28] whereas a study by Walsh et al.[29] demonstrates that patients 65 and older are less likely to report the constellation of symptoms that define CRF, that is, fatigue, weakness and lack of energy. Moreover, many of the studies on fatigue in advanced cancer patients are conducted in palliative care settings, usually inpatient units, limiting their generalizability to outpatients contending with fatigue.[25, 30–31] Despite the limitations of the extant studies, it has been proposed that CRF is a highly prevalent, distressing, and inadequately understood and managed symptom in advanced cancer patients.[11,29,31] Given the multiple symptoms associated with advanced cancer, it is not clear whether the distress stems from the fatigue, co-occurring symptoms, existential concerns or a combination of all these factors. Moreover, late middle-aged and older patients with advanced disease might interpret and contend with CRF in a unique manner given their age-related expectations regarding normal fatigue and physical functioning. By investigating the attributions they make for their fatigue and how they attempt to integrate the symptom into their lives, we can begin to enhance our understanding of this subjective and multifaceted symptom.

Methods

Sample Description

The present analysis is based on qualitative in-depth interviews with 35 adult patients with advanced cancer who reported experiencing fatigue in the 30 days prior to the interview. These patients were recruited as part of a larger study with a sample of 80 patients and 51 informal caregivers. The study investigated the symptom interpretations and remedial coping responses of these patients. Eligible patients had to: 1) be 55 years of age or older; 2) according to their treating physician, have advanced disease with a poor prognosis; and 3) also according to their treating physician, be physically and cognitively competent to participate in the study.

The study also interviewed the patient's informal caregiver, wherever available and willing to participate. We decided to interview caregivers because they might influence the patient's symptom interpretation and assist in communicating with health care providers and carrying out self-care activities. To be eligible, a caregiver had to be identified by a patient as the family member or friend who assumed primary responsibility for their informal care. No age restrictions were imposed for the caregivers. Eligible patients were not required to have an informal caregiver to participate, but caregivers were not enrolled without a patient counterpart. Twenty-nine enrolled patients did not have a caregiver. Among the 35 patients who reported fatigue and are included in this analysis, 10 did not have a primary caregiver. For this analysis, we focus on the 35 patients' accounts of their fatigue. Given the subjective and multidimensional nature of the symptom and the lack of in-depth data on how late middle-aged and older adults with advanced disease experience and contend with fatigue, we considered it important to first analyze the patients' accounts.

The majority of the 35 patients identified as White non-Hispanic (77%), 14% as Black or African American, 6% as Hispanic, and 3% as Asian. Fifty-four percent of this subsample was female and 46% male. The age range was 56–88 years old (mean age 67 years); 26% were 55–59 years old, 37% 60–69, 31% 70–79 and 6% 80–88 years old. Seventeen percent of the patients had lymphoma, 11% multiple myeloma, 9% had either leukemia, pancreatic or lung cancer, and 6% had either prostate, breast, or colon cancer. According to their treating oncologists, at the time of interview, all patients had advanced disease and a poor prognosis, defined as stages IV or late III, depending on the type of cancer. At the time of interview, 83% of the patients were receiving chemotherapy as outpatients, and 17% were not receiving any cancer treatment.

Patients initially were asked to report all the symptoms they had experienced in the past 30 days. They were then asked to identify and discuss in-depth two symptoms: first, the "most difficult symptom" they had to contend with, and second, the symptom with "the most recent onset." Following pain, fatigue was the second most frequently reported and discussed symptom in the study. Specifically, of the total sample of 80 patients, 44% reported experiencing fatigue and 51% pain. Among the 35 patients who reported fatigue, 21 (60%) identified fatigue as the most difficult and 14 (40%) as the most recent symptom. Of these 35 patients, 49% identified pain as their other primary symptom, 20% gastrointestinal symptoms, and the remaining 31% reported a variety of symptoms, including unsteadiness, shortness of breath, depression and disorientation.

Recruitment

All patients were recruited from a large comprehensive cancer center in a university-based medical center in New York City. Eligible patients were identified either through their treating oncologist and/or nurses, or through review of patients' medical records. For all patients, treating physicians were consulted to confirm disease stage, physical and cognitive competence for study participation, and for permission to mail a letter to the patient's home describing the study and inviting the patient to call to be screened on the phone. Some patients also were approached on the day of their medical appointment by the interviewers, reminded of the study letter and, those interested were screened in person. Patients provided contact information for their primary caregiver who also was screened over the phone or in person at the hospital. The Institutional Review Board of the authors' university and the cancer center that served as the recruitment site approved the study and its procedures.

