



# “There is no expiration date”: a qualitative analysis using the Social Cognitive Theory to identify factors influencing physical activity among adults living with advanced cancer

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## Abstract

**Purpose** To identify cognitive, behavioral, environmental, and other factors that influence physical activity in adults with advanced cancer using qualitative, semi-structured interviews.

**Methods** Eighteen semi-structured interviews were conducted with adults living with stage IV breast, prostate, or colorectal cancer; or multiple myeloma recruited from the University of Wisconsin Carbone Cancer Center. We used the Social Cognitive Theory to design the interview guide and a reflexive thematic approach for analysis.

**Results** Participants were 62 years old on average and currently receiving treatment. Despite reporting numerous barriers to physical activity, most participants discussed engaging in some physical activity. Participants reported difficulties coping with changes in physical functioning especially due to fatigue, weakness, neuropathy, and pain. While cold weather was seen as a deterrent for activity, access to sidewalks was a commonly reported feature of neighborhood conduciveness for physical activity. Regardless of current activity levels, adults with advanced cancer were interested in engaging in activities to meet their goals of gaining strength and maintaining independence. Having a conversation with a provider from their cancer care team about physical activity was seen as encouraging for pursuing some activity.

**Conclusions** Adults living with advanced cancer are interested in pursuing activity to gain strength and maintain independence despite reported barriers to physical activity. To ensure patients are encouraged to be active, accessible resources, targeted referrals, and interventions designed to address their goals are critical next steps.

**Relevance** Integrating conversations about physical activity into oncology care for adults living with advanced cancer is an important next step to encourage patients to remain active and help them improve strength and maintain quality of life and independence.

**Keywords** Physical activity · Well-being · Advanced cancer · Quality of life · Intervention

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## Introduction

The United States (US) is home to a large and growing population of survivors of cancer. Due to an aging population, improved screening rates, and advances in cancer treatments, the U.S. population of survivors of cancer is expected to grow to 26 million by 2040 [1]. Many survivors of cancer face physical and/or psychological sequelae including functional limitations, fatigue, anxiety, and depression due to their diagnosis and treatments [2–5]. Increasing physical activity is particularly important for survivors of cancer, as it is known to reduce treatment side effects and improve health-related quality of life (HRQoL) but evidence on the feasibility and benefits of physical activity for those living with advanced cancer diagnoses is limited [6, 7]. The term “advanced cancer” is typically used to describe cancers that are unlikely to be cured [8]. Adults living with advanced cancer vary greatly with respect to treatment, functional status, and prognosis [9]. The National Cancer Institute’s Surveillance, Epidemiology, and End Results (SEER) Explorer demonstrates a wide range in five-year survival rates for those diagnosed with distant metastases, indicating that some adults live with advanced cancer for many years, while others have a short prognosis [10].

Most physical activity interventions in cancer populations have targeted those who have survived breast or colon cancer, and few have included individuals with stage IV disease [6, 9]. Individuals with stage IV disease historically have been excluded from physical activity research for two reasons. First, there has been a lack of consensus on the safety and efficacy of randomized physical activity trials among adults living with advanced cancer, however evidence is growing that physical activity is safe, feasible, and beneficial for this population [11, 12]. Second, recruiting and retaining participants living with advanced disease to a physical activity trial poses methodological challenges (e.g., the need to plan for lower adherence and high attrition due to treatment side effects, disease symptoms/progression, and mortality) [13, 14]. The consequent exclusion of this group from physical activity research has resulted in a gap in knowledge. As the population of people living with stage IV cancer continues to grow, it is important to understand the physical activity abilities, goals, and preferences of this group.

While adults living with advanced cancer have been underrepresented in physical activity trials to date, they may benefit from physical activity interventions designed to slow physical decline, maintain or improve functioning, and promote overall quality of life [6, 15]. Due to the often intensive and ongoing nature of treatments undertaken by those living with advanced cancer, mounting treatment

side effects can adversely impact quality of life [16]. A few previous studies have demonstrated the benefits of exercise interventions for improving aerobic capacity, strength, fatigue, and quality of life among adults with advanced cancer, so finding ways to deploy physical activity interventions to improve both physical function and quality of life are essential [17–19].

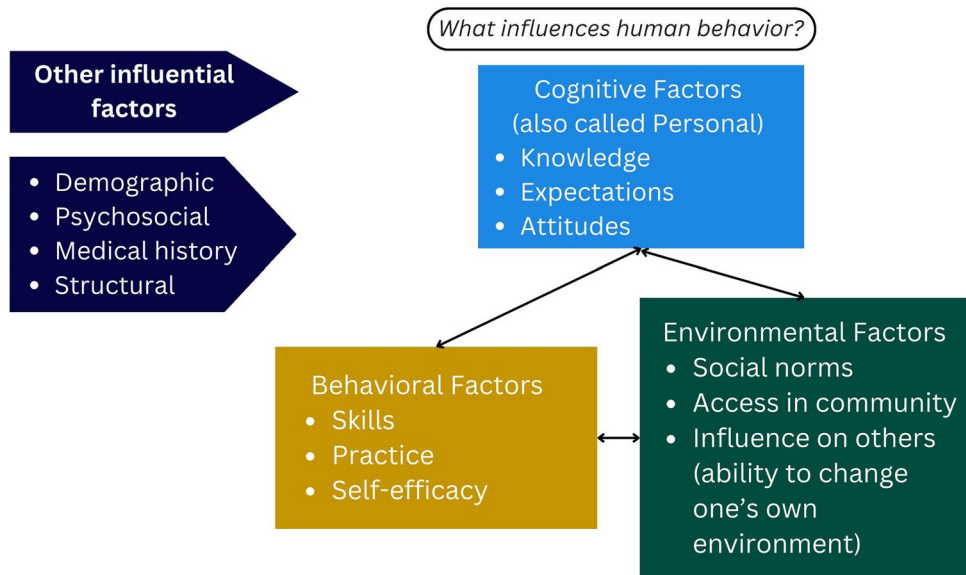
Designing interventions based on the abilities, goals, and preferences of the target population is important to create efficacious programs with strong enrollment, retention, adherence, and potential for sustained maintenance of physical activity. A recent study by Knowlton et al. (2020) investigated barriers to exercise among survivors of cancer, including those with advanced disease, and found the most commonly reported barriers were: limitations by other conditions/illnesses (36%), not having enough free time (16%), and not knowing how much to exercise (8%) [9]. Furthermore, researchers found high levels of willingness to increase exercise among patients living with advanced disease, with 79% of survivors of cancer interested in obtaining more information about physical activity and exercise despite reported barriers to exercise [9]. An overall assessment of abilities, goals, and preferences of this unique population across contexts is needed to inform the design of future interventions.

