

# Perceived Benefits and Barriers to Exercise for Recently Treated Adults With Acute Leukemia

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**Purpose/Objectives:** To explore perceived exercise benefits and barriers in adults with acute leukemia who recently completed an inpatient exercise intervention during induction therapy.

**Research Approach:** Descriptive, exploratory design using semistructured interviews.

**Setting:** Inpatient hematology/oncology unit at North Carolina Cancer Hospital in Chapel Hill.

**Participants:** 6 adults with acute leukemia aged 35–67 years.

**Methodologic Approach:** Content analyses of semistructured interviews that were conducted with each participant prior to hospital discharge.

**Findings:** Most participants were not meeting the recommended physical activity levels of 150 minutes of moderate-intensity exercise per week before their diagnosis. Patients were highly pleased with the exercise intervention and the overall program. Common barriers to exercise were anxiety and aches and pains.

**Interpretation:** Overall, participants experienced physical and psychological benefits with the exercise intervention with no adverse events from exercising regularly during induction chemotherapy. Referrals for cancer rehabilitation management will lead to prolonged recovery benefits.

**Implications for Nursing:** Findings inform the nurses' role in encouraging and supporting adults with acute leukemia to exercise and be physically active during their hospitalization. Nurses should also be responsible for assisting patients with physical function activities to increase mobility and enhance overall health-related quality of life.

Acute myelogenous leukemia (AML) and acute lymphocytic leukemia (ALL) are two rapidly progressing cancers of the blood and bone marrow. An estimated 21,380 people will be diagnosed with AML and 5,970 will be diagnosed with ALL in the United States in 2017 (American Cancer Society, 2017). Incidence of AML increases with age, whereas ALL is most commonly diagnosed in children and has less favorable outcomes for those treated later in life (Marks, 2015).

Because of the rapidly progressing nature of these high-risk cancers, patients are promptly treated with induction chemotherapy with the goal of achieving a complete remission (Sekeres & Stone, 2002). Depending on the treatment regimen, patients will generally remain in the inpatient hospital setting for about four weeks to allow for recovery from myelosuppression and treatment-related side effects. Although chemotherapy for AML and ALL improves overall patient survival, burden is placed on the musculoskeletal system, leading to decreased physical activity levels (Smith-Turchyn & Richardson, 2015). Consequently, researchers have focused on the effects of exercise and physical activity interventions in solid and non-solid tumor cancers (Schmitz et al., 2010), and

there is a growing interest in the cancer community for using exercise training for the alleviation of treatment-related symptoms in patients with acute leukemia (Bergenthal et al., 2014). The promotion of physical activity during treatment also has been shown to be a contributor for improvements in health outcomes in this cancer population (Battaglini et al., 2009; Bergenthal et al., 2014; Jones, Eves, Haykowsky, Freedland, & Mackey, 2009; Jones, Eves, Haykowsky, Joy, & Douglas, 2008). The current empirical evidence provides oncology nurses with essential information in encouraging adults with acute leukemia to be more physically active while undergoing treatment.

As exercise training interventions are implemented in the hospital setting, focus should be on the qualitative aspects of exercise training as well as the objective fitness outcomes, including body composition measures. Objective measures, such as  $VO_2$  peak, six-minute walk test, percent body fat, and percent lean body mass, are frequently used to explore changes in physical fitness and overall function outcomes during and after treatment (Jones et al., 2008).  $VO_2$  peak is the rate of oxygen consumption and the submaximal cardiopulmonary response to exercise, which often is tested using a treadmill or cycle ergometer (Jones et al., 2008, 2009). Because of the growing body of evidence on the benefits of exercise for cancer survivors, the American College of Sports Medicine (Schmitz et al., 2010) endorsed physical activity guidelines that include weekly engagement of 150 minutes or more in moderate-intensity aerobic activity (Bergenthal et al., 2014; Jones et al., 2008). Physical activity has been associated with a number of outcomes, including biological (decreased inflammatory markers), physiological (increased muscle strength and mass), and psychological (decreased depressive symptoms), as well as decreased fatigue (Alibhai et al., 2012; Battaglini et al., 2009; Chang et al., 2008; Klepin et al., 2011), leading to health benefits among adults with acute leukemia.