Data Collection

The full sample (80 patients and 51 caregivers) was interviewed over a 16-month period by one male and four female interviewers. Consistent with patients' preferences, 90% of interviews took place in the patients' home, and the rest at the authors' offices near the cancer center.

Patients and caregivers were interviewed separately. Each interview session lasted approximately two and a half hours. First, the interviewer administered a brief sociodemographic questionnaire and elicited information on the patient's cancer, treatments and how they might interfere with activities of daily living in the past 30 days. These questions took approximately 20 minutes. The remaining time, over two hours, was devoted to the qualitative interview. Each participant received a $25 honorarium for completing the interview.

An interview guide was used for the qualitative interview. It focused primarily on exploring the two primary symptoms the patient had been experiencing in the past 30 days, the impact of the symptom and the cancer on their lives, and their coping responses. The present analysis is based on the sections of the guide addressing the following topics in relation to fatigue: s*ymptom characteristics, causal attributions* for the symptom and how they were derived, and *symptom consequences* (e.g., disruption of activities, impaired role performance). When necessary, insights from the whole interview were included in the present analysis.

Qualitative Data Analysis

All qualitative interviews were audio-recorded and transcribed verbatim for analysis using ATLAS.ti (ATLAS.ti Scientific Software Development GmbH, Berlin, Germany), a qualitative data analysis program.[32] The interviews were interpreted through an iterative process of content analysis based on the construction and application of a coding scheme. This scheme was developed using the following steps: 1) the researchers read half of the patient and the caregiver transcripts multiple times to become familiar with how participants discuss their experiences with symptoms and advanced disease; 2) transcripts from twenty patient-caregiver dyads and ten from patients without a caregiver were selected and read independently by each researcher to begin identifying the topics and concerns participants discussed in relation to symptoms, treatments and advanced cancer; 3) next, the researchers shared and discussed the topics identified and collaboratively constructed a list of preliminary codes/subcodes by interacting with the data; 4) each researcher independently tested these preliminary codes/subcodes on the same 50 interviews and defined additional codes/subcodes needed to capture all the data; 5) after reconciling any interpretative differences, the researchers jointly constructed an updated coding scheme; 6) the scheme was tested on additional transcripts from ten patient-caregiver pairs and five patients without caregivers to ensure it adequately captured and addressed all data; 7) based on the scheme's application to these additional transcripts, the coding scheme was further refined; 8) the final coding scheme was applied to the full data set in ATLAS.ti. The present analysis is based primarily on the following codes and their associated subcodes: symptom characteristics; causal attributions for symptoms and rationale; health care provider: preparation for symptoms; role of printed media; beliefs about cancer.

Results

This section addresses the variety of attributions patients offer for their fatigue, and the rationale for these causal attributions.

Cancer Treatment as the Master Attribution

Approximately 40% of the patients identified their cancer treatment, usually chemotherapy and more rarely radiation or surgery, as the cause of their fatigue. Treatment was usually perceived as the direct and only cause of fatigue and the symptom was often called a “side effect” of chemotherapy and/or radiation. When explaining why they attributed their fatigue to the cancer treatment, several participants referred to a temporal association between their treatment and the symptom that led them to conclude that there was also a causal association between the two. Experiencing fatigue soon after initiating or while under treatment convinced participants that treatment was the cause. Many referred to the exact day after receiving a dose of chemotherapy or initiating a cycle of radiation when their fatigue appeared. A 60-year-old White woman with lymphoma explained that the regularity of the symptom’s onset assured her that the chemotherapy was causing her fatigue:

> I could set my clock by it [fatigue]. I got the treatments on Friday and the following Friday, in the morning, it, I got up maybe it felt still great and then, woom, I was basically out like a light. I couldn’t, I was completely collapsing. That was every time the same routine. …it was very obvious [the chemotherapy was the cause].