Assessing barriers to physical activity experienced by adults living with advanced cancer is necessary to develop effective interventions. Both cancer-specific barriers and general barriers to physical activity, such as lack of access to physical activity promoting amenities, including sidewalks and trails; and weather concerns, are addressed in this study. Due to the geographically diverse nature of Wisconsin, which has a high proportion of rural areas in addition to suburban and urban areas, residents have a variety of experiences in terms of places to be physically active. In Wisconsin, lack of access to safe spaces for physical activity and traffic and safety concerns may be important considerations among our target population [20]. Consequently, these topics are explored to determine if they are impactful barriers to physical activity for adults with advanced cancer living in non-urban settings.

The purpose of this investigation is to identify cognitive (knowledge, attitudes, expectations), behavioral (skills, practice, self-efficacy), environmental (social norms, access), and other factors that influence physical activity in adults with advanced cancer using qualitative, semi-structured interviews. We hypothesized that there would be commonly identified barriers and facilitators to activity as well as goals for future physical activity that will be critical for future intervention development for the adult advanced cancer population.

**Fig. 1** The theoretical framework, Social Cognitive Theory, with constructs adapted from Bandura (1998) [25]

## Social Cognitive Theory



## Methods

### Study overview

The investigation used qualitative research methods, with data collection consisting of semi-structured interviews with  $N = 18$  adults living with advanced cancer (stage IV breast, prostate, colorectal cancer; or multiple myeloma). This study was approved as minimal risk by the University of Wisconsin-Madison's Minimal Risk Institutional Review Board (Protocol #2019-0767) and by the Carbone Cancer Center's Protocol Review and Monitoring Committee (Protocol UW18135). The study reflects COREQ considerations to ensure quality and transparency of reporting (Supplemental Material A) [21].

The Social Cognitive Theory (SCT) was used to develop the interview guide, with questions designed around the cognitive, behavioral, and environmental constructs (Supplemental Material B: Interview Guide and Social Cognitive Theory Constructs) [22, 23]. The SCT contains three core constructs: (1) cognitive/personal factors, including attitudes, knowledge, and expectations; (2) behavioral factors, like self-efficacy, practice, and skills; and (3) environmental factors, such as traffic, safety, and access to amenities like gyms and trails (Fig. 1) [23]. The SCT provided a suitable theoretical framework to explore a variety of factors that may impact physical activity engagement among adults with advanced cancer and has been used previously to investigate physical activity engagement among long-term breast cancer survivors [24]. Follow-up questions and probes based on responses were used to facilitate a deeper understanding of participants' experiences.

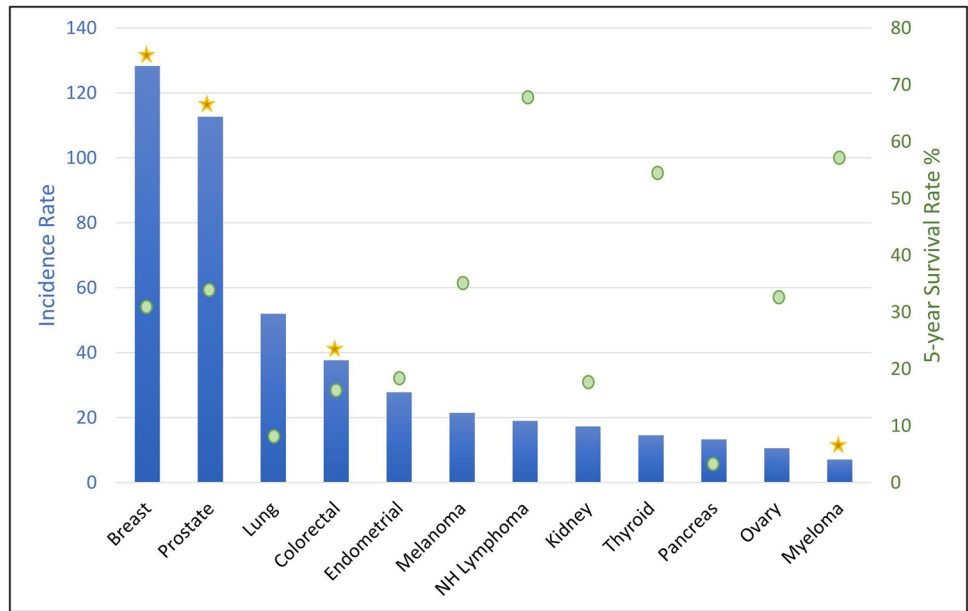
### Recruitment and participants

Using the NCI SEER\*Explorer, incidence rates and 5-year distant survival rate percentages were assessed for a variety of cancers using the most recently available data (Fig. 2). Three common cancer types were selected including breast, prostate, and colorectal cancers. The less common diagnosis, multiple myeloma, was also selected due to its high 5-year survival rate, with approximately 59% of patients expected to live 5 or more years after diagnosis.

Patients were recruited through the University of Wisconsin's Carbone Cancer Center (UWCCC) by informing oncologists about the study and asking clinicians to refer eligible patients to research staff at the Wisconsin Physical Activity Epidemiology Lab. Patients were purposively sampled based on their cancer type. Each included oncologist was given the eligibility criteria and asked to refer four patients seen face-to-face in their clinic who met the following criteria: 18–75 years of age; stage IV breast, colorectal, or prostate cancer, or multiple myeloma diagnosis; an Eastern Cooperative Oncology Group's (ECOG) Performance Status rating of 0, 1, or 2; and fluent in spoken and written English. We excluded patients who were incapable of self-care or confined to a bed or a chair for more than 50% of their waking hours, i.e. ECOG status of 3–4, as these patients were not expected to have capacity to engage in recommended levels of physical activity [26]. Similarly, we excluded patients with significant cardio-metabolic abnormality including heart failure.

