RESEARCH

Trajectories of participation in daily life among individuals newly diagnosed with cancer: A 5-month longitudinal study

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Abstract

Purpose To determine how participation in daily life is impacted during the first six months following a new cancer diagnosis and to identify risk factors for participation restrictions. Patient-reported outcomes (PROs) were used to suggest referrals to rehabilitation services.

Methods Participants ($n = 123$) were adults (> 18 years) with the newly diagnosed primary brain, breast, colorectal, or lung cancer. PROs were collected at baseline (within 30 days of diagnosis/treatment initiation), two and five months post baseline. Daily life participation was assessed through the community participation indicators (CPI) (score range: 0–1) and patient-reported outcome measurement information system (PROMIS) ability to participate, (score range: 20–80; mean: 50, SD: 10). PROMIS-43 profile was also completed. Linear mixed-effect models with random intercept evaluated change in participation over time.

Results The baseline total sample mean CPI score was 0.56; patients reported mildly impaired participation based on PROMIS scores (baseline: 46.19, 2-month follow-up: 44.81, 5 months: 44.84). However, no statistically significant changes in participation were observed over the study period. Risk factors for lower participation included receiving chemotherapy, lower physical function, higher anxiety and fatigue, and reduction in employment, $p < 0.05$. PROs indicated that roughly half of the participants may benefit from physical or occupational therapy or mental health support, but only 20–36% were referred by their medical team.

Conclusion People newly diagnosed with cancer experience impaired participation, but they are infrequently referred to supportive services such as rehabilitation. The use of PROs to assess participation, physical function, and mental health can promote access to supportive care services by identifying patients who may benefit from rehabilitation beyond those identified through routine clinical care.

Keywords Cancer · Rehabilitation · Quality of life · Patient-reported outcome measures

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Daily life participation, defined as doing what an individual finds important or meaningful in their daily life, is a priority among people living with and beyond cancer [1]. However, participation is rarely included in outcome assessments or clinical care [2–4]. The lack of focus on participation may relate to underdetection and treatment of cancer-related disability [5, 6]. There are a number of competing priorities in oncology care as providers work with patients to balance disease survival, treatment toxicities, and quality of life (QOL) [7]. Participation in daily life is another important area to address because it is prioritized by patients, can protect against cognitive decline, improve QOL, and decrease mortality [8–11].

Restricted participation is only one facet of disability; people with a cancer history can experience challenges in health domains such as physical function, cognition, and mental health [4, 12–18]. This multitude of potential challenges can make it difficult to comprehensively screen for impairments and refer patients to supportive services. Although some perceive biopsychosocial screening as burdensome, this comprehensive screening approach can enhance patient-provider communication and care efficiency, capture nuanced disease-related changes, and pinpoint patient priorities [19].

Comprehensive screening should include an assessment of daily life participation, but this is not common practice [4, 20, 21]. Using patient-reported outcome (PRO) measures is a promising approach to evaluating participation without increasing clinical burden. Evaluating participation can facilitate conversations between patients and clinicians about daily life challenges and support early intervention and referral to supportive services [4, 20, 22]. The current study prospectively examined the degree to which participation changes during the first six months after a new cancer diagnosis. We hypothesized that participation would decrease over time. Secondarily, we identified risk factors for participation restrictions and used PROs to suggest referrals to rehabilitation services.

Methods

Participants

Eligible participants were over 18 years old with a new primary diagnosis of brain, breast, colorectal, or lung cancer, able to read and understand English, had an email or phone number, and were able to communicate independently. Patients were enrolled within 30 days of initiating treatment or surgery for their diagnosis. A history of a different cancer type (e.g., prostate) did not exclude participants. We excluded individuals with cancer recurrence of the four included diagnoses, aphasia, or impaired cognition

inhibiting their ability to provide informed consent, as judged by the medical team.

To identify potential participants, we screened clinic lists and attended team rounds and in-person clinic visits. Medical team approval was provided prior to contacting patients. From March to September 2021, 228 of 271 eligible individuals were contacted by the study lead (AL) over the phone or in person during clinic visits to participate. All measures were completed at baseline (within 30 days of diagnosis/treatment start), two- and five-month follow-up. Most participants completed the measures online at home (Table 1); they received an email with a personalized survey link for all surveys. Family members/friends or a study team member supported survey completion when needed. Data were collected from March 2021 to February 2022. The institutional review board and protocol review and monitoring committee at Washington University in St. Louis School of Medicine approved this study.

Measures

The community participation indicators (CPI) evaluates participation in productive, social and community activities through self-report [23]. Scores range from 0 to 1; higher scores indicate participation in more important activities [24]. CPI was selected as the primary outcome because using comprehensive measures of participation (e.g. CPI) is essential to understand the scope of participation restrictions experienced by people with cancer [2]. Additionally, as part of the team's formative work, 40 cancer survivors with brain, breast, colorectal, and lung cancer were interviewed about their preferences for participation measures. These participants identified the CPI as the measure that would do the best job of capturing their daily life participation experiences. The CPI has been validated in a large sample of individuals with a variety of disabling conditions [23, 24] but has not been used within oncology. Following the CPI, patients completed a checklist reporting how cancer impacted their participation in daily life. For additional measurement properties see Online Resource 1.

The patient-reported outcome measurement information system [25] (PROMIS) is a measure of physical, mental, and social health validated with individuals recently diagnosed with cancer [26, 27]. Participants completed the PROMIS-43 profile (evaluates physical function, anxiety, depression, fatigue, sleep disturbance, ability to participate in social roles and activities, and pain interference and intensity) and supplemental items from the satisfaction with participation in social roles and discretionary social activities, instrumental support, and social isolation item banks. PROMIS T-scores have a mean of 50 and a standard deviation of 10; scores within five points of the mean are considered mild impairments and within 10 points are considered moderate

