Differences in activity limitations and participation restrictions between young adults with cancer and older age groups: A cross-sectional study

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Research Article

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Abstract

Purpose: To explore whether young adults with cancer have different activity limitations and participation restrictions compared to older age groups with cancer.

Methods: A cross-sectional study including 654 people with cancer participating in a rehabilitation stay. Participants were in the age groups: 1) Young adults (n=121) = 18-39 years; 2) Middle-aged (n=406) = 40-64 years; and 3) older people (n=127) = ≥65 years. Outcomes were activity limitations and participation restrictions encompassing physical, role, social, and cognitive functioning, measured using the European Organization for Research and Treatment of Cancer Quality-of-Life Questionnaire Core 30. Mean differences between age groups were calculated using linear regression analyses.

Results: Young adults had a mean age of 32.1 years (SD = 5.1); middle-aged adults 53.4 years (SD = 6.8); and the older people 71.1 years (SD = 4.8). The majority of the participants were women (81.9%) with breast cancer (42.9%). Young adults had a statistically significant higher physical functioning compared to those middle-aged (-3.90: (95% CI: -6.84; -0.95)) and the older age group (-7.63: (95% CI: -11.29; -3.96)). Young adults had statistically significant lower role functioning (7.11: (95% CI: 1.13; 13.08)) and cognitive functioning (13.82: (95% CI: 7.35; 20.29)) compared to older people. There was no statistically significant difference in social functioning between the age groups.

Conclusion: Young adults had different activity limitations and participation restrictions compared with higher age groups. Our findings suggest the need for further research and an increased clinical rehabilitation focus on different activity and participation challenges across age groups.

Introduction

Worldwide, approximately 1 million young adults aged 18 to 39 are diagnosed annually with cancer [1, 2]. A growing body of literature shows that young adults with cancer are prone to have activity limitations and participation restrictions [3–8]. Yet, knowledge about the specific of these and the resulting consequences for young adults with cancer is limited.

The International Classification of Functioning, Disability, and Health (ICF) provides a common terminology for understanding and measuring health and disability [9]. The ICF defines activity limitations as difficulties the individual may have in performing activities, whereas participation restrictions are problems an individual may experience in everyday life [9]. It is well-known that participation in work, education and other activities influences how people develop their identity and roles in life, which in turn may affect their capacity for socializing with other people and belonging to communities [10, 11]. A cancer diagnosis and the experience thereof may inhibits activity and participation and therefore have serious consequences for the everyday lives of young adults, whichin turn may reduce their quality of life [12].

Improvements in cancer treatment have increased survivorship for most young adults [13]. The treatment of young adults with cancer is, however, often more intrusive, multimodal and long-lasting than in older age groups because they are expected to tolerate stronger doses better [14]. This may cause long-term side effects that in turn, affect the young adults in re-establishing their everyday life [12]. In addition, a number of studies show that people in older age groups with cancer are often more settled in their everyday lives and retain better coping strategies than younger people [15–17]. Young adults with cancer may therefore be in a particularly exposed position because they are diagnosed during a period of their life in which they may be establishing relationships and a family, finishing their education or in the early stages of gaining employment [7, 12, 18, 19]. Because of where they are in life and in terms of development, young adults with cancer expectedly have needs and face problems which are different to those in older age groups with cancer [20]. Although some studies have pointed to young adults with cancer as a population with special needs related to their life phase [20, 21], so far no previous study has investigated if young adults with cancer have other activity limitations and participation restrictions, compared to people with cancer in older age groups.

In order to provide tailored support to young adults with cancer and optimize their chances for the continuing development of adult life roles, relationships and obligations in society, it is necessary to investigate the possible differences in activity and participation between the age groups, in order to inform a tailored approach to rehabilitation services for young adults with cancer [21]. The present study aims to examine which kind of activity limitations and participation restrictions young adults with cancer report and whether these are different compared to those in older age groups with cancer.

Methods

Study design and setting

This cross-sectional study is based on information from a clinical research database established by REHPA, the Danish Knowledge Centre for Rehabilitation and Palliative Care. REHPA shares and contributes to knowledge within the field of rehabilitation and palliative care for people suffering from life-threatening diseases in Denmark [22]. The present study is reported according to the principles of Strengthening the Reporting of Observational Studies in Epidemiology [23]. According to the Regional Committee on Health Research Ethics for Southern Denmark, the present study was not notifiable. The Danish Data Protection Agency approved the collection (18/27843). The participants received verbal and written information about the study procedures and both verbal and written consent were obtained.