A similar conviction about the accuracy of his attribution was expressed by a 57-year-old White man with lymphoma. He adamantly believed that his fatigue was a product of chemotherapy because he experienced it after his first treatment and his physician informed him that it was a potential side effect. In explaining why he attributed his fatigue “only to the treatment” he said: “I got my first experience [of fatigue] after my first chemo. And I know what ‘side effect’ means: tingling, numbness, pain, [being] uncomfortable, [and] weakness!” Classifying his fatigue as a side effect seemed to minimize its salience, “Because side effect is side effect. It’s minor.” Also relying on temporal ordering, a 59-year-old White woman with lung cancer attributed her fatigue initially to surgery and later chemotherapy:

> I mean with all these operations you get tired. So I'm not surprised I'm tired because I've been in the bed so long. I mean a year since I started. After you get chemo, I'd get very tired. It's like this last treatment that I had, for some reason it made me exhausted. Not the first two days. The first two days, well, the first day after, I'm fine because I know they give me the steroids and I feel OK and my appetite is OK. It's the third day that I am, well, one, two, three, the fourth day for about five days, six days, I'm totally exhausted.

Her oncologist, the infusion nurses, and a chemotherapy pamphlet distributed by the hospital had informed her that fatigue was one of the treatment’s side effects, information she found emotionally reassuring:

> …the nurses you talk to, they're very helpful, like if you ask if you're supposed to get tired like this or something. Yeah, they would tell you. Yeah, you know, everybody is different. Everybody has different symptoms. Maybe that one might not feel tired, maybe she would feel something else, you know? At least I think anyway. Me personally, I think it was the chemo. No, what else could it be? … Well, I had a booklet on it also. And I was reading the book. It tells you all the different symptoms that you get. [I: Was it helpful to know about it before you got it?] Yeah, in a way because then you don't say oh Lord, what's happening to me? [Otherwise] you get frightened.

When health care providers told patients to anticipate fatigue prior to treatment initiation, or explained during a medical visit that it was a common concomitant of treatment, this seemed to normalize it and decrease patients’ distress. For instance, a 76-year-old White woman with colon cancer stated: “No, I don’t think about it [fatigue] at all because I know, the doctors told me, I know that it is natural in my situation [receiving chemotherapy as an inpatient]. ... [doctors told me] tiredness is something inevitable, and especially on the third day of the chemotherapy…"

Another factor that minimized the salience of the fatigue and its distressing effect was that many providers described it as a side effect patients have to tolerate and integrate into their lives. As a 56-year-old White woman with adrenal cancer indicated, her physician explained that chemotherapy causes fatigue and there is no remedy for it: "And the doctor told me. He says, you're going to feel tired, more tired from it [chemotherapy], and there is nothing to do for it. You're just gonna have to stop. He says, you'll just lie down." Knowing the cause of her fatigue eliminated her concern, "I don't think much about it. If I'm tired, I lay down. If I have something to do, I go and do it. It doesn't keep me."

Although normalizing fatigue as a side effect relieved participants' concern, it might have undermined their efforts to address it. Indicatively, a few participants who identified treatment as the sole cause of their fatigue did not even report it to their providers because they perceived it as untreatable as well as inevitable. A 59-year-old White man with bladder cancer that attributed his fatigue to his surgery and chemotherapy explained why he did not mention the symptom to his physician:

> I noticed, right after the operation I was very fatigued. And I started gradually getting my strength back. I don't think I'm up to full form yet either but, as I said before if I, if I feel the least bit tired I just lay down. [I: Did the doctor tell you to expect it?] No, the doctor didn't have to tell me that. I just, I knew it would be related to the surgery. It's, it knocks the tar out of you. I had major surgery, I had, I received six pints of blood during the surgery. …I think first of all some of it must be related to the chemotherapy because that wreaks havoc on your body. Ah, it hasn't done as much to my body as other people's, thank God. I'm very fortunate my immune system hasn't been stripped. …[I:…have you talked to the doctor about the fatigue?] No, not at all. I don't think that there's any need to. I think it's a part, a natural part of the recovery.

Unlike radiation, chemotherapy also was defined as an indirect cause of fatigue, that is, as the cause of other health conditions that bring about fatigue, such as anemia, loss of appetite, or weight loss. Participants described a vicious cycle where chemotherapy caused loss of weight and/or appetite and these conditions caused fatigue, and in turn, fatigue undermined eating patterns and prevented weight gain. A 56-year-old White woman with adrenal cancer described this vicious cycle below:

> …Lunch I can eat but, you know, it depends. But supper is the problem. Sometimes either I could not even want it, or I eat just so little because I can't stand, I just have no appetite. …I knew it was the medicine [that caused tiredness]. …it's suppertime already, if we don't eat early, like five-ish or so, and if I'm tired then I don't feel like eating. And then if we'll eat out, I can't eat because either I'm tired or it's the food. Probably it's because I'm tired.