Oncologists asked eligible patients to complete a written permission to contact form which included information about the study and preferences for contact time and mode

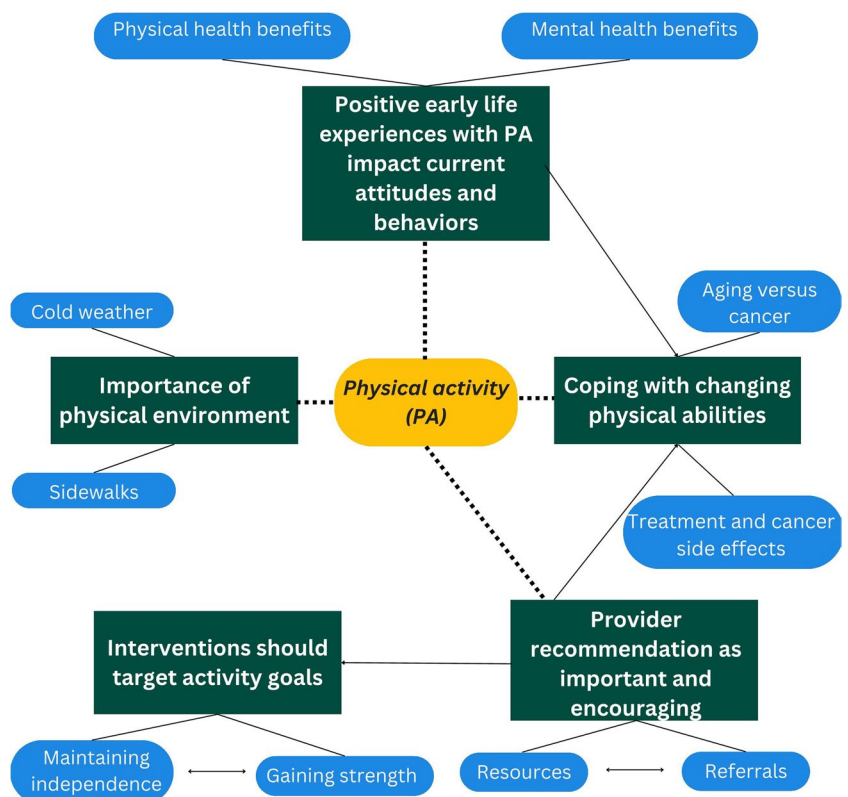
**Fig. 2** Age-adjusted incidence rates (# of new cases/year per 100,000 population) and 5-year distant survival rate % (% of people with distant disease who lived at least 5 years). Distant refers to a stage IV diagnosis. Cancers in this study are marked with a star. *NH Lymphoma* Non-Hodgkin’s lymphoma. Data source: NCI SEER\*Explorer, 2024



(by phone or email). Research staff at the Wisconsin Physical Activity Epidemiology Lab made up to three attempts to contact eligible patients. Once contact was made with a patient, they were screened to ensure eligibility criteria and willingness to complete an interview about physical activity, and to inquire about current participation in any other physical activity studies (none reported). During the screening

call, interested individuals provided verbal consent to participate following a study explanation which included a description of study goals. Interviews were scheduled based on the participant’s preferred date and time. Research staff obtained participants’ permission to record their interviews during the screening phone call and again at the time of the interview; participants were also told when the recording

**Fig. 3** Thematic map illustrating relationships between the major themes and associated subthemes



**Table 1** Demographic and Clinical Characteristics of Interview Respondents

Characteristics	<i>n</i> (%)
<b>Demographics</b>	
Age Group	
40–49 years	2 (11%)
50–59 years	1 (5%)
60–69 years	12 (67%)
70–75 years	3 (17%)
Education	
High school graduate	8 (44%)
Some college	5 (28%)
Bachelor's or higher	5 (28%)
Gender	
Men	10 (56%)
Women	8 (44%)
Race	
White	17 (94%)
Black/African American	1 (6%)
<b>Clinical Characteristics</b>	
Cancer Type	
Breast	5 (28%)
Colorectal	4 (22%)
Multiple Myeloma	4 (22%)
Prostate	5 (28%)
Disease Stage	
Metastatic	17 (94%)
Locally Advanced	1 (6%)
Current Treatment Type <sup>a</sup>	
Chemotherapy	11 (61%)
Hormone therapy	6 (33%)
Immunotherapy	2 (11%)
Bone treatment	3 (17%)
Stem cell transplant (< 3 months ago)	1 (6%)
Steroid injections	2 (11%)
Treatment Status	
On Treatment	18 (100%)

<sup>a</sup>Sums to > 100% because patients could receive more than one treatment type

was started and stopped. Research staff who conducted the interviews developed initial rapport with participants during the screening calls.

Oncologists reported failed screening for a small number of patients who were above the age limit ( $n = 6–8$ ) or not fluent in spoken and written English ( $n = 1$ ). Oncologists referred a total of  $n = 30$  eligible patients who were willing to be contacted about the study. Research staff attempted to

contact  $n = 25$ , and of those patients,  $n = 5$  were not reachable after three contact attempts and  $n = 2$  were no longer interested after learning more about the study. A total of  $n = 18$  (72% of those contacted) agreed and completed the interview.

## Data collection

Trained research staff conducted one-on-one, semi-structured interviews in-person at the UWCCC prior to the onset of the COVID-19 pandemic ( $n = 5$ ; August–November 2019), and over the phone afterward ( $n = 1$ ; March 2020;  $n = 12$ ; October–December 2022). A trained PhD-level researcher with educational training in psychology and epidemiology, LCB, conducted the in-person interviews, while a trained MPH-level researcher and doctoral student with educational training in epidemiology and qualitative methods, MA, conducted the phone interviews. Researchers were female and had personal experience participating in collegiate sports and physical activity.

Interviews were recorded with permission from each participant and transcribed verbatim by a research assistant (MR). Research staff (LCB, MA) wrote field notes during the interviews. The interviews were expected to last 30 min, and the mean duration of the interviews was 31 min (range = 21 – 43 min). Participants were given \$40 as a token of appreciation for their time. Data on the participants' demographics (age group, education level, gender identity, and race) were collected at the end of the interview.

## Data analysis

A reflexive thematic approach was used as it allowed for flexibility of using a theoretical framework (deductive), the Social Cognitive Theory, as a lens to both develop the line of inquiry and situate as researchers, while allowing the ability to develop our analysis inductively (data-driven) to share the perspectives of people living with advanced cancer [27–29]. A constructivist epistemological position was taken which recognized the co-construction of meaning produced by the researcher and participant [30, 31]. Subjectivity of the researcher and insider knowledge about physical activity were considered resources for this research [30].