Table 1 Baseline characteristics of participants

	Total (n = 123)	Brain (n = 19)	Breast (n = 36)	Colorectal (n = 36)	Lung (n = 32)
Mean, SD (range)					
Age	59.0, 12.7 (21–82)	52.4, 14.9 (21–70)	59.3, 12.5 (39–77)	57.5, 13.0 (27–81)	64.4, 9.0 (45–82)
Charlson comorbidity index score	3.5, 2.1 (2–10)	2.1, 0.46 (2–4)	2.3, 0.86 (2–6)	4.1, 2.4 (2–10)	5.1, 2.2 (2–8)
n (%)					
Gender					
Female	78 (63)	9 (47)	36 (100)	17 (47)	16 (50)
Male	45 (37)	10 (53)	0	19 (53)	16 (50)
Race					
Asian	2 (2)	0	1 (3)	1 (3)	0 (0)
Black	15 (12)	1 (5)	8 (22)	3 (8)	3 (9)
White	106 (86)	18 (95)	27 (75)	32 (89)	29 (91)
Hispanic/Latinx	1 (1)	0	0	0	1 (3)
Highest level of education					
Less than high school graduate	4 (3)	0	0	1 (3)	3 (10)
High school graduate or GED	22 (18)	2 (10.5)	4 (11)	8 (22)	8 (25)
Associate degree	6 (5)	2 (10.5)	1 (3)	2 (6)	1 (3)
Some college	29 (24)	2 (10.5)	11 (30)	6 (16)	10 (31)
College graduate	41 (33)	9 (47.4)	10 (28)	14 (39)	8 (25)
Master's degree	21 (17)	4 (21.1)	10 (28)	5 (14)	2 (6)
Cancer stage					
0		N/A	3 (8)	0	0
I			20 (55)	1 (3)	4 (12.5)
II			11 (31)	5 (14)	4 (12.5)
III±			2 (6)	19 (53)	10 (31)
IV			0	11 (30)	14 (44)
Cancer grade±*					
I		0	Not extracted		
II		2 (11)			
III		3 (17)			
IV		13 (72)			
Cumulative treatment					
Surgery	79 (64)	19 (100)	35 (97)	15 (42)	10 (31)
Chemotherapy/Targeted therapy	84 (69)*	14 (74)*	14 (39)	31 (86)	25 (78)
Mean (SD) # days exposed to chemotherapy	120 (53)	112 (59)	108 (60)	126 (49)	122 (51)
Radiation	69 (57)*	16 (85)*	22 (61)	15 (42)	16 (50)
Mean (SD) total radiation dose (cGy)	4225 (1526)	5603 (633)	4038 (1198)	2806 (828)	4500 (1789)
Gamma knife	4 (3)	0	0	0	4 (13)
Hormone therapy	20 (16)	0	20 (56)	0	0
Mean # days exposed to hormone therapy		N/A	111 (range: 35–169)	N/A	N/A
Immunotherapy	6 (5)	0	1 (3)	0	5 (16)
Employment status[+]					
Full-time	36 (29)	2 (10)	12 (33)	11 (31)	11 (34)
Part-time	6 (5)	0	4 (11)	1 (3)	1 (3)
Unemployed	12 (10)	2 (10)	2 (5.5)	7 (19)	1 (3)
Medical leave	13 (10)	6 (32)	0	6 (17)	1 (3)
Disability	11 (10)	3 (16)	1 (3)	2 (5)	5 (16)
Retired	42 (34)	6 (32)	15 (42)	9 (25)	12 (38)

Table 1 (continued)

	Total (n = 123)	Brain (n = 19)	Breast (n = 36)	Colorectal (n = 36)	Lung (n = 32)
Other	3 (2)	0	2 (5.5)	0	1 (3)
Change in employment status since cancer diagnosis+					
Yes (typically decreased work)	41 (33.3)	10 (24)	6 (15)	14 (34)	11 (27)
No	41 (33.3)	3 (7)	16 (39)	13 (32)	9 (22)
Retired before diagnosis	41 (33.3)	6 (15)	14 (34)	9 (22)	12 (29)
Financial toxicity+					
(Has your physical condition or medical treatment caused you financial difficulties?)					
Not at all	54 (44)	7 (37)	23 (64)	13 (36)	11 (34)
A little bit	47 (38)	8 (42)	9 (25)	14 (39)	16 (50)
Quite a bit	15 (12)	2 (10.5)	3 (8)	5 (14)	5 (16)
Very much	7 (6)	2 (10.5)	1 (3)	4 (11)	0
Mode of survey completion					
Online	93 (76)	17 (90)	32 (89)	26 (72)	18 (56)
Paper forms	18 (14)	2 (10)	1 (3)	5 (14)	10 (31)
Online or paper forms at cancer center	10 (8)	0	2 (5)	5 (14)	3 (10)
Read to participant	2 (2)	0	1 (3)	0	1 (3)

±Tumor grade extracted only for brain tumor group

*Tumor stage, chemotherapy, and radiation data unknown for one participant in the brain tumor group due to transfer of care to outside hospital not linked to the cancer center's electronic medical record

+Time-varying variables; data from last completed survey reported

impairments [28]. Participation domains are detailed in this report; other PROMIS domains were tested as covariates in longitudinal analyses. CPI and PROMIS items were completed at all time points. Participants were provided with up to three reminders when they did not return follow-up surveys.

The total assessment battery was expected to take approximately 30 min to complete. Participants self-reported demographics, change in employment status since diagnosis/last survey, financial toxicity (single item from EORTC quality of life questionnaire-C30 [29]), use of mobility support, and comorbidities, measured by the Charlson comorbidity index (CCI) [30]. CCI score was dichotomized in the analysis to scores > 2 and ≤ 2 to compare individuals with additional comorbidities beyond their cancer diagnosis to those without. Referrals to rehabilitation or mental health services since diagnosis were reported by the participant and cross-checked in the medical record during extraction of treatment and disease history.

COVID-19

For the 20 areas of participation on the CPI, follow-up questions were added to further elucidate the impact of cancer versus COVID-19 on participation. Participants used a sliding bar (electronic version) or placed an "x" on a line to rate how much (1) cancer and the side effects of treatment and (2) COVID-19 have impacted how often they do each activity. The sliding scale ranged from 0 (doing much less) to 100 (doing much more); 50 indicated no change. To summarize these data, mean impact ratings were calculated. Of note, this was the area where the most missing data existed. Furthermore, some participants shared with the research team that they did not understand why/did not want to rate the impact of COVID-19 because COVID-19 had not impacted their life. Following the CPI, participants were asked: "Do you believe COVID-19 has had an additional impact on your daily life participation beyond the impact of cancer?" with response options of yes, no, and unsure.

Statistical Analysis

Baseline characteristics between disease groups and individuals who were lost to follow-up versus those who were not were compared using independent sample t-tests, one-way ANOVA, or chi-square tests, as appropriate. To compare means between the disease groups at each time point, one-way ANOVA was performed.