Participants with blood cancers were more likely to describe chemotherapy as an indirect source of their fatigue. They referred to chemotherapy-induced anemia as the cause of fatigue and their accounts were replete with references to red and white blood cells. For instance, a 61-year-old White male with lymphoma provided the following explanation for his weakness:

> …since I started chemotherapy, the fatigue has been as a result of the chemotherapy. ...again my understanding of the science of chemotherapy that it kills the blood cells along with the cancer cells and the blood reports showing the

> hemoglobin count was between 7.6 and 7.9. Well, it is much higher now. Normal like is above 10. And probably my guess is that it’s the, the anemia caused by the low blood cell count that’s the main cause of the weakness.

Multiple Attributions and Explanatory Ambiguity

Approximately half of the participants attributed their fatigue to multiple and varied causes as a result of the symptom’s multidimensional nature and the participants’ older age. Age, cancer and depression, at times coupled with cancer treatment, were the most frequently mentioned clusters of attributions for fatigue. With the exception of chemotherapy-induced anemia, other comorbidities were very rarely identified as causes of fatigue. Similarly, very few participants referred to treatment for comorbidities, such as anti-hypertensive and antidepressant medication, as causes of the symptom.

Age and Other Less-Threatening Causes of Fatigue

Age was perceived as a cause of fatigue usually among participants 75 years and older. Age was often discussed as one source of the symptom alongside other less-threatening conditions (i.e., treatment after-effects, sleep disturbances, loneliness). An 88-year-old White woman with multiple myeloma implicated pain from her hip fracture, age and social isolation when explaining her fatigue:

> …I feel very tired often. Fatigued. And it is an effort for me to function, like to go down and do my shopping or so. But I do blame it mainly on the fracture, the hip replacement. …I do not know if it's the cancer and I don't believe that it is the cancer. …It is due to this, the extreme difficulty to walk, to function, without pain. It is still, after a year and a half, I'm still in pain, some days more than others. Maybe the weather too influences your bone structure or whatever but I wish I could tell you more precisely what I attribute to the cancer. But I don't. I don't feel it. Knock wood. I don't feel it.… Well, naturally if you are 88 you are entitled to be tired. But I wasn't, I wasn't, acting my age. I wasn't mentally, I wasn't physically. Nowhere near my age. And now I'm an old broad. ...I say to myself that the fatigue sometimes could be boredom or loneliness or the lack of, you see that I don't see people. I'm a people person. I need people. I always was in touch with life and with people and I was right in there in the middle, enjoying it. And now I'm very much and very often alone. …And so my tiredness may have other reasons than physical.

Although expressing some uncertainty about her attributions, this participant avoided identifying cancer as a cause and, by comparing herself to others who also had hip replacement surgery, she concluded, “…my gut feeling is that it is not the myeloma.” Age also was identified as an innocuous cause of fatigue when the symptom persisted post treatment completion, and participants that had initially attributed it to treatment had to search for different or additional causes. An 82-year-old White woman with bladder cancer suggested that her fatigue was a lingering symptom of her having received radiation and added her age as another cause: “Well, I still think it's a residue from the radiation. And of course, I'm 82 years old which is another consideration.” After treatment completion, a 68-year-old White woman with breast cancer identified age and sleep disturbances as potential causes of her fatigue:

> [Initially] I knew it was a side effect of chemo. Yes, I was told [by providers]. …[I: Do you still think it's the chemo?] No I don't. I just started thinking it's the age. The aging process slows you down. [I: What makes you think that it's aging?] I guess maybe for lack of anything else. Or you're thinking maybe it's interrupting, the sleeping interrupted with these leg cramps, but now I haven't had that, you know, in ten days. And whether it would take longer for the energy to come back because of

> this lack of sleep I don't know. I just think it has to do with the age. [I: When do you think you changed your mind that it wasn't caused by the chemo anymore?] I think, I would suspect probably after being, it was also, not only the chemo but the radiation. …All the treatments have been over since July that I don't know, you know, I figure it's long enough that it wouldn't be a side effect of either one of those.

Although she concluded that age was the reason for her fatigue through a process of elimination, “I guess maybe the lack of anything else,” she eschewed identifying the disease or its progression as possible causes.