The purpose of this study was to explore perceived benefits of and barriers to exercise interventions in adults with acute leukemia while receiving initial induction treatment. This insight may provide guidance to establish programs that are safe, feasible, effective, and are welcomed by patients as part of the treatment plan.

## Methods

### Research Participants

This study used participants of the Exercise and Quality of Life in Leukemia Adults (EQUAL) randomized, controlled trial at the University of North Carolina Lineberger Comprehensive Cancer Center (Bryant

et al., 2017). Participants in the exercise intervention arm ( $n = 9$ ) were approached for an interview for this study. Inclusion criteria for participants on the EQUAL trial consisted of (a) being an adult aged 21 years or older, (b) being newly diagnosed with AML or ALL, (c) receiving induction therapy to begin chemotherapy with an expected hospital stay of 3–4 weeks, and (d) being able to speak and understand English. Exclusion criteria included cardiovascular disease; acute or chronic respiratory disease; acute or chronic bone, muscle, or joint abnormalities; altered mental state, dementia, or any other psychological condition that would prevent understanding of informed consent; another active malignancy; and active bleeding, acute thrombosis, ischemia, hemodynamic instability, or uncontrolled pain. Reasons for the low number of participants in the EQUAL study is related to the exploratory aim focused on cardiopulmonary exercise testing (CPET) in the acute leukemia population undergoing treatment. Participants with acute or chronic cardiovascular, respiratory, or bone conditions were excluded from the study because it was contraindicated in CPET; 39% of potential eligible participants were excluded because they had one of these comorbidities.

### Intervention Components

Patients who agreed to participate were randomized to either the control or intervention group. Participants in the intervention arm participated in an individualized, mixed-modality exercise program supervised by exercise sport science specialists. Participants were approached four times a week, twice per day (morning and afternoon session) for aerobic (walking or stationary bike) and resistance training (use of different strengths of resistance bands). This progressive exercise model consisted of aerobic training for 5–15 minutes and resistance training for 10–20 minutes. Upper body exercises were completed in the morning and lower body exercises in the afternoon. Exercises were adapted based on the patient's physical limitations. A cool-down session included five minutes of stretching at the end of each session. Participants in the control arm received standard of care and were monitored on their activity level during the hospitalization period using daily activity logs.

### Procedure

The principal investigator (PI) (ALB) monitored the laboratory values of each intervention participant daily via the electronic health record to anticipate date of discharge. When discharge was anticipated within 72 hours, each intervention participant was contacted by telephone by the PI requesting time to conduct an interview with them 24–48 hours before discharge. The

PI scheduled time to meet with the patients in their hospital rooms and conducted the semistructured interview. Although participants were aware of the possibility of interviews from the start of the study, they gave additional written consent at the time of the interview. All interviews were audio recorded and transcribed and ranged in length from 10–28 minutes. Interviews took place from November 2014 to November 2015. A \$10 gift card was given as the incentive. This study was approved by the University of North Carolina at Chapel Hill Institutional Review Board.

## Measures

Data were collected using semistructured interviews guided by the following questions developed by the research team and modified based on initial interviews and analyses:

- What was your level of physical activity before your diagnosis?
- How did the exercise intervention make you feel before and after exercise in the hospital?
- What are your overall perceptions of the inpatient exercise intervention?
- What feedback can you provide us on frequency of the sessions?
- What are your perceptions of what will help you continue to be physically active?
- What resources would be helpful as you transition from the hospital to home?
- Do you have general suggestions for improvement of the intervention?