Linear mixed-effect regression model with random intercept was used to assess change in mean participation between the disease groups over time using SAS PROC MIXED. Separate models were created for the primary and secondary outcomes. Continuous variables were grand mean centered. An initial model including time, group, and their

interaction was used to examine changes over time between groups. For multivariable models, potential effect modifiers (age, diagnosis group by age interaction) and confounding variables (comorbidities) were entered into the model one at a time. A variable was considered an effect modifier when $p < 0.05$ and a confounder when beta estimates changed by more than 10% with the addition of the variable.

To identify risk factors for participation restrictions over time, linear mixed-effect longitudinal modeling was used. Univariate analyses were first run where models were constructed as a function of time since baseline, group, time by group interaction, and each predictor. When univariate analyses were significant ($p < 0.05$), exploratory variables were entered into the longitudinal model one at a time using backward selection to identify the most parsimonious model. Clinically important predictors were included in the multilevel longitudinal model regardless of significance (Online Resource 2). Missing data were minimal and were left as missing because multilevel models are robust to missing data. Additional information on sample size calculation is in Online Resource 3.

PRO findings were used to identify participants who may benefit from rehabilitation. When PROMIS physical function, participation, or mental health domains were more than one standard deviation from the mean, referrals were suggested to the patient and their medical team for physical therapy (PT), occupational therapy (OT), and mental health support, respectively. OT was also suggested when the CPI score was below an identified cut point of 0.60 based on data from previous research [24, 31] and our preliminary data from survivors. See Online Resource 4 for an overview of the study processes.

Results

We recruited 123 participants with the newly diagnosed brain ($n = 19$), breast ($n = 36$), colorectal ($n = 36$), and lung (32) cancer. Ninety-nine (80%) completed measures for all three-time points (Fig. 1). The attrition rate was 20%; 58% lost to follow-up and 42% died or transitioned to hospice. The participant's mean age was 59 years. Half had a college education or higher, 63% were female, and 86% reported White race (Table 1). There were no notable differences between group participant characteristics except for higher age in the lung cancer (mean: 64.4, SD: 9.0) compared to the brain cancer group (mean: 52.4, SD: 14.9). Financial toxicity was significantly higher (Cramer's $V = 0.28$, $p = 0.019$) for participants under 65 years old (63% with strain) compared to those over 65 (34% with strain) at their last completed survey (5-month follow-up or ceased study participation).

The difference in participation by cancer type at each time point

Baseline participation scores for the total sample were 0.56 for CPI and 46.19 for PROMIS ability to participate (Fig. 2a, b). There were no statistically significant differences in average participation based on cancer type at baseline or follow-up. However, patients with breast and colorectal cancer demonstrated median participation scores within the mildly impaired range at all time points, including baseline (Fig. 2b). The lung cancer group demonstrated mildly impaired participation at two and five-month follow-up. Average participation by diagnosis group across time for all participation domains is available in Online Resource 5.

Change in participation over time

The initial models, including the outcome (CPI or PROMIS) as a function of time, group, and group-by-time interaction, were not significant, indicating there were no differences in participation over time between individuals of different cancer types. Adjusted analyses did not identify age or age by diagnosis group interaction as effect modifiers ($p > 0.05$) or comorbidity as a confounding variable (Table 2). Initial model intraclass correlation coefficients (ICCs) were 0.44 (CPI) and 0.57 (PROMIS), indicating that patients demonstrated considerable heterogeneity in participation scores.

Risk factors for participation restrictions

Following univariate analyses (Online Resource 6), higher fatigue and change in employment since cancer diagnosis were identified as risk factors for lower participation over time as measured by CPI (Table 3; ICC = 0.46). For PROMIS, a diagnosis of lung or brain cancer and higher physical function was associated with higher participation. Receiving chemotherapy/targeted therapy, higher anxiety or fatigue, and being referred to rehabilitation services by the medical team were significant predictors of lower participation (Table 3; *ICC* = 0.47).

Consistent with longitudinal model findings that fatigue is a risk factor for participation restrictions, when participants reported factors that made it challenging to participate in daily life, fatigue was most frequently endorsed (Baseline: 61%, 2-month follow-up: 77%, 5 months: 78%). While patients endorsed numerous factors that negatively impacted their daily life participation (e.g., pain, psychosocial challenges, bathroom urgency), more than half also endorsed that cancer changed their outlook on life and resulted in a greater appreciation for the activities they do (Online Resource 7).

Fig. 1 Study CONSORT diagram outlining participant enrollment and retention
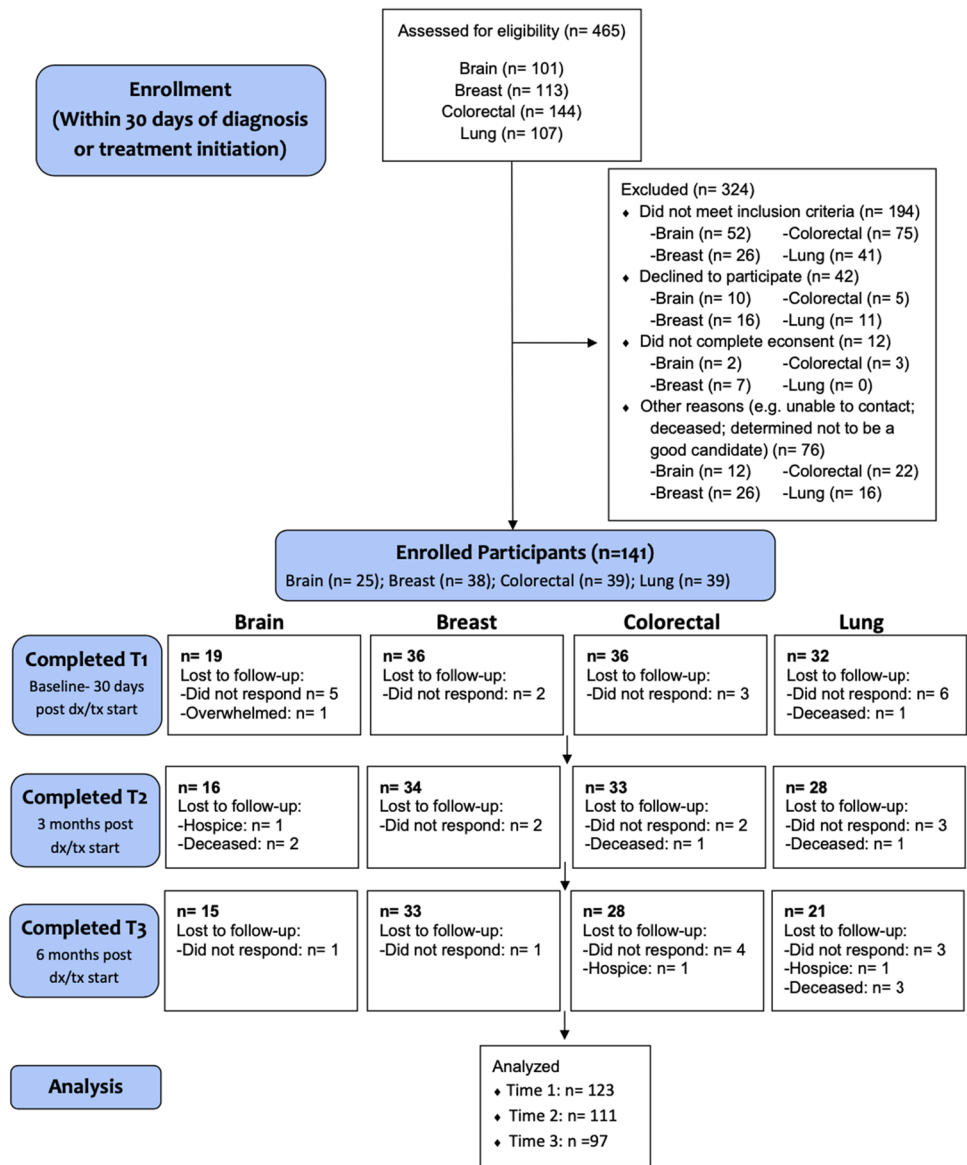