Participants

Included participants were those who had attended residential stays at REHPA from 2017–2020. The residential stays included workshops with a focus on physical training, symptoms, mindfulness, motivation, sexuality and existential needs. The participants were adults with cancer (≥ 18 years), included from all over Denmark and were able to manage self-care independently but still reported a need for rehabilitation. The participants had to be referred by their general practitioner or by a doctor at the

hospital, they were required to speak and understand Danish and be willing to fill out questionnaires and participate in interviews.

Data collection

Data for this study was collected prior to the participants entering the residential stay at REHPA. The data from the clinical database is used for quality development and for research purposes. Information from standardized questionnaires includes sociodemographic and sickness-specific items. One of the questionnaires is the European Organization for Research and Treatment of Cancer Quality-of-Life Questionnaire Core 30 (EORTC QLQ C-30), which is a cancer-specific questionnaire composed of both functioning, health-related quality of life and symptoms scales [24]. The clinical database has been described in detail elsewhere [22].

Variables

Outcome

Four outcomes assess activity limitations and participation restritions [9]: physical functioning, social functioning, role functioning and cognitive functioning. These were measured with EORTC QLQ C-30 [24]. All the scales range in scores from 0 to 100 [25]. Higher scores represent higher levels of functioning or higher levels of symptoms [25]. Differences of 10 points are considered clinically important [26]. A study by Johnsen et al. [27] has suggested the following categorisation of the functioning scores: ≤33.3 corresponds to having severe problems, ≤ 66.7 equals moderate problems and > 66.7 equals having minor or no problems [27]. EORTC QLQ C-30 is a validated and reliable instrument in people with cancer [24].

Physical functioning relates to activity level and encompasses self-care and mobility. Role functioning relates to participation level and includes work and other daily activities, as well as leisure and hobbies. Social functioning is on the level of participation and encompasses family and social life. Lastly, cognitive functioning is on the activity level and encompasses concentration on activities such as reading, watching television, as well as general memory [9, 24].

Descriptive data

Included demographic and clinical data were age, gender, in a relationship, living alone, employment status and cancer diagnosis. In addition, pain, fatigue, nausea/vomiting, dyspnoea, insomnia, appetite, constipation and diarrhea were also included from the EORTC QLQ C-30 [24].

Statistical Analysis

Normally distributed continuous data were presented using mean value and standard deviation (SD). Categorical data were presented by means of frequencies and percentages. Univarite and multiple linear regression analyses were used to explore differences in age groups regarding the four functioning outcomes, all entered as continuous variables: physical functioning, social functioning, role functioning

and cognitive functioning. Age was categorised into three groups: 1) Young adults with cancer = 18 to 39 years [28]; 2) Middle-aged adults with cancer = 40 to 64 years; and 3) older people with cancer ≥ 65 years [29] Analyses were performed with and without adjusting for the most common and important confounders according to the litterature: gender [30], living alone [31] and pain [32, 33]. Living alone was dichotomised into yes/no, while pain was dichotomised into no pain (≤ 33.3) and pain (> 33.3) [27]. QQ-plots were used to test for model assumptions. Only complete cases with regard to each of the four outcomes were included in the analyses. Estimates were presented with 95% confidence intervals (CI). The analyses were computed using STATA software version 16.1. P-values below 0.05 were considered statistically significant.

Results

Two participants were excluded because of several missing answers in the outcome measures. The final eligible sample consisted of 654 participants (Table 1).

Descriptive data

The distribution of the socio-demographic and clinical characteristics for each age group is presented in Table 1. Young adults had a mean age of 32.1 years (SD = 5.1), while middle-aged adults had a mean age of 53.4 years (SD = 6.8), and mean age for older people was 71.1 years (SD = 4.8). There was a minority of men represented in this study (18.8%). The majority of the participants were in a relationship (62.5%). Overall, 33.6% of the participants were on sick leave, 27.5% were retired and only 4.8% were working full time.

>>> Insert Table 1

Table 2 presents the functioning scores for each age group and their degree of problems with the different activity and participation domains. The mean functioning scores were relatively high in all age groups, particularly for physical functioning. The majority of the age groups reported no activity limitations in physical functioning and they typically had moderate activity limitations and participations restrictions across the remaining domains. Very few participants had severe problems (See Table 2).