## Data Analysis

Demographic data were collected and managed using REDCap electronic data capture tools (Harris et al., 2009). The REDCap database was password protected. Data were entered by the PI, and 10% of the data entered were checked for quality assurance and found to be 100% correct. Data were then analyzed in SPSS®, version 22.0. Descriptive statistics, including frequencies, were calculated for all demographic variables. Interviews were transcribed by a professional transcription agency and the content was analyzed by the PI, who also was the interviewer and a second coder. *A priori* codes were those that the investigators expected to emerge and were placed in a code book prior to coding, such as prediagnosis exercise participation, frequency of intervention, and suggestions for program. There were also *emergent* codes that arose through the analyses that were added, such as barriers to exercise, symptoms, and praise for the program. Coding was done using ATLAS.ti software. While the PI coded, she listened to the interviews again to help with context and quality checking of the transcription.

The second coder (ALW) was familiar with the aims of the study but had not personally met or interviewed the participants. The second coder also coded 100% of the data. For every place where the two coders did not agree on their initial code, they underwent a code negotiation and transcript review (Patton, 2002). Their initial agreement in coding was only 29%, but that rose to 100% after code negotiation. Much of the initial discrepancy in coding centered on the subcodes for frequency and timing of the intervention. Furthermore, both coders added codes that were not in the initial code book and that required additional discussion.

## Results

### Sample

Of the nine eligible participants, one dropped out shortly after consent, and two had been discharged from the hospital months before interview data were collected; therefore, six patients were interviewed. Of the six interviewed participants, all were diagnosed with AML, five were White non-Hispanic males, and one was African American female. The age of the sample ranged from 35–67, with a mean age of 55 years. Five of the six participants lived with someone and were either married/partnered. Education levels varied, with one participant having less than a high school education, two with college degrees (BA/BS), and three with advanced degrees (MA/PhD). The average length of stay was 31 days, ranging from 27–37 days. Baseline characteristics are shown in Table 1.

### Prediagnosis Exercise Activity

Three participants had taken part in some type of activity within six months prior to diagnosis and the remaining were not physically active before their diagnosis. One participant who was not physically active stated the following:

Before I was diagnosed, I was not physical at all. I was pretty fatigued all the time, really tired, didn't know why. I just thought that, um, that it was stress.

Another participant had a similar statement.

No. I didn't exercise, I was just working, but regular job, housekeeping, and one night I was at work and I just got weak all of a sudden and got shortness of breath and just realized that I need to go to the hospital. And when I got to the hospital that's when I found out that I was diagnosed with leukemia, so that's how I ended up here.

Most had not met the recommended guidelines of 150 minutes of moderate-intensity physical activity per week.

**TABLE 1. Sample Characteristics (N = 6)**

Characteristic	$\bar{X}$	Range
Age (years)	55	34–67
Characteristic	n	
<b>Gender</b>		
Male	5	
Female	1	
<b>Race</b>		
White	5	
African American	1	
<b>Education</b>		
Less than high school	1	
College degree	2	
Advanced degree	3	
<b>Marital status</b>		
Married/partnered	5	
Divorced	1	
<b>Acute myelogenous leukemia</b>	6	

Of those who did exercise, hiking, walking, and playing tennis were the most commonly reported activities. One participant who was active stated the following:

I played tennis at least three times a week, went to the gym probably one time a week, at least. I would try to exercise at least every other day. Take my dog for an hour walk in the woods. So I would say, daily, I had either pretty high level or at least moderate exercise every day.

Participants spoke of their varying level of exercise intensity before diagnosis. Hiking and playing tennis were activities considered of light-to-moderate intensity.

### Perceived Benefits of Exercise

All participants reported benefits of the structured exercise intervention. These benefits were both physical and psychological. One participant reported, “[The] exercise that I did, it made me feel better.” Another participant was more specific. “All these really chronic physical aches and pains went away and it is sort of kind of same here; I really haven’t felt any anxiety over this.” The benefits of exercise were also expressed.