Rehabilitation referrals

Most participants were not referred to rehabilitation services (Fig. 3a). Speech-language pathology received the lowest number of referrals (9%), followed by mental health (18%). One-third of those referred to PT (41% of the total sample referred) and half referred to OT (33% of the total sample referred) were referred for a one-time postoperative inpatient evaluation but no ongoing services. PROs identified 53% of the sample may benefit from OT or PT and 45% from mental health support (Fig. 3b, green and gray bars). However, only 20% of individuals with PRO scores indicating a potential need for OT were referred (Fig. 3b, gray portion of the bar). Similarly, 31% of those who may benefit from PT and 36% of those who may benefit from mental health support had been previously referred by their medical team. Based on

PROs, 133 new referrals were suggested for supportive services: 45 PT, 52 OT, and 36 mental health. Individuals with brain tumors were significantly more likely to be referred to and/or utilize PT and OT by their medical team compared to all other disease groups (79% and 74% referred, respectively, $p < 0.01$), and males were more likely to be referred to and/or utilize OT than females (47% versus 26%, $p < 0.05$). Based on PROs, males (36% versus 53% of females referred, $p = 0.05$) and those reporting Black race (20% versus 51% reporting White race referred, $p = 0.03$) were significantly less likely to be referred to mental health support. Retirees were less likely to have PRO scores indicating a referral to PT or OT than unemployed individuals (PT: 49% retired versus 70% unemployed; OT: 47% retired versus 76% unemployed, $p < 0.05$). There were no differences in referrals from the medical team or based on PRO scores by disease stage.

Fig. 2 **a** Change in community participation indicator score over time by the diagnosis group. **b** Change in PROMIS ability to participate score over time by the diagnosis group
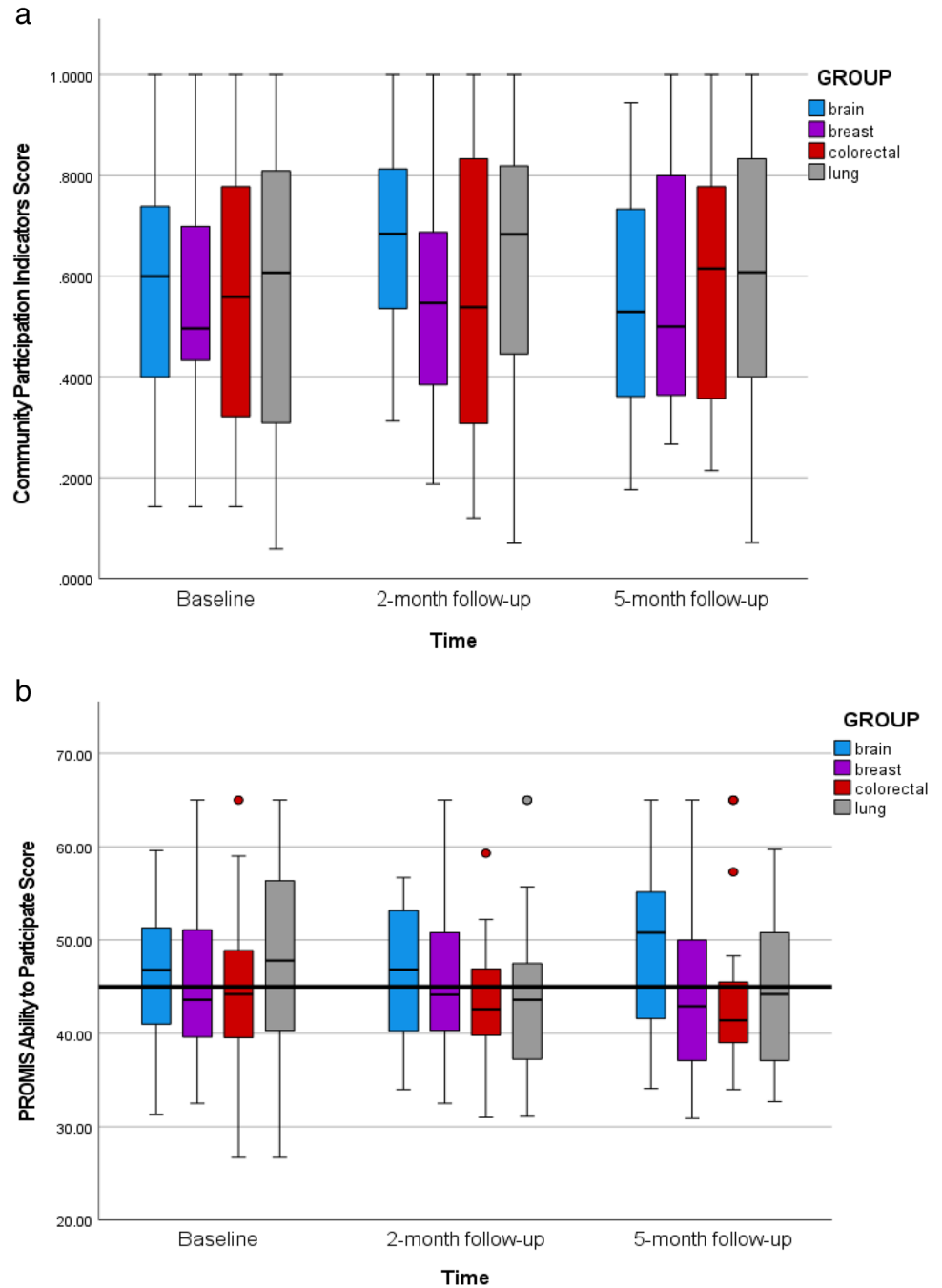
COVID-19 impact