The analysis began with the first author (MA) familiarizing herself with the data through listening to each interview and ensuring the accuracy of the transcripts [27, 32]. MA and MR open coded three transcripts with variation in cancer type to generate initial codes and met to discuss their initial findings. While both researchers independently coded the transcripts, they had regular research meetings to ensure codes were accurately capturing the data and discuss the evolving data structure and codes. MA developed a codebook to allow for ease of mapping the developing codes for both coders [33]. Recruitment

stopped when researchers reached thematic saturation and sampling targets of at least four patients per cancer type. Four patients per cancer type was selected a priori to meet qualitative

research recommendations for thematic saturation [34]. During the coding process, codes were condensed, deleted, or added to better reflect the data. MA reviewed the transcripts and codes

**Table 2** Representative Quotes of Major Themes

Major Themes	Representative Quotes	
Positive early life experiences with physical activity (PA) impact current attitudes and behaviors	<i>"I have always had good physical activity. I worked a lot and played ball and whatnot all my life. [...] Well, softball, baseball."</i> (Colorectal A, 60–69 years old)	
	<i>"I've always had physical jobs [...] lifting heavy parts [on] a daily basis, always active..."</i> (Colorectal B, 60–69 years old)	
	<i>"...I didn't have a lot of terrible side effects, but I was tired from it, and I lost some weight from it. So, I really just stopped doing any kind of regular working out during that time. I would say that probably lasted for five months where I kind of didn't feel like I wanted to work out. And then getting back into it, it was probably somewhat easier for me since I have been doing it my whole life, but I will say, that it kind of made me—it went two ways, one was I knew I had to do it because it was good for me to do—it would help my cancer diagnosis. And another was that I didn't know if my body was ready for it or not, so I started really slow and really easy."</i> (Breast A, 40–49 years old)	
	<b>Physical and mental health benefits of physical activity</b>	
	<i>"...believe it or not, it's relaxation to me. It clears my mind, makes my body feel better. It's a goal that I want to continue reaching."</i> (Prostate B, 60–69 years old)	
	<i>"...[swimming] for me it's almost like just a sign of meditation or kind of like a meditation."</i> (Breast D, 70–75 years old)	
	<i>"Well, I certainly feel like it could improve my health. There's no doubt about it, I would be stronger and safer, you know? I'd be happier mentally and I [ould] do more things."</i> (Myeloma A, 60–69 years old)	
	<i>"Oh, I feel like it would improve my health for sure, because I just feel better about myself. I've gained a lot of weight which I also somewhat attribute to the steroids, but also, it's probably just having to deal with everything."</i> (Myeloma B, 40–49 years old)	
	Coping with changing physical abilities	<b>Treatment and cancer side effects</b>
		<i>"...I used to have a lot more stamina. But with the cancer and stuff and the strength—so, I lost a lot of muscle mass and that's hard to get used to, but I can still do it if I want to. It may take a little bit longer, you know, to find different ways to do things."</i> (Prostate C, 60–69 years old)
<i>"...it's much more of a chore to go do something that I want to do than it was before. I can't say that I don't do the things that I like to do, it just takes me longer and I might not be everything exactly the way I used to."</i> (Myeloma D, 60–69 years old)		
<i>"...shooting pains would come up my legs all the way to my hips and my arms, you know, from my hands all the way up my arms, you know? They would wake me up and I just couldn't sleep."</i> (Colorectal B, 60–69 years old)		
<i>"...with the fractured vertebrae and these broken ribs, and so I was not doing a lot of anything because it hurt to move. I had to be dragged out of the chair. [...] I was walking with a walker, barely. So, that was certainly a big slow down."</i> (Myeloma A, 60–69 years old)		
<i>"I still get tired, but I have, you know, a few hours in there, where I can be quite busy and going and doing, but then by four or five o'clock, I have to stop. And that is not like me."</i> (Colorectal C, 50–59 years old)		
<b>Grappling with functional declines due to aging, cancer, treatment, or some combination of factors</b>		
<i>"I'm not steady on my feet like I used to be. And, like I said, I don't know if it's from the medicine or the age."</i> (Prostate D, 60–69 years old)		
<i>"I don't feel like I have the strength that I used to have. Once in a while, I am just like, wow, this isn't—I just don't have the juice in my joints, but I guess I don't feel as though my cancer has affected my activity, it's more my age."</i> (Breast C, 60–69 years old)		
Provider recommendation to engage in physical activity is important and encouraging		<i>"You don't know what to expect and, you know, you're thinking they told me you've got to keep active, you just gotta keep doing what you're doing, so that's what I kept doing."</i> (Prostate E, 60–69 years old)
	<i>"Well, they tell me to do what I can, you know, to try to stay active, which I do. I try not to be a total coach potato here; I get up and do things. I try to do a lot of housework, you know, vacuuming and whatnot when I can."</i> (Colorectal A, 60–69 years old)	
	<i>"They encourage me to—both my nurse practitioner and my oncologist are like just if you even just walk every day, it will do wonders."</i> (Myeloma B, 40–49 years old)	
	<i>"Well, they want me to get up and walk and be active and I'm trying to do that. You know, sometimes you've just gotta drive yourself to do it, like I said, and it's hard, you know? But, like I said, I'm an outdoorsman. I have a yard, a big garden, I mean I'm always outside and putzing and doing something probably maybe not as physically demanding as it should be, but I go until I get tired and then I sit down."</i> (Prostate D, 60–69 years old)	
	<b>Recommended resources and referrals are needed</b>	
	<i>"When I was first diagnosed, I said, 'what should I do to help myself', and she said, 'keep yourself healthy', and I said, 'what would that mean for me? What would you suggest for me?' and she said, 'keep yourself healthy'. And I'll never forget that because I thought that's not enough."</i> (Breast C, 60–69 years old)	
	<i>"And [physical therapy] was tremendously helpful, strengthening the core and helping with my back issues with the fractures and everything."</i> (Myeloma A, 60–69 years old)	
	<i>"[Physical therapy] was something that we talked about while I was in the hospital. It was a consensus between me and the doctors to help me out. [...] it was something that I had to do to get better. It was no second thought with me [...] I was going to try to do it."</i> (Myeloma C, 70–75 years old)	