Physical activity helps with anxiety. Physical activity helps with sleeplessness, to me. I just have always believed if I exercise, I’ll feel better, and I sleep better. Now, sleep here is a different animal.

Overall, benefits were decreased aches and pains, lower fatigue, and decreased anxiety.

Another reported benefit was timing of the intervention.

Probably the morning and afternoon was good. It keeps you busy and it is not until like 7 o’clock at night when you finish dinner and everything else, that you really finally get to settle in. Otherwise, I mean it would be really easy, when your stomach is a little off, just curl up, lay in bed.

Another participant described the social connectedness with the exercise trainers.

I like the interaction with people. I got to talk and meet with some different people. It was, like I said, it got me out of my room and got me up off my bed . . . exercising where I might not have done that near as much.

Lastly, a common reported benefit was how the exercise routine motivated each participant.

It gives you real power. It, um, it motivates you. It wants you to get up and make yourself stronger because, when you lay in the bed, you just seem to get weaker and weaker. But when you have someone either pushing you or someone there that’s, you know, wanting to see you succeed and get out of the bed, you know, that, that makes you want to do it, not just for yourself but for everyone that’s around you; for your nurses, for you, your family, just overall. I mean, it, it was just—it’s the willpower, you know, but it’s the motivation that really drove me to do it. And when I heard about the study, you know, that’s what drove me because I was like, well, if they will help me with my treatment and throughout the treatment to be more active so I can get better quicker, then of course I want to do that so I can get out of here and go home sooner. I mean, I would rather exercise a couple of times a day as opposed to just laying in the bed and then being here two or three months. And that’s pretty much what it’s come down to because, without moving, if I would have stayed in the bed and if I didn’t exercise at all, my numbers would still be down and I don’t know when I’d be going home. And that’s what this program has allowed.

Recovery from the symptoms of acute leukemia and side effects of treatment, motivation, and social connectedness were commonly reported benefits.

### Perceived Barriers of Exercise

The most common barriers to exercise were closely connected with the role of physical and psychological symptoms.

Well, there were a couple of times when I had to cancel it because either I wasn’t feeling right or it conflicted with something having to do with my treatment. So the fixed schedule nature of it was

a little inflexible, which I understand, although there were a couple of sessions that we did schedule for an hour earlier. But I would say that it created conflicts and, unfortunately the physical intervention had a lower priority than some of those conflicts.

Another participant described physical symptoms.

I've had some stomach issues, some intestinal issues, and so just wasn't . . . and then I've had an infection that kind of made bouncing up and down and running a little inconvenient. So, there were a couple of times when I just didn't have the physical or mental edge to do it, I guess.

Although most patients enjoyed the timing of the intervention during their hospital stay, not knowing the typical hospital schedule for patients with AML beginning induction chemotherapy at the beginning of the intervention led one participant to report that the intervention times (9 am and 2 pm) were not always possible and needed to be rescheduled. Barriers to completing daily exercise activities included symptoms that prohibited adherence and frequency and sometimes the timing of the exercise intervention.

### Post-Hospital Plan and Resources

Participants received the intervention four times per week, as many as two times per day. During this time, they built relationships with the exercise trainers and began to anticipate their daily exercise. The research team inquired about participants' exercise plans after discharge and there were varying responses of projected level of activity after discharge.

Yeah, we've got a treadmill at home, we've got a . . . some stationary weights at home that, um, that should provide any of that resistance that we need, so it's just a matter now of making it happen.

Another participant expressed a willingness to continue to walk.

So, I will still do much walking. Actually, I don't know how. . . . I probably wouldn't have the energy to be walking four, four-and-a-half miles a day, but every day this good, we will walk up to the road and back and that's plus the two miles and I think we were generally maybe on the average four or five days a week.

Another expressed the value of exercising.