The total sample average baseline cancer impact rating was 39.07, and COVID-19 impact rating was 39.41, indicating that those who responded experienced similar levels of impact on their participation from cancer and COVID-19 (Online Resource 8). At baseline, 71 participants (58%) reported that COVID-19 had an additional impact on their participation beyond the impact of cancer alone. Forty (33%) reported no impact of COVID-19 on their participation, and 10 (8%) were unsure (Online Resource 8).

Discussion

This is the first study, to our knowledge, to prospectively evaluate participation in a cohort of adults with various solid tumors. In the first six months after a new cancer diagnosis, patients reported mildly impaired ability to participate in social roles and activities. Mild impairments were reported within one month of diagnosis among individuals with colorectal and breast cancer. The average baseline CPI score for the total sample was 0.56, representing a low level of participation and is similar to a

Table 2 Mixed-effect regression model for change in participation over time—assessment of effect modification and confounding

Effect	Initial model			Age and age*group added			Comorbidity added		
	Estimate	Standard error	p-value	Estimate	Standard error	p-value	Estimate	Standard Error	p-value
Community participation indicators (CPI)									
Intercept	0.590	0.056	<.001	0.590	0.056	<.001	0.602	0.041	<.001
Time	−0.015	0.032	0.647	−0.015	0.032	0.647	−0.014	0.022	0.556
Diagnosis group	−0.005	0.013	0.711	−0.007	0.013	0.600	−0.004	0.069	0.568
Diagnosis group*time	0.004	0.007	0.567	0.004	0.007	0.565	0.004	0.032	0.612
Age	N/A			−0.002	0.003	0.541	N/A		
Age*group				0.001	0.001	0.117	−0.004	0.048	0.209
Comorbidity				N/A			−0.035		
PROMIS ability to participate in social roles and activities									
Intercept	44.303	1.884	<.001	43.609	1.940	<.001	45.426	1.910	<.001
Time	0.609	0.981	0.536	0.529	0.982	0.591	0.638	0.982	0.516
Diagnosis group	0.410	0.423	0.333	0.546	0.433	0.209	0.465	0.416	0.264
Diagnosis group*time	−0.376	0.218	0.087	−0.361	0.218	0.100	−0.390	0.218	0.075
Age	N/A			−0.160	0.118	0.177	N/A		
Age*group				0.030	0.028	0.282			
Comorbidity	N/A			N/A			−3.059	1.308	0.020

Reference group = breast cancer

Table 3 Risk factors for participation restrictions over time

Factors	Community participation indicators (CPI)			PROMIS ability to participate in social roles and activities		
	Estimate	Standard error	p	Estimate	Standard error	p
Intercept	0.548	0.049	<.001	45.495	1.491	<.001
Time	0.030	0.022	0.175	−0.403	0.669	0.548
Brain	0.109	0.064	0.093	3.929	1.945	0.045
Colorectal	0.082	0.055	0.134	1.390	1.635	0.396
Lung	0.126	0.057	0.029	5.778	1.721	<.001
Brain*time	−0.003	0.036	0.923	1.274	1.116	0.255
Colorectal*time	−0.010	0.030	0.744	0.193	0.890	0.828
Lung*time	−0.019	0.031	0.541	−0.975	0.939	0.301
Surgery	−0.006	0.038	0.883	−0.451	1.149	0.695
Chemotherapy/targeted therapy	−0.011	0.031	0.729	−3.291	0.910	<.001
Radiation	−0.032	0.030	0.294	0.868	0.894	0.333
Physical function	N/A			0.263	0.050	<.001
Anxiety	N/A			−0.128	0.045	0.005
Fatigue	−0.006	0.001	<.001	−0.156	0.045	<.001
Employment change (yes vs no)	−0.157	0.035	<.001	N/A		
Medical team referred to rehabilitation	N/A			−1.951	0.816	0.018

Reference group = breast cancer

Statistical significance defined as $p < 0.05$

sample of individuals with mild to moderate stroke (mean CPI: 0.53) [31].

Differences in participation based on cancer type were not identified at individual time points or over time. The lack of change may be partly attributed to nearly all participants having initiated treatment before the baseline survey. Low baseline scores and lack of change over time may indicate that patients experience participation restrictions even before diagnosis. Participation restrictions preceding diagnosis parallel how changes in function are often early signs/symptoms of cancer [32, 33]. Alternatively, low baseline participation may reflect the impact of other pre-cancer person characteristics such as mental health and socioeconomic status. Although specific time points or disease groups to prioritize for intervention were not identified, findings suggest there is a need to evaluate participation in the early phases after diagnosis to proactively prevent and address cancer-related disability.

Despite more than half the sample having PRO findings indicating they may benefit from PT and OT, only 20% (OT) to 31% (PT) of this set of patients had been previously referred. When patients were referred to PT or OT by their medical team, they were often referred for a one time inpatient evaluation only. Continued therapy services and outpatient referrals were rare. If patients are more likely to receive rehabilitation services while inpatient, the inpatient environment may offer a critical opportunity to provide more comprehensive assessment, education, and planning related to an individual's rehabilitation needs throughout the cancer continuum. Even if an individual is safe to discharge home and does not require acute rehabilitation services, inpatient therapists can facilitate referrals to comprehensive outpatient cancer care. Although not commonly studied, low referral rates to rehabilitation are a pattern within oncology [6, 34, 35]. Mental health services followed similar trends. Eighteen percent of participants were referred for mental health support, which was more than double the 7.2% of cancer survivors using services in a 2002 study [36]. However, in our study, PROs indicated that 45% of participants may benefit from mental health support; most had not been referred (Fig. 3b). Our findings demonstrate that low referral rates are common for PT, OT, and mental health for individuals with brain, breast, colorectal, and lung cancer.