**Table 2** (continued)

Major Themes	Representative Quotes
Interventions should target activity goals	<p><b>Gaining strength and maintaining independence</b></p> <p>“I want to move and get around and go shopping when I need to go shopping and I can do it on my own. That’s good for me. I know there’s going to come a time when I can’t do that.” (Myeloma C, 70–75 years old)</p> <p>“And so, my goal would probably be to continue doing what I’m doing so that I’m able to keep doing it. You know, if you don’t use it, you lose it. Even though I’ve lost so much, but I’m maintaining what I have, and that’s the goal to me...” (Prostate C, 60–69 years old)</p> <p>“...that was the kinda the impetus to do the yoga thing because at least that’s what it’s all about is balance and I can make myself stronger without killing myself saying like ‘oh I have to run even though it makes me feel miserable,’ so that was the biggest thing, but yeah, I definitely think it would help my mental and physical well-being to just be more in balance and have a better physical activity.” (Myeloma B, 40–49 years old)</p> <p>“... ‘cause I’m afraid that if I don’t keep moving and doing things, that it’ll just– it’ll get worse, so I don’t want that to happen. You know, totally dependent on other people or something.” (Myeloma D, 60–69 years old)</p> <p>“...that has always been my goal is to go out jogging– going out and doing things. Stage four does not– there is no expiration date. You could live for a long, long time.” (Breast B, 60–69 years old)</p>
Importance of physical environment	<p>“I bike on roads because I live in [CITY] and there [are] no bike paths, so I go on a country road that is less traveled. I don’t like going on highways of course, you know, with the busy travel.” (Prostate E, 60–69 years old)</p> <p>“Oh, a ton of opportunities [for physical activity], there’s always something to do out here. You know, we mow about six acres of land.” (Prostate B, 60–69 years old)</p> <p>“To me, the neighborhood was not important. [...] I kinda value privacy and we wanted the acreage, so that was more important than having a neighborhood with sidewalks and stuff like that.” (Breast A, 40–49 years old)</p> <p><b>Sidewalks</b></p> <p>“I live on a country road that is not safe to walk on. [...] There is no edge and a lot of traffic.” (Colorectal C, 50–59 years old)</p> <p>“Well, we just had, a couple years ago, they put sidewalks in. So, it’s a very residential area, so there’s lots of places to walk. There’s a lot of parks. You know, I feel like it’s a safe place to live.” (Myeloma D, 60–69 years old)</p> <p>“Uh, the one direction I don’t go because the sidewalks are not very good. The other way, the sidewalk’s a lot flatter and less cracks.” (Colorectal B, 60–69 years old)</p> <p><b>Cold weather</b></p> <p>“I was thinking about joining a fitness club during the wintertime because it is getting colder and stuff like that just to work on my muscles. I got cardio down, but you know, the muscle part kind of worries me sometimes.” (Prostate E, 60–69 years old)</p> <p>“Other than me going to the store or to school to pick up the kids or to the park, I don’t go walking around through the park in the winter. I did in the summer when it was warm.” (Myeloma C, 70–75 years old)</p>

for preliminary themes after both coders coded the transcripts and developed the preliminary themes based on the codes and data relevant to our research question and theoretical framework. We reviewed the data associated with the preliminary themes and further refined them into themes and subthemes. We then defined the themes and MA created a thematic map to illustrate the relationships between themes and subthemes (Fig. 3) [28]. Participant quotes representative of each theme were identified to provide illustrative examples. Findings were presented to the UWCCC’s Statewide Community Advocacy Board to allow for reflections and insights from the local community affected by cancer [30, 31]. Coding was completed by MA and MR using Dedoose 9.0 software.

## Results

### Participant characteristics

Demographic and clinical characteristics of the participants ( $n = 18$ ) are provided in Table 1. The average age

of participants was 62 years (range: 42–74). Most of the participants identified as men (56%) and White (94%), and had a diversity of educational attainment. All of the participants were currently receiving one or more forms of treatment for their cancer including chemotherapy ( $n = 11$ ), hormone therapy ( $n = 6$ ), immunotherapy ( $n = 2$ ), bone modifying treatment ( $n = 3$ ), steroid injections ( $n = 2$ ), and/or had a stem cell transplant within the last 3 months ( $n = 1$ ). More than half of the participants reported engaging in physical activity on a regular basis ( $n = 10$ ).

### Major themes

Five major themes were identified. The first theme, *positive early life experiences with physical activity impact current attitudes and behaviors*, investigates the types of activities that participants engaged in over their lifetime (including before their cancer diagnosis) as well as the physical and mental health benefits of those activities. The second theme, *coping with changing physical abilities*, reflects discussions of how cancer and its treatment have

impacted participants' activity and specifically, grappling with changes in physical functioning due to cancer and/or aging. The third theme, *provider recommendation as important and encouraging*, describes the conversations participants recall having with their providers around physical activity and their importance for pursuing activity. The fourth theme, *interventions should target activity goals*, focuses on participants' specific goals of maintaining independence and gaining strength. The fifth theme, *importance of physical environment on physical activity decision making*, relates to the extent to which participants described features of their environment, such as sidewalks and weather, as important for engaging in physical activity. Representative quotes from the main text and additional quotes that were not placed in the main text can be found in Table 2.

### Theme One: Positive early life experiences with physical activity impact current attitudes and behaviors

Many of the participants discussed positive early life experiences with physical activity whether for team sports or leisure. Team sports were a common source of positive early life activity discussed by both male and female participants. A male participant stated, *"I have always had good physical activity. I worked a lot and played ball and whatnot all my life. [...] Well, softball, baseball."* (Colorectal A, 60–69 years old). Several participants described early life physical activity for leisure, like biking and hiking. Jobs requiring manual labor were also a source of physical activity for a few male participants, like a male participant living with colorectal cancer who stated, *"...I've always had physical jobs [...] lifting heavy parts [on] a daily basis, always active."* (Colorectal B, 60–69 years old).

Positive early life experiences with physical activity impacted participants' current attitudes towards physical activity as being beneficial for them despite reported illness-related barriers. One female participant spoke of how her chemotherapy treatment affected her physical activity, but her early life experiences with physical activity made it easier for her to resume being more active after her diagnosis:

*"...I didn't have a lot of terrible side effects, but I was tired from it, and I lost some weight from it. So, I really just stopped doing any kind of regular working out during that time. I would say that probably lasted for five months where I kind of didn't feel like I wanted to work out. And then getting back into it, it was probably somewhat easier for me since I have been doing it my whole life, but I will say, that it kind of made me-- it went two ways, one was I knew I had to do it because*

*it was good for me to do-- it would help my cancer diagnosis. And another was that I didn't know if my body was ready for it or not, so I started really slow and really easy."* (Breast A, 40–49 years old).