Well, [sighs] I'm going to have to continue this lifestyle. I'd rather continue staying active. Um, I know that with the diagnosis that I have, um, it was unexpected. It's something that was . . . it's like you see those commercials. "Oh, that will never be me. That will never happen." Well, guess what?

Here you are. You know, you know, it doesn't work like that. But I wanted to continue my walking, my strengthening, and everything that I have to do to keep pushing myself to make myself stronger because, at this point, with the chemo[therapy], and I still have more treatments to go. Without exercising and staying up out of the bed, I won't make it. And it's going to take exercising, me moving around, and continuing what I'm doing now to finish this treatment because I get so weak.

Each participant was able to articulate an activity plan after discharge, ranging from walking to being active with friends or a companion.

### Praise for the Overall Program

Overall, the participants found the exercise intervention and program beneficial.

What I liked best was it was structured exercise so that I didn't have to decide, "Okay, I'm going to go down and ride the stationary bike." I didn't have to find the internal motivation because that was a little tough to find during my treatments. If I knew they were coming every Monday, Tuesday, Thursday, and Friday at 9 and 2 o'clock, I just got ready for it and did it. I enjoyed having the structure and the consistency.

Another participant expressed the value of exercising five days per week.

Like I said, I was thrilled to be . . . I think it's had a positive impact on my recovery. I think it's been, for me, I'm a structured kind of person and so it's been nice to have a structure to kind of . . . and it's helped pass the time, to be perfectly honest with you. Those days go a little faster than the days when I didn't have, like on Wednesdays. So, I'm not even sure why they do Monday, Tuesday, Thursday, Friday and don't do Wednesday. I don't know if it's ability to find trainers or if that's based on physical therapy, giving your muscles a chance to rest or whatever, but I'd have done it on Wednesdays, too. But, I didn't go out and do it myself.

Overall, the participants had a strong sense of pride about the program and encouraged others newly diagnosed with acute leukemia to participate in a structured exercise intervention for physical and psychological benefits.

### Suggestions for Program

Two suggestions were given to make the program more successful. One participant preferred the same trainer during hospitalization.

I loved all the trainers. I did. But I think it should be one trainer and that trainer throughout the

whole program while you're doing it and not different ones. That way, if you become sick, if something happens, you can call that one, and not sit there, and think, "Okay, whose number? Who do I need to get in contact with, with whoever? What was their name? I don't remember." So, I think it should just be one trainer for one participant throughout the program. And it would just make it a lot easier on the patient. And it could probably be helpful for the trainer too because, at the same time, when they're going to go and see a patient, and a participant hasn't called, and said, "Okay, well, I don't want to do it today." . . . So, I think if it's one-on-one, it's going to make that participant work harder because they've got that same person, they get used to that person, and that's the only thing that I would pretty much change about it is just having the same buddy trainer always throughout the whole program.

The second suggestion was about wearable devices and use of an app to track activity.

The app, it can keep you on track for both of you and it can kind of be like a, um, competition, so to speak, you know, a little fun competition. It's like, okay, well, here's where I stand on my app. Where do you stand on yours? So, I think it can be both having your buddy and then having your app at the same time. You know, I think, I think it'd be a good idea.

The two suggestions will be incorporated in future exercise studies.

## Discussion

Patients were highly pleased with the exercise intervention and overall program; the most prominent benefits were physical and psychological and the ability to socially interact and connect with the exercise trainers. Barriers to exercise were symptoms such as anxiety, aches and pains, fatigue, and gastrointestinal symptoms that interfered with the exercise routine.