>>> Insert Table 2

Main results

The regression analyses show that middle-aged and older adults had statistically more significant activity limitations regarding physical functioning, compared with young adults (middle-aged adults: -3.90: (95% CI: -6.84; -0.95); $p = 0.009$), (older people: -7.63: (95% CI: -11.29;-3.96); $p = 0.000$). Young adults had statistically significant more participation restrictions regarding role functioning compared with the older people (7.11: (95% CI: 1.13;13.08); $p = 0.020$). A clinically significant difference was observed in cognitive functioning between young adults and older people, with a difference of > 10 points (13.82: (95% CI: 7.35;20.29); $p = 0.000$). No other significant differences were found. (Table 3).

>>> Insert Table 3

Discussion

This cross-sectional study is, to our knowledge, the first of its kind to investigate differences in activity limitations and participation restrictions between different age groups with cancer. Our findings show different patterns in activity limitations and participation restrictions due to age. Cognitive functioning levels in younger adults were especially concerning. Hence our findings point towards tailored rehabilitation intervention to different age groups.

Results of activity and participation

A pooled analysis of randomised controlled trials by Quinten et al. and a cross-sectional study by Mols et al. found physical functioning to be worse with increasing age [29, 34]. This is consistent with the results of our study where the two older groups had more activity limitations regarding physical functioning compared with young adults. Both studies addressed cancer-specific diseases (melanoma and thyroid cancer) with age-ranges different (18–49 and 18–35 years) from our study. The comparability between our study and the other studies is therefore questionable, but still confirms our finding of older adults with cancer (> 65 years) being more impaired in self-care and mobility [29, 34]. Yet, our findings were not clinically relevant which is important to bear in mind. We found no other differences except for activity limitations in physical functioning between young adults with cancer and middle-aged adults with cancer. An explanation could be that the two groups were too similar to detect any differences. This assumption is supported by the overall largely identical socio-demographic data in the two groups. The majority of the young adults also had an age close to 40 years. The cross-sectional study by Mols et al. also found the two youngest groups (18–35 and 36–64 years) to be more homogeneous compared with the oldest group (≥ 65) [29]. It is therefore not unanticipated that the greatest heterogeneity in our study existed between young adults with cancer and older people with cancer.

Another finding from our study was that young adults with cancer reported more participation restrictions regarding role functioning compared with older people with cancer. If impairments affect the ability to participate in everyday life, or external factors create circumstances that prevent participation, then identity may be threatened [35]. This is particurlarly problematic for young adults with cancer, for whom life roles and development of identity primarily lie within work, education, and leisure time, and for whom,

being less able to participate in these activities is associated with decreased health [5, 7, 36]. Besides the difference in role functioning between young adults and older people with cancer, there were also differences in cognitive functioning. This is an important finding, as the difference between young adults and older people with cancer was clinically relevant, albeit the 95% CI also shows that it could have been the opposite. Nevertheless, it calls for an increased focus in rehabilitation services for young adults with cancer on activity limitations caused by challenges in cognitive functioning. This is also illustrated in an exploratory study by Sodergren et al. where young adults with cancer aged 18–25 reported difficulties with concentrating when engaging in daily activities because they worried too much about being sick and how it would interfere with their future life plans [6]. Generally, older people with cancer experience less psychological distress after diagnosis, enabling them to better adapt to their activity limitations compared with young adults with cancer [17]. It is somewhat surprising that no differences were found in participation restrictions regarding social functioning between the three age groups, especially as previous research shows that young adults with cancer have difficulties with social relations after receiving invasive and long-term cancer treatment [12, 34].

Focus of rehabilitation for young adults with cancer

Our study supports the common perception in the research field that young adults with cancer are likely to differ from other cancer age groups in some areas [29, 34]. Current rehabilitation research for young adults with cancer has paid more attention to the effect of exercise to improve physical function than it has to facilitating activity and participation in everyday life [37, 38]; yet a growing body of evidence shows that young adults with cancer still have difficulties and unmet needs with everyday life [12, 37, 39]. Hence, to provide appropriate rehabilitation for young adults with cancer which they find relevant and meaningful, the intervention focus must target their specific needs and problems. Our findings suggest that there may be a difference between young adults and older age groups with cancer on selected areas of activity and participation, and this could advocate for tailored support for the younger age group and thus inform the development of future rehabilitation interventions that are more closely tailored to their needs. A proposition made by Hauken et al., emphasises the importance of including components focusing on work/school and leisure activities when developing interventions for young adults with cancer [39]. Hauken et al. further suggest that young adults with cancer benefit from a goal-oriented and multi-component intervention with physical activity, psycho-education, peer-to-peer support, and continuous follow-up on goal-setting in order to increase participation [39]. However, more research is needed. Future research should synthesize existing scientific evidence and identify patient preferences and clinical knowledge informing the content of a cancer rehabilitation program for this group of people. This kind of knowledge is important to develop an evidence-based rehabilitation program for young adults with cancer.