PRO findings can be used as a method to identify areas where an individual may benefit from additional supportive care. As with oncology symptom management systems [22], when PROs indicate an area of concern, the discussion between the patient and provider should occur. Patients with cancer may not advocate for their supportive care needs [37]; consequently, the patient and provider should collaborate to develop an appropriate plan to meet each individual's supportive care needs, which may include referrals to rehabilitation services.

One solution to address low rehabilitation referral rates is implementing a prospective surveillance model (PSM) of care. The PSM includes evaluation from an interdisciplinary

Fig. 3 **a** Participants referred to rehabilitation by medical team. **b** Rehabilitation referrals identified from study patient-reported outcomes
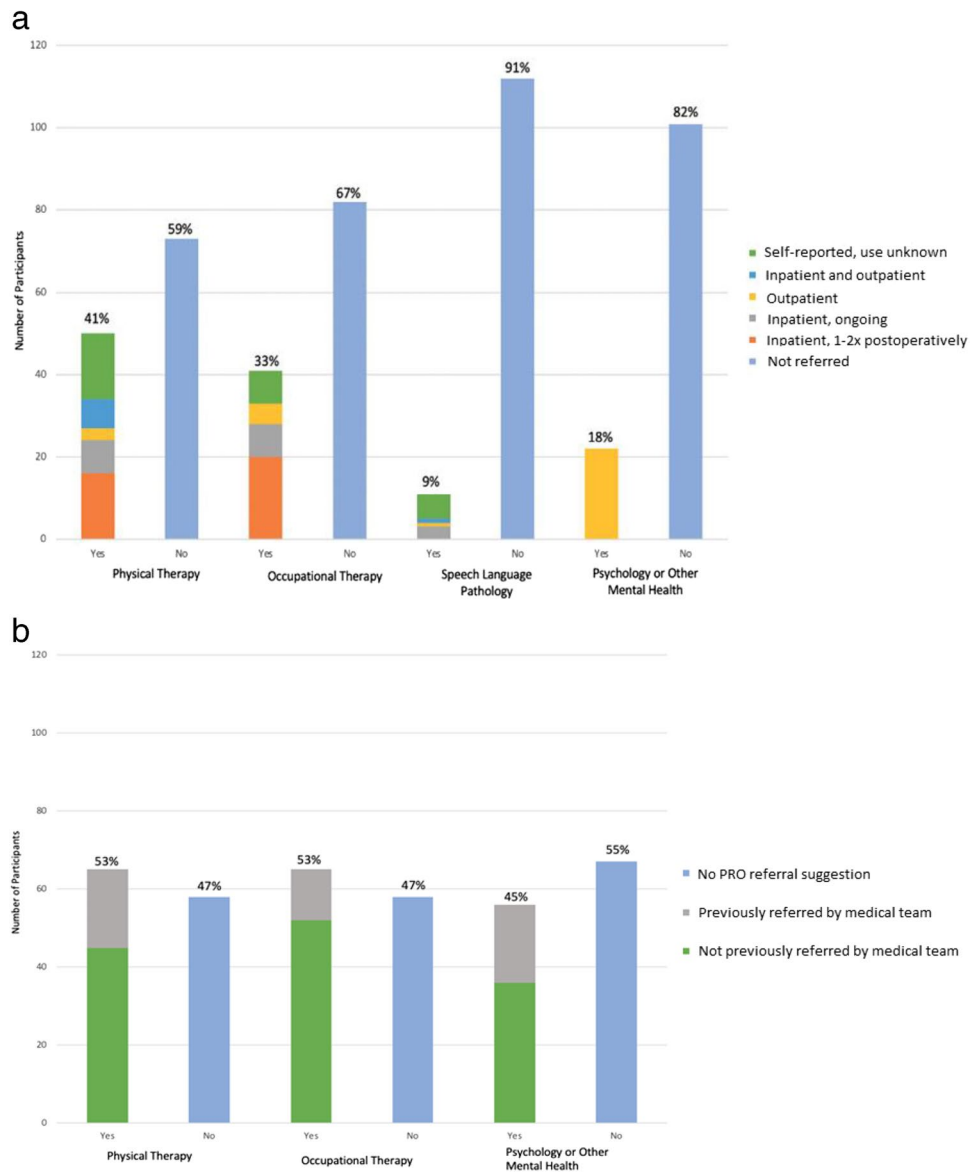
rehabilitation team at the point of diagnosis and ongoing surveillance of needs during and beyond cancer treatment [38]. PSM care is the recommended standard for cancer rehabilitation [20] and supports early identification and treatment of cancer-related functional impairments and participation restrictions, which can contribute to disability [38]. However, the PSM has been tested primarily among individuals with breast cancer and is an underrecognized and underutilized model of care among other cancer populations [39].

Patterns of participation restrictions differed based on the outcome measure. Differences in outcomes may be due to how participation is conceptualized in these measures. PROMIS focuses on the ability to participate while CPI examines the desire for increased participation in valued activities [24]. Despite experiencing a decrease in ability, some patients may not have the desire to change their

participation. Others may be too overwhelmed by their cancer experience to think about or know how to take action to make a change, which highlights the importance of referring to supportive care services. CPI ratings may be more influenced by what people think is reasonable for them to accomplish given their cancer diagnosis [40], while PROMIS takes a more objective approach to measurement. Discordance between PROMIS and comprehensive participation measures was previously reported, and the need to use comprehensive measures was suggested [41]. Findings from the current study cannot recommend one measurement for identifying patients in need of rehabilitation services due to the heterogeneity of means across time points and disease groups. There remains an ongoing need to identify optimal measures to screen individuals living with and beyond cancer for rehabilitation needs [42], which can be

used to facilitate conversations between patients and providers. When identifying screening measures, it is critically important to use measures that are sensitive enough to detect impairments and changes among individuals of all racial and gender identities to support equitable access to supportive care.

Identification of risk factors for participation restrictions generated hypotheses about (1) factors to investigate in targeted studies about participation and (2) groups of patients to prioritize for assessment and intervention. Individuals who received chemotherapy/targeted therapy and had an employment change or higher anxiety or fatigue were at higher risk for participation restrictions. Higher physical function was associated with higher participation. These factors may signify groups of individuals to target for rehabilitation services. To build towards a PSM of care where all individuals diagnosed with cancer have access to rehabilitation and other supportive care services throughout the care continuum, cancer centers could consider first enhancing access among individuals who receive chemotherapy given their higher risk for participation restrictions. To comprehensively address participation, a multidimensional and multidisciplinary approach to treatment is needed to address factors such as anxiety, fatigue, and physical function. Rehabilitation interventions effectively address fatigue and physical function amongst individuals living with and beyond cancer, but limited data exists on methods to improve participation [43, 44].