The target population was relatively homogeneous based on disease and race. Limitations to this study include one interview versus serial interviews during the hospitalization or postdischarge, small sample size, lack of ethnic and racial diversity, and range in exercise history. Even with the small sample size, the study findings contribute to future studies by understanding perceived benefits and barriers to exercise during treatment. Changes to the exercise prescription can be modified based on the participants' quotes. This study was only able to provide a snapshot of these adults' experiences while hospital-

## Knowledge Translation

- Understanding the experiences of adults with acute leukemia during treatment provides opportunities for structured activities in the hospital during a time of uncertainty.
- Oncology nurses can help adults with acute leukemia achieve their exercise prescription and plan through various activities to strengthen their endurance, flexibility, and overall health-related quality of life.
- A home-based exercise intervention for adults with acute leukemia after induction treatment may provide additional physical and psychological benefits, leading to improved well-being.

ized, since follow-up interviews were not conducted to determine their level of activity. Because of the low numbers and lack of racial and gender diversity, the authors were not able to determine differences among these variables.

Less than half of the participants were meeting the recommended guidelines of 150 minutes of moderate-intensity physical activity per week prior to initiating treatment, which is similar to previous multiple myeloma studies (Craike, Hose, Courneya, Harrison, & Livingston, 2013; Jones et al., 2006). None of the participants had taken part in vigorous activity before their diagnosis, and this may be for a variety of reasons, including not being motivated to exercise, symptoms of leukemia that impeded their ability to exercise, or not having time to exercise. The short- and long-term goal is to avoid inactivity and to encourage patients to return to their activities as quickly as possible (Bergenthal et al., 2014). Most leukemia cases occur in older adults—with the mean age being 55 in the current sample—and recommendations for how to appropriately encourage physical activity in this population are vague. Burhenn, Bryant, and Mustian (2016) provided a detailed review of potential exercise recommendations for oncology providers who are involved in functional assessment and intervention, including occupational therapists, physical therapists, recreational therapists, exercise physiologists, and RNs.

Fatigue is the most prominent, distressing symptom for adults with acute leukemia during and after treatment (Leak Bryant, Lee Walton, Shaw-Kokot, Mayer, & Reeve, 2015), and can be viewed as a barrier to completion of exercise (Alibhai et al., 2012; 2015). In addition, non-physical symptoms emerged, such as improved anxiety and overall mental well-being due to the exercise. These findings are similar to Craike et al. (2013), who found that patients with multiple myeloma who participated in physical activity improved physical and psychological health.

For future studies, a suggestion was made that the structure of the program of two times a day, including a morning and afternoon session, remain. Participants preferred the same exercise trainer, but this may not be possible because of competing obligations and vacations for the individual exercise trainer. Ideally, no more than two trainers per participant was the goal for this study. The use of wearable devices for participant-generated health data was mentioned by participants and may assist them after discharge (Bennett et al., 2016; Wood, Bennett, & Basch, 2015). Use of these devices in the hospital and then continued monitoring of participants postdischarge may be valuable to research.

## Implications for Practice

Evidence of the benefits of exercise for adults with acute leukemia during treatment is growing; benefits include decreased fatigue, better psychological health, and enhanced quality of life (Alibhai et al., 2012; Battaglini, 2011; Chang et al., 2008; Jarden et al., 2013). With an increasing number of cancer survivors, oncology nurses must be aware of the exercise guidelines for people with cancer and encourage patients to work toward a goal of achieving at least 150 minutes of moderate-intensity exercise per week. Exercise physiologists should work closely with physical and occupational therapists to maximize potential, particularly for adults with any functional or musculoskeletal issues, and to allow patients to gain the physical and psychological benefits of exercise and, therefore, improve overall recovery.

## Conclusion

The health benefits of exercise are well known and well documented (Blair, 2009; Courneya, 2010; Mustian et al., 2009; Wolin, Schwartz, Matthews, Courneya, & Schmitz, 2012); however, there remains a disconnect to implementing these exercise guidelines into practice for adults with acute leukemia. Findings inform the need for symptom management to facilitate and support adults with acute leukemia to exercise and be physically active and maintain functional status during their hospitalization, supporting the need for a nurse-led intervention to manage and intervene on symptoms to enhance patient engagement during hospitalization.

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