Cancer But Not Cancer Progression as One of Many Causes

When cancer was offered as an attribution, it usually was coupled with chemotherapy, anemia, and other less-threatening causes like age or overexertion. For instance, a 76-year-old White man with pancreatic cancer who perceived his cancer as exacerbating his pre-cancer anemia also implicated his age as a possible cause of his fatigue:

> [Initially] I would think, I would have probably just thought that it comes with my age. One, I related old age to lack of energy. [I: Anything else you thought might be causing the fatigue?] I had a low red blood count. What do you call that? [I: Anemia?] Anemia. [I: Before you were diagnosed?] Yeah. …[Post-cancer diagnosis] Only I thought that the cancer enhanced the fatigue. [Now] All of the above [the cancer, the anemia, the age are causing it]. [I: And what made you think that the cancer might enhance or intensify fatigue?] Well, it draws upon, as I understand it, it draws upon all the energy that you have, a good deal of energy, in the body's efforts to combat it.

Another participant, a 61-year-old Black woman with esophageal cancer, identified cancer as the primary attribution for her fatigue. However, she added as possible causes hypotension, weight loss, and anemia, conditions she tentatively related to her disease:

> I knew what was causing it, it was from the cancer. Because I had already been told that I had it and I just attribute it to that. …Well, it was the fact that I was so anemic and my pressure was so low. But all of that, I just took it all as part of the thing that went with the cancer. …And then, like I said, with the Procrit, I think it was called that, but anyway it builds up your red blood cells. So it was like from the cancer and then being anemic and then being, you know, my pressure's so low and then the weight loss, it was just a combination of everything, but it was all, I guess, related to the cancer.

Only two participants diagnosed with blood cancers attributed their fatigue exclusively to cancer. A 75-year-old White man with leukemia attributed his fatigue to his “tired blood” and said, “I assumed it was leukemia, I assumed that leukemia was making me tired and my blood is all screwed up. My blood-making apparatus don't make the right cells.” Similarly, a 74-year-old Black woman with lymphoma said about the cause of her fatigue: “Oh, I think that it's the sickness. …Because I, I do so much for my health, for myself and I still feel this. And that's why I feel that it is the same blood disorder.” Although they both identified cancer as the only cause of their fatigue, they did not refer to the disease’s progression or advanced stage. The few participants that identified their worsening physical condition as a possible source of their fatigue also referred to additional causes, as if to diffuse the salience of cancer progression. A 77-year old Asian man with prostate cancer who associated his fatigue to his “natural deterioration” also discussed treatment and slight anemia as causes:

> …when I feel this fatigue and the weakness the first suspicious thing is, is this a side effect of both or one of these drugs. …Another possibility, one possibility is

> the slight anemia. Another possibility, I guess, is the tumor itself because maybe there is some secretions. And maybe it's the tumor [that] has caused fatigue. [Another] cause of my weakness, I think is a natural deterioration of my whole body. .. As recent as three or four years [ago] the deterioration on my, of my heart, of my whole physical, I think physically is on the fast track. I feel it.

Discussion

The late middle-aged and older adults with advanced cancer participating in this study provided a variety of attributions for their fatigue, thus confirming the symptom's subjective and multidimensional nature.[11] The analysis also revealed that understanding patients' attributional processes sheds light on the significance they assign to fatigue, the concomitant distress they might experience, and their motivation to communicate their concerns to their provider and/or integrate the symptom into their lives.

Treatment, usually chemotherapy but also radiation and surgery, was often regarded as the only cause of participants' fatigue. Patients seemed to have a cancer-treatment representation that included fatigue among the typical side effects of chemotherapy, radiation and surgery. Many also referred to the temporal ordering between treatment and fatigue as further evidence that the former caused the latter. They reported specific days after receiving a chemotherapy or radiation treatment when their fatigue would appear and when it would subside. This regularity in the symptom's onset and duration contributed to the certainty of their attribution. Their confidence in the accuracy of their attribution also was based on their health care providers' frequent mention of fatigue as a common treatment side effect, both prior to treatment initiation and during treatment. Almost all these participants explicitly stated that being told by their providers that fatigue was a treatment side effect normalized the symptom and reduced its salience and the feelings of threat a symptom can evoke, thus alleviating their psychological distress. However, in discussing fatigue as an expected treatment side effect, some providers seem to also have conveyed that it was unavoidable and patients had to adapt to the symptom and its debilitating consequences. A few who perceived fatigue as an inescapable side effect refrained from reporting it to their provider or discussing it at length and asking for ways to manage the symptom. This suggests that when providers discuss fatigue as a common treatment side effect, they might inadvertently be communicating to patients that the symptom is inevitable and untreatable. This inference is supported by a study revealing that the symptom's common and expected nature deterred cancer patients from developing comprehensive descriptions of their fatigue for their providers.[15] The cancer patients interviewed in another study[16] also indicated that they did not anticipate that their providers could manage their fatigue. Therefore, although patients' conceptualization of fatigue as a common treatment side effect may render it less threatening, it also has the potential to undermine patients' motivation to address it. These findings can inform the clinical management of fatigue that remains inadequate, as the literature has substantiated.[2,7,17]