Surprisingly, lung and brain cancer was associated with higher participation over time. Smaller sample sizes in these groups may have contributed to these findings. The lung cancer group had high attrition; half of those lost to follow-up had stage four disease, so information about how participation may have changed in this group is missing. The poor prognosis of many in the lung and brain cancer groups may have influenced survey responses. Limited life expectancy may result in altered priorities [12] and influence participation scores. Future mixed methods studies should investigate participation and patient priorities about what matters most to them while living with advanced disease.

Future investigations should evaluate participation pre-treatment, when possible, to support comparisons over time. Monitoring participation over multiple years can identify populations of individuals with whom and when rehabilitation should intervene [20]. Preliminary findings on risk factors should be used to inform more targeted investigations to develop risk-based rehabilitation triage protocols [4, 20]. This work can also lead towards the development of a risk prediction model to identify patients at high risk for impairments amenable to rehabilitation, such as participation, and provide personalized care. Determining the impact of cancer on patients' daily life participation will build towards interventions to enhance participation among people with cancer,

an emerging area of research [3]. With larger sample sizes, future studies can investigate how participation and referrals to supportive services vary based on prognosis and expected length of survival. Last, we need to understand how a referral to rehabilitation translates to uptake. Patients are often overwhelmed after diagnosis and unaware of the potential benefits of rehabilitation which may further limit their interest in these supportive services [45, 46].

Study limitations

This study is limited by the small sample size, heterogeneity of treatment approaches, inclusion of only self-report measures, and lack of a normative comparison for the primary outcome, CPI. While the use of CPI within oncology is novel, the assessment is not validated with the population, and there are limited comparison data. Findings are also limited by the lack of a pre-cancer baseline to evaluate change over time. We enrolled patients in early phases after diagnosis, but most had initiated treatment before the baseline measure. These results may over-represent the experiences of people who could participate in life given our exclusion of individuals with aphasia and cognitive impairments. Furthermore, people who are highly motivated or healthier may have been more likely to participate. Last, this study was conducted during the COVID-19 pandemic, which may have further limited life participation. While efforts were made to understand the differential impact of COVID-19 on participation, the complexity of responses, missing data, and evolving nature of COVID-19 made it difficult to form conclusions about how COVID-19 impacted participation versus how cancer impacted participation.

Conclusions

There is a need to integrate the concept of participation into cancer care to understand how patients' daily lives are impacted by cancer. Using PROs to evaluate participation and other health domains is an effective method to identify patients who may benefit from rehabilitation services. PROs can facilitate conversations between patients and providers about supportive care needs and relevant referrals.

Declarations

Ethics approval and consent to participate Approval was obtained from the Human Research Protections Office Institutional Review Board and Peer Review and Monitoring Committees of Washington University in St. Louis. The procedures used in this study adhere to the tenets of the Declaration of Helsinki. All participants provided informed consent to participate in the study.

Consent for publication Patients provided informed consent regarding publishing their anonymized data.

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References

1. L'Hotta AJ et al (2022) Cancer survivors' perspectives of participation: a qualitative analysis. Arch Rehab Res Clin Transl 4:100212. https://doi.org/10.1016/j.arrct.2022.100212

2. L'Hotta AJ et al (2020) Assessments used to measure participation in life activities in individuals with cancer: a scoping review. Support Care Cancer 28:3581–3592. https://doi.org/10.1007/s00520-020-05441-w

3. Brick R et al (2022) Impact of non-pharmacological interventions on activity limitations and participation restrictions in older breast cancer survivors: a scoping review. J Geriatr Oncol 13:132–142. https://doi.org/10.1016/j.jgo.2021.09.010

4. Newman RM et al (2019) Catalyzing research to optimize cancer survivors' participation in work and life roles. OTJR (Thorofare N J) 39(4):189–196

5. Cheville AL et al (2009) The detection and treatment of cancer-related functional problems in an outpatient setting. Support Care Cancer 17:61–7. https://doi.org/10.1007/s00520-008-0461-x

6. Cheville AL, Kornblith AB, Basford JR (2011) An examination of the causes for the underutilization of rehabilitation services among people with advanced cancer. Am J Phys Med Rehabil 90:S27–S37. https://doi.org/10.1097/PHM.0b013e31820be3be

7. Shrestha A et al (2019) Quality of life versus length of life considerations in cancer patients: a systematic literature review. Psycho-Oncology 28:1367-1380 10.1002/pon.5054

8. Agahi N, Parker MG (2008) Leisure activities and mortality: does gender matter? J Aging Health 20:855–71. https://doi.org/10.1177/0898264308324631

9. Maier H, Klumb PL (2005) Social participation and survival at older ages: is the effect driven by activity content or context? Eur J Ageing 2:31–39. https://doi.org/10.1007/s10433-005-0018-5

10. Fratiglioni L, Paillard-Borg S, Winblad B (2004) An active and socially integrated lifestyle in late life might protect against dementia. Lancet Neurol 3:343–353

11. Law M (2002) Participation in the occupations of everyday life. Am J Occup Ther 56:640–649. https://doi.org/10.5014/ajot.56.6.640

12. Lyons M et al (2002) Doing-being-becoming: occupational experiences of persons with life-threatening illnesses. Am J Occup Ther 56:285–95. https://doi.org/10.5014/ajot.56.3.285

13. Ness KK et al (2006) Physical performance limitations and participation restrictions among cancer survivors: a population-based study. Ann Epidemiol 16:197–205. https://doi.org/10.1016/j.annepidem.2005.01.009

14. Brandao T, Schulz MS, Matos PM (2017) Psychological adjustment after breast cancer: a systematic review of longitudinal studies. Psychooncology 26:917–926. https://doi.org/10.1002/pon.4230

15. Brezden CB et al (2000) Cognitive function in breast cancer patients receiving adjuvant chemotherapy. J Clin Oncol 18:2695–2701. https://doi.org/10.1200/jco.2000.18.14.2695

16. Curran L, Sharpe L, Butow P (2017) Anxiety in the context of cancer: a systematic review and development of an integrated model. Clin Psychol Rev 56:40–54. https://doi.org/10.1016/j.cpr.2017.06.003