Specifically, participants with positive early life experiences freely spoke about the mental and physical health benefits (e.g., relaxation and increased energy) they experienced when they engaged in activity on a regular basis. A male participant with prostate cancer discussed the physical and mental benefits of physical activity, describing it as *"... believe it or not, it's relaxation to me. It clears my mind, makes my body feel better. It's a goal that I want to continue reaching."* (Prostate B, 60–69 years old).

Although some participants reported not engaging in much current activity, they still spoke of the many positive effects and thought that if they were more active, it would be beneficial for their mental and physical health. One female participant with myeloma discussed how she thought getting more exercise could improve her mental health and self-esteem, *"Oh, I feel like it would improve my health for sure, because I['d] just feel better about myself. I've gained a lot of weight which I also somewhat attribute to the steroids, but also, it's probably just having to deal with everything."* (Myeloma B, 40–49 years old).

### Theme Two: Coping with changing physical abilities

Most participants discussed coping with changes in physical functioning from their cancer and side effects of treatments. Participants discussed some common functional changes including increased fatigue, weakness, pain, and neuropathy. One male participant discussed how he'd noticed a reduction in his stamina and strength which made him change how he did things:

*"...I used to have a lot more stamina. But with the cancer and stuff and the strength-- so, I lost a lot of muscle mass and that's hard to get used to, but I can still do it if I want to. It may take a little bit longer, you know, to find different ways to do things. More with equipment or machinery, you know?"* (Prostate C, 60–69 years old).

A female participant with myeloma expressed a similar sentiment that she couldn't do things in the same way as she did prior to her cancer diagnosis, *"...it's much more of a chore to go do something that I want to do than it was before. I can't say that I don't do the things that I like to do, it just takes me longer and I might not be everything exactly the way I used to."* (Myeloma D, 60–69 years old).

Pain and neuropathy were more frequently discussed by participants with colorectal cancer and myeloma. A participant living with colorectal cancer explained how he



was struggling with related changes to his physical function, “shooting pains would come up my legs all the way to my hips and my arms, you know, from my hands all the way up my arms, you know? They would wake me up and I just couldn’t sleep.” (Colorectal B, 60–69 years old). These challenges with pain were particularly apparent for myeloma participants due to bone fractures. One woman discussed the impact of her disease on her bone integrity which led to fractures, and in turn, severe pain, “with the fractured vertebrae and these broken ribs, and so I was not doing a lot of anything because it hurt to move. I had to be dragged out of the chair. [...] I was walking with a walker, barely. So, that was certainly a big slow down.” (Myeloma A, 60–69 years old).

During several of the interviews, participants discussed the challenge of accurately attributing declines in physical functioning to aging, cancer, treatment, or some combination of factors. The following example illustrates a participant describing his uncertainties, “I’m not steady on my feet like I used to be. And, like I said, I don’t know if it’s from the medicine or the age.” (Prostate D, 60–69 years old). Others discussed how it had been a few years since their diagnosis and they expected some decline in their activities as they got older. In contrast, a few participants discussed how they thought their decline in ability was due to aging, not their cancer. One participant with breast cancer discussed how she thought most of her decline in mobility was due to aging and her lack of exercise, but not her cancer:

*“I don’t feel like I have the strength that I used to have. Once in a while, I am just like, wow, this isn’t-- I just don’t have the juice in my joints, but I guess I don’t feel as though my cancer has affected my activity, it’s more my age.”* (Breast C, 60–69 years old).

### Theme Three: Provider recommendation as important and encouraging

For those participants who discussed having a conversation with a member of their oncology care team about physical activity, a provider recommendation to be active was seen as important and encouraging. Almost all participants mentioned having conversations with their providers about physical activity. One male with prostate cancer described the following recommendation, “You don’t know what to expect and you know you’re thinking they told me that you’ve got to keep active, you just gotta keep doing what you’re doing, so that’s what I kept doing.” (Prostate E, 60–69 years old). Another male participant recounted how his providers discussed activity with him and how these conversations encouraged him to try to remain active:

*“Well, they tell me to do what I can, you know, to try to stay active, which I do. I try not to be a total coach*

*potato here; I get up and do things. I try to do a lot of housework, you know, vacuuming and whatnot when I can.”* (Colorectal A, 60–69 years old).

When asked about whether they received information from their providers about physical activity, several participants described the general recommendation from their providers to “stay active” which encouraged them to do so. Those participants who were already active felt as if they had what they needed and encouragement from their provider was sufficient to continue to engage in physical activity.

A few participants made it clear that they were the ones to bring up the topic of physical activity with their providers to ask for advice. They noted feeling as though their clinicians did not provide them with resources or enough information. For example, a woman with breast cancer recalled a time when she asked her provider about ways to keep herself healthy and felt like she didn’t receive adequate information:

*“When I was first diagnosed, I said, ‘what should I do to help myself?’, and she said, ‘keep yourself healthy’, and I said, ‘what would that mean for me? What would you suggest for me?’ and she said, ‘keep yourself healthy’. And I’ll never forget that because I thought that’s not enough.”* (Breast C, 60–69 years old).

Participants with myeloma mentioned that their providers encouraged them to be active but advised caution in their activities. In addition, all participants with myeloma discussed their oncologist’s referral to physical therapy as an important resource for them to either maintain strength before treatment or increase their strength after treatment. One woman with myeloma discussed her experience with physical therapy and how helpful it was for her, “And [physical therapy] was tremendously helpful, strengthening the core and helping with my back issues with the fractures and everything.” (Myeloma A, 60–69 years old).

### Theme Four: Interventions designed to help adults living with advanced cancer meet their goals are needed

In terms of activity goals for the future, most participants spoke of wanting to maintain a certain level of independence for as long as possible. One male participant with myeloma discussed his goal of wanting to do things on his own, like shopping. He stated, “I want to move and get around and go shopping when I need to go shopping and I can do it on my own. That’s good for me. I know there’s going to come a time when I can’t do that.” (Myeloma C, 70–75 years old). Another male participant with prostate cancer described his goal of wanting to maintain what he’s doing:

*“And so, my goal would probably be to continue doing what I’m doing so that I’m able to keep doing it. You*

*know, if you don't use it, you lose it. Even though I've lost so much, but I'm maintaining what I have, and that's the goal to me...*" (Prostate C, 60–69 years old).