Some participants also perceived chemotherapy as an indirect cause of fatigue in that it caused anemia, loss of appetite, and weight loss, conditions that also resulted in fatigue. They discerned the development of a vicious cycle according to which their fatigue, induced by losing weight and/or appetite, interfered with eating regularly and gaining weight, strategies that could combat their fatigue. This has important clinical implications particularly for cancer patients with advanced disease who tend to suffer from cachexia and anorexia that our participants identified as both causes and consequences of fatigue.[33] Moreover, finding that patients causally relate the symptoms of fatigue and loss of appetite and weight might also inform the operationalization of the newly-defined notion of symptom clustering that is particularly salient for late middle-aged and older adults with cancer given their age-related comorbidities.[10] With respect to symptom clustering, a number of studies have identified pain, anemia, and depression as symptoms that concurrently occur with fatigue.[1, 28, 35] We propose an additional symptom cluster in which loss of appetite and weight co-occur with fatigue, a finding that might prove useful to clinicians.

Given the participants' advancing age and late disease stage, surprisingly few identified other comorbidities and/or their treatments as causes of fatigue. Possibly, fatigue was not attributed to other comorbidities because participants' illness representation of cancer as a serious and often fatal disease rendered it a master illness that eliminated all other illnesses as potential causes.

Approximately half of the participants ascribed their fatigue to multiple causes, including age, cancer, and treatment. Age was typically coupled with other non-threatening explanations such as overexertion, deconditioning, sleep disturbances and cancer treatment. Some who had ended their treatment and could not evoke it as a cause offered age as another plausible, non-threatening reason for their fatigue. When cancer was raised as a plausible cause, it was usually discussed with other more innocuous reasons such as age or overexertion and more controllable conditions such as chemotherapy-induced anemia or hypotension. Having additional explanations for the symptom may have served to decrease the attributional significance participants would have to assign to the cancer had it been the sole cause of their fatigue. Furthermore, in their attributional accounts, participants tended to avoid evoking the disease's serious and advanced nature. Therefore, it is possible that participants engaged in a process of motivated reasoning when they attributed their fatigue to age and other more benign causes or when they mentioned cancer but not cancer progression as one among many causes. This cognitive strategy might have been an attempt to normalize and minimize both the salience of the symptom and of the disease's advanced nature, motivated by a desire to ward off fear and distress. These interpretations are consistent with the only other study we identified that examined older breast cancer survivors' causal attributions for fatigue and substantiated that they attributed their fatigue primarily to age and very infrequently to the disease.[35] Moreover, the survivor's distress was associated with identifying cancer, but not age, as a cause of fatigue. This inference is also supported by the authors' research on attributions for fatigue among older adults with HIV, demonstrating that offering rival explanations in addition to the HIV disease rendered the symptom less intimidating.[34]

Although participants' accounts of multiple attributions can be perceived as an effort to decrease the symptom's and the disease's threat and minimize their psychological distress, it could also introduce attributional uncertainty that intensifies distress. This complex relationship between symptom interpretation and psychological well-being can refine our understanding of how fatigue and other cancer-related symptoms lead to distress, a question that has yielded equivocal findings and requires further research.

Some study limitations are acknowledged. First, participants represented a convenience sample of late middle-aged and older patients with advanced disease and, as such, might under-represent the most impaired patients. Second, given that provider permission was required to approach potential participants, some provider-related bias in their referrals might have been introduced. Despite these limitations, this analysis clearly reveals that eliciting the patients' causal attributions for fatigue enhances our understanding of the symptom's impact on their physical and emotional well-being, their communication with providers, and ways of integrating fatigue into their lives. Moreover, it is among the few studies that address fatigue among late middle-aged and older patients with advanced cancer who live in the community and not in a palliative care residential setting.

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