17. Jansen CE et al (2005) A metaanalysis of studies of the effects of cancer chemotherapy on various domains of cognitive function. Cancer 104:2222–2233. https://doi.org/10.1002/cncr.21469

18. Lyons KD et al (2013) Changes in activity levels of older adult cancer survivors. OTJR: Occup Particip Health 33:31–39. https://doi.org/10.3928/15394492-20120607-02

19. Loscalzo M et al (2013) Role of biopsychosocial screening in cancer care. Cancer J 19:414–420. https://doi.org/10.1097/PPO.0b013e3182a5bce2

20. Alfano CM, Pergolotti M (2018) Next-generation cancer rehabilitation: a giant step forward for patient care. Rehab Nurs J 43:186–194. https://doi.org/10.1097/rnj.0000000000000174

21. Ramsey I et al (2021) A core set of patient-reported outcomes for population-based cancer survivorship research: a consensus study. J Cancer Surviv 15(2):201–212

22. Basch E et al (2016) Symptom monitoring with patient-reported outcomes during routine cancer treatment: a randomized controlled trial. J Clin Oncol 34(6):557–565

23. Heinemann AW et al (2011) Measuring participation enfranchisement. Arch Phys Med Rehab 92:564–571. https://doi.org/10.1016/j.apmr.2010.07.220

24. Plow MA et al (2015) Correlates of participation in meaningful activities among people with multiple sclerosis. J Rehab Med 47:538–545. https://doi.org/10.2340/16501977-1948

25. Cella D et al (2010) The patient-reported outcomes measurement information system (PROMIS) developed and tested its first wave of adult self-reported health outcome item banks: 2005–2008. J Clin Epidemiol 63:1179–1194. https://doi.org/10.1016/j.jclinepi.2010.04.011

26. Jensen RE et al (2017) United States population-based estimates of patient-reported outcomes measurement information system symptom and functional status reference values for individuals

with cancer. J Clin Oncol : Off J Am Soc Clin Oncol 35:1913–1920. https://doi.org/10.1200/JCO.2016.71.4410

27. Jensen RE et al (2015) Validation of the PROMIS physical function measures in a diverse US population-based cohort of cancer patients. Qual Life Res 24:2333–2344. https://doi.org/10.1007/s11136-015-0992-9

28. HealthMeasures. *PROMIS score cut points*. 2022 [cited 2022 March 4]; Available from: https://www.healthmeasures.net/score-and-interpret/interpret-scores/promis/promis-score-cut-points.

29. Fayers P, Bottomley A (2002) Quality of life research within the EORTC—the EORTC QLQ-C30. Eur J Cancer 38:125–133. https://doi.org/10.1016/S0959-8049(01)00448-8

30. Charlson ME et al (1987) A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. J Chronic Dis 40:373–83. https://doi.org/10.1016/0021-9681(87)90171-8

31. Toglia J et al (2019) Participation in younger and older adults post-stroke: frequency, importance, and desirability of engagement in activities. Front Neurol 10:1108. https://doi.org/10.3389/fneur.2019.01108

32. Beckles MA et al (2003) Initial evaluation of the patient with lung cancer*: symptoms, signs, laboratory tests, and paraneoplastic syndromes. Chest 123:97S-104S. https://doi.org/10.1378/chest.123.1_suppl.97S

33. Alentorn A, Hoang-Xuan K, Mikkelsen T (2016) Chapter 2 - Presenting signs and symptoms in brain tumors. In: Berger MS, Weller M (eds) Handbook of Clinical Neurology. Elsevier, pp 19–26

34. Stubblefield MD (2017) The underutilization of rehabilitation to treat physical impairments in breast cancer survivors. PM&R 9:S317–S323. https://doi.org/10.1016/j.pmrj.2017.05.010

35. Cheville AL et al (2008) Prevalence and treatment patterns of physical impairments in patients with metastatic breast cancer. J Clin Oncol : Off J Am Soc Clin Oncol 26:2621–2629. https://doi.org/10.1200/JCO.2007.12.3075

36. Hewitt M, Rowland JH (2002) Mental health service use among adult cancer survivors: analyses of the National Health Interview Survey. J Clin Oncol 20:4581–90. https://doi.org/10.1200/jco.2002.03.077

37. McEwen S et al (2016) "I didn't actually know there was such a thing as rehab": survivor, family, and clinician perceptions of rehabilitation following treatment for head and neck cancer. Support Care Cancer 24(4):1449–1453

38. Stout NL et al (2012) A prospective surveillance model for rehabilitation for women with breast cancer. Cancer 118:2191–200. https://doi.org/10.1002/cncr.27476

39. Houdeshell MJ et al (2021) Limitations of current rehabilitation practices in pediatric oncology: implications for improving comprehensive clinical care. Arch Phys Med Rehab 102:2353–2361. https://doi.org/10.1016/j.apmr.2021.05.021

40. Lyons KD (2011) A pilot study of activity engagement in the first six months after stem cell transplantation. Oncol Nursing Forum 38:75–83. https://doi.org/10.1188/11.ONF.75-83

41. Brick R, Bender C, Skidmore E (2020) Impact of cancer and cancer-related treatments on participation restrictions. Brit J Occup Ther. https://doi.org/10.1177/0308022620923858

42. Marshall TF et al (2019) Consensus-Building efforts to identify best tools for screening and assessment for supportive services in oncology. Disabil Rehab 42:2178–2185. https://doi.org/10.1080/09638288.2018.1555621

43. Sleight AG et al (2022) A systematic review of functional outcomes in cancer rehabilitation research. Arch Phys Med Rehabil. https://doi.org/10.1016/j.apmr.2022.01.142

44. Hunter EG et al (2017) Systematic review of occupational therapy and adult cancer rehabilitation: part 2. Impact of multidisciplinary rehabilitation and psychosocial, sexuality, and return-to-work interventions. Am J Occup Ther 71:7–7

45. Tuinman MA, Gazendam-Donofrio SM, Hoekstra-Weebers JE (2008) Screening and referral for psychosocial distress in oncologic practice. Cancer 113:870–878. https://doi.org/10.1002/cncr.23622

46. Stout NL et al (2016) Toward a national initiative in cancer rehabilitation: recommendations from a subject matter expert group. Arch Phys Med Rehab 97:2006–2015. https://doi.org/10.1016/j.apmr.2016.05.002