Many participants also discussed the goal of gaining strength. A woman living with myeloma described how she'd like to make herself stronger and more in balance through yoga:

*"...that was the kinda the impetus to do the yoga thing because at least that's what it's all about is balance and I can make myself stronger without killing myself saying like 'oh I have to run even though it makes me feel miserable,' so that was the biggest thing, but yeah, I definitely think it would help my mental and physical well-being to just be more in balance and have a better physical activity."* (Myeloma B, 40–49 years old).

In addition, a few participants discussed wanting to get back to activities they previously enjoyed, such as playing with their grandchildren and light-intensity activities like bowling. Although some participants discussed goals in the context of the goal question, others described goals in response to the question on how physical activity might improve or worsen health. For example, one woman with myeloma responded that she was afraid of becoming totally dependent on other people due to health declines, something she did not want. She explained, *"...I'm afraid that if I don't keep moving and doing things, that it'll just—it'll get worse, so I don't want that to happen. You know, totally dependent on other people or something."* (Myeloma D, 60–69 years old).

### **Theme Five: Importance of physical environment on physical activity decision making**

Participants were asked several questions about their neighborhood environment to better understand their access to opportunities for physical activity close to home and perceived importance of their neighborhood's conduciveness for physical activity. Responses to these questions were mixed, with some participants feeling that the traffic and lack of sidewalks in their neighborhood were problematic for engaging in physical activity while others reported that their neighborhood did not impact their physical activity because they did their activity indoors. One male participant discussed that he chooses to bike on roads with less traffic, noting, *"I bike on roads because I live in [CITY] and there [are] no bike paths, so I go on a country road that is less traveled. I don't like going on highways of course, you know, with the busy travel."* (Prostate E, 60–69 years old). Another male said he doesn't feel safe due to the lack of a shoulder on the road and too much traffic, stating, *"I live on a country road that is not safe to walk on. [...] There is no edge and a lot of traffic."* (Colorectal C, 50–59 years old).

Sidewalks were the most reported feature of participants' access to opportunities to be active. One participant with myeloma described how sidewalks make it accessible and safe for walking, stating, *"...a couple years ago, they put sidewalks in. So, it's a very residential area, so there's lots of places to walk. There's a lot of parks. You know, I feel like it's a safe place to live."* (Myeloma D, 60–69 years old). One participant discussed how he chooses to walk in one direction due to the condition of sidewalks in his neighborhood, noting, *"...the one direction I don't go because the sidewalks are not very good. The other way, the sidewalk's a lot flatter and less cracks."* (Colorectal B, 60–69 years old). Interestingly, a few participants who lived in rural settings felt that where they lived was "walkable" because they enjoyed walking on their own property and didn't have concerns about traffic or lack of sidewalks when considering their activities.

Cold weather was another environmental factor that impacted participants' physical activity. This type of environmental barrier to activity is an important consideration in Wisconsin and other temperate climates. One participant discussed wanting to join a fitness club in the winter to manage the cold, stating, *"I was thinking about joining a fitness club during the wintertime because it is getting colder and stuff like that just to work on my muscles."* (Prostate E, 60–69 years old). In another interview, a participant mentioned avoiding walking outside in winter, only doing so *"in the summer, when it was warm"* (Myeloma C, 70–75 years old).

## **Discussion**

### **Major themes**

Our study sought to assess cognitive (knowledge, attitudes, expectations), behavioral (skills, practice, self-efficacy), environmental (social norms, access), and other factors that influence physical activity in adults living with advanced cancer. We found that participants recounted positive early life experiences with physical activity, current challenges coping with their illness and treatment side effects, and common goals for future activity. To our knowledge, this is the first study to investigate both individual and contextual factors that may impact physical activity decision making among adults living with several types of advanced cancer in the US.

We found that most participants discussed engaging in some form of physical activity during early life (e.g., team sports, general activities for fun like biking and walking, or manual labor jobs), not just for formal exercise. Already having experience engaging in regular physical activity can lead to a higher self-efficacy for exercise

(i.e. behavioral factor) which is an important predictor of engagement in future in physical activity, according to the Social Cognitive Theory [23, 25]. In addition, these past experiences can influence one's knowledge, attitudes, and expectations (i.e. cognitive factors) towards the behavior of physical activity [23, 25]. Positive early life experiences with physical activity impacted participants' current beliefs about the benefits of physical activity despite reported barriers imposed by their illness and side effects of treatment. Further, currently inactive participants who spoke about the positive physical and mental health benefits of activity were interested in engaging in activity to reap those benefits. A study by Bland et al. (2022) found that exercise offered people with advanced cancer and cachexia psychological benefits such as improved mood and served as an emotional outlet to help take one's mind off their diagnosis. Similarly, patients in our study spoke of the various mental health benefits of being active whether from exercise or participation in activities of daily living [35].

When designing an appropriate physical activity intervention for this population, it is important to consider multiple potential drivers (e.g., aging, the cancer itself, treatment side effects) of declining physical functioning. If patients consider their declining function as a normal aspect of aging, they may be less likely to bring them up to their oncology care team as concerns related to side effects of treatment or symptoms of their cancer. In certain cases, some of these declines can be treated by therapies such as physical therapy (PT) or occupational therapy (OT). If patients discuss these concerns, specifically declines in balance and strength, an oncology care provider could make a necessary referral and it's possible that these deficits could be reduced. In addition, cases where cancer may be causing pain could be treated using palliative modalities and referral to a palliative care provider might be warranted. Accelerated aging is also a necessary consideration among this population as they may experience greater physical declines compared to similarly aged individuals as a result of intensive and ongoing cancer treatments [36, 37].

For patients who may not be as familiar with physical activity, a provider recommendation from the oncology care team along with resources and/or referrals to get them started may be needed. Social support for physical activity, especially from a healthcare provider, was seen as motivating for some participants, and could reinforce already established positive beliefs about the importance of physical activity (i.e., environmental factor—social norms) [35]. A qualitative study by Chang et al. (2020) focused on people living with metastatic lung cancer and similarly found that physician social support was critical to encourage patients with advanced cancer to exercise [38]. Other research has

shown that recall of physical activity advice from a provider after diagnosis with colorectal cancer was associated with higher levels of physical activity [39]. Among a sample of adults living with breast, prostate or blood cancer in England, patients discussed a lack of guidance and appropriate resources, such as exercise classes, as a barrier to activity [40]. A few participants in our study described not receiving enough information on physical activity from their providers, so acknowledging the significance of targeted resources and referrals from providers is a critical next step. Incorporating social support for physical activity from a member of an oncology care team could be a critical piece of any physical activity intervention designed for patients with advanced cancer. Since many of the participants reported how highly they valued their care team in other parts of the interview, a recommendation from a member of their care team could be vital to the success of a patient's attempt(s) to engage in more physical activity. It is important to note that this type of recommendation may be more impactful and important for patients not engaging in any activity and who have less prior experience engaging in activity than some of the participants in our sample. Among the sample with myeloma, a referral to physical therapy was viewed as an important factor in maintaining strength before or increasing strength after treatment.

It is imperative to tailor a physical activity intervention to meet the target population's physical activity goals. A study by Phillips and McAuley (2013) found goals, outcome expectations, and social support influenced physical activity among a sample of long-term breast cancer survivors [24]. Goals provide motivation and can give the participant a sense of control, and in the case of adults living with advanced cancer, there is a lack of control in other aspects of their lives making this a key component of a future intervention [25]. Many of the participants discussed the goal of wanting to maintain independence for as long as possible, and this was true especially among older participants. An overall desire to improve strength to maintain independence and feel stronger was also discussed by several participants across the age spectrum of our sample.

Participants openly discussed barriers to physical activity including those caused by side effects of their treatments and their cancer. Similar to findings in a sample of Canadian adults living with advanced cancer from Shallwani et al. (2023), we found many participants were impacted by barriers of fatigue, neuropathy, and pain [41]. A fear of increased risk of falls and subsequent fractures was also discussed by our sample of patients living with myeloma [41, 42]. A survey study of outpatients with metastatic cancer in Germany by Frikkel et al. (2020) found physical symptoms and fatigue as major barriers to physical activity as well [43]. Interestingly, a lack of interest in an exercise program was reported

by 53% of patients with metastatic cancer, which we did not find to be a major barrier to physical activity in our sample of adults with advanced cancer [43]. While most individuals with advanced cancer were interested in physical activity, side effects of treatment and cancer were the major barriers to engaging in physical activity.

An important contribution of our study was the consideration of both individual-level barriers to physical activity among people living with advanced cancer and contextual barriers, such as relevant aspects of the neighborhood environment. We hypothesized that the neighborhood's conduciveness for activity would be important for this population since light-intensity activities, like walking, may be preferred based on existing literature [35, 42]. Overall, some participants felt that their neighborhood was an important factor, particularly the presence of sidewalks for walking, but some participants who lived in rural environments considered their own property to be equally safe or safer with natural spaces and no traffic. The importance of access to exercise facilities (i.e., environmental factor – access in community) was not mentioned by many of the participants because they either already had space in their home or on their property to be active or were able to drive to bike paths and other locations that suited their needs [44]. In terms of safety for exercising outdoors, the importance of the availability of bike paths and sidewalks for walking that are separated from traffic was discussed by a few participants [44, 45]. In a small study of female cancer survivors, DeGuzman et al. (2019) found that regular activity was supported by access to walking paths and visual variety in the built environment [45]. Although not a major theme identified in our study, some participants discussed the varied terrain and parks as pleasurable environments for walking in their neighborhoods. In addition to neighborhood, several participants reported the cold weather as a common barrier, which is consistent with other studies investigating physical activity among people with advanced cancer and the general population [46, 47].

### Strengths and limitations

One major strength of our study is that participants were diverse in terms of gender, age, cancer type, and treatments received, which allowed for capturing a wide range of experiences among participants. Another major strength was using a theory-informed interview guide so we could better capture the scope of individual- and neighborhood-level factors that may influence one's engagement in physical activity.

Our sample may be subject to selection bias on the part of the clinician identifying patients to recruit into study. We asked clinicians to recruit both active and inactive patients in terms of physical activity, however, it is possible that

clinicians chose to approach those patients who were more likely to engage in physical activity. We had diversity in our responses to questions about current physical activity engagement, prior experiences with physical activity, and future activity goals, so we do not expect this to be a major source of bias in our sample. Another possible source of selection bias is that patients more interested in physical activity may have agreed to participate in the study as opposed to those who decided not to participate, however only five patients declined to participate after agreeing to be screened; three patients did not respond to multiple contact attempts and two patients decided they were no longer interested during screening.

### Conclusions

Despite participants reporting numerous cancer- and treatment-specific barriers to physical activity, some adults living with advanced cancer were still participating in physical activity. Most of the adults living with advanced cancer, regardless of current activity level, were interested in engaging in activities to meet their goals of gaining strength and maintaining independence. Some participants also described a desire to get back to pre-diagnosis activities, such as playing with their grandchildren and light intensity activities like bowling.

Having a conversation with a provider from their cancer care team about physical activity was seen as important and encouraging for pursuing some activity. Most of the participants who spoke about physical activity with a provider were already pursuing some activity and discussed the important physical and mental health benefits of physical activity. To ensure that all patients are encouraged to be active, including those with limited engagement in physical activity and those who lack self-efficacy, more direct resources and motivational referrals are needed. Further, there is a need for physical activity interventions designed to meet the unique needs of adults living with advanced cancer, specifically to help them meet their goals of maintaining independence and gaining strength.

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**Data Availability** The data generated and analyzed in this study are not publicly available due to the sensitive nature of interview transcripts. Additional information may be made available upon request by contacting the corresponding author.

## Declarations

**Ethics approval and consent to participate** This study was conducted in accordance with the 1964 Declaration of Helsinki and its later amendments. It was approved as minimal risk by the University of Wisconsin-Madison's Minimal Risk Institutional Review Board (Protocol #2019-0767) and by the Carbone Cancer Center's Protocol Review and Monitoring Committee (Protocol UW18135).

**Consent to participate and publish** An IRB approved study information sheet was available for patients before completing the written permission to contact form. Individuals provided verbal consent by agreeing to participate following a study explanation during the screening call.

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