Methodological considerations

Although few participants had missing values in the outcome measures in the EORTC QLQ C-30, there are some methodological considerations that need to be addressed in our study. First, the age-range represented in the literature emphasises inconsistencies in how to define young adults from middle-aged

adults and adolescence [6, 40, 41]. It is worth considering whether a narrower age range would better reflect the specific needs related to each stage of life [6, 19]. Thus, it is questionable whether the age range of young adults chosen for this study captures the activity limitations and participations restrictions reflected in both the youngest and the oldest participants of the young adults with cancer age group. Second, the majority of the participants in this study were women between 40–64 years with breast cancer who were well-functioning, thereby reducing the diversity among the participants. On the other hand, the study had a relatively large group of young adults with cancer, which provide diversity to some extent. Only participants who were able to manage self-care independently were offered a residential stay at REHPA. These people may therefore tend to have less activity limitations and participation restrictions compared with the wider population of people with cancer. This is also reflected in the functioning scores, where few participants reported severe activity limitations and participation restrictions. It is therefore likely that the results of this study are only representative of the better functioning people with cancer. Finally, we adjusted for some of the most important confounding factors according to the research literature [30–33], but it could have been relevant to adjust for time since diagnosis, co-morbidity, educational level and income, because these factors are known to be important for the association between age and functioning, including activity and participation [42–44]. However, these variables did not exist in the research database. The identified differences among the three groups may therefore not only be explained by age alone, but may be caused by other confounding factors.

Conclusion

When compared to older age groups with cancer we found that young adults with cancer have different activity limitations and participation restrictions regarding physical, role and cognitive functioning. Our findings suggest an increased focus on tailored rehabilitation services for young adults with cancer, although more research is needed.

Declarations

Conflict of interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

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Availability of data and material

The data were stored in the Research Electronic Data Capture.

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Tables

Table 1. Participant characteristics

	All participants (n= 654)		YAC (n=121)		MAC (n=406)		EC (n=127)	
Age, mean (SD)	52.8	(13.5)	32.1	(5.1)	53.4	(6.8)	71.1	(4.8)
Woman, n (%)	524	(81.2)	99	(83.9)	346	(86.3)	79	(62.7)
Missing, n (%)	9	(1.4)	3	(2.5)	5	(1.2)	1	(0.8)
In a relationship, n (%)	387	(62.5)	67	(57.3)	247	(65.2)	73	(59.4)
Missing, n (%)	35	(5.4)	4	(3.3)	27	(6.7)	4	(3.1)
Living alone, n (%)	241	(37.1)	44	(36.4)	138	(34.2)	59	(46.8)
Missing, n (%)	4	(0.6)	0	(0.0)	3	(0.7)	1	(0.8)
Occupational status, n (%)								
Retired	177	(27.5)	13	(10.9)	52	(13.1)	112	(88.9)
Sick leave	216	(33.6)	44	(36.9)	170	(42.7)	2	(1.6)
Flexjob[a]	18	(2.8)	4	(3.4)	14	(3.5)	0	(0.0)
Unemployed	12	(1.9)	2	(1.7)	9	(2.3)	1	(0.8)
Working part time[b]	129	(20.1)	29	(24.4)	93	(23.4)	7	(5.6)
Working[c]	31	(4.8)	7	(5.9)	24	(6.0)	0	(0.0)
Studying	7	(1.1)	7	(5.9)	0	(0.0)	0	(0.0)
Other	53	(8.2)	13	(10.9)	36	(9.0)	4	(3.2)
Missing	11	(1.7)	2	(1.7)	8	(2.0)	1	(0.8)
Primary tumor site, n (%)								
Breast cancer	250	(42.9)	35	(35.5)	188	(50.3)	27	(24.5)
Haematological	75	(12.9)	24	(24.2)	32	(8.6)	19	(17.3)
Gastrointestinal	63	(10.8)	5	(5.1)	48	(12.8)	10	(9.1)
Gynecological	60	(10.3)	12	(12.1)	37	(9.9)	11	(10.0)
Head and neck	51	(8.7)	11	(11.1)	26	(7.0)	14	(12.7)
Lung	34	(5.8)	3	(3.0)	20	(5.3)	11	(10.0)
Prostate and/or testicular	24	(4.1)	2	(2.0)	8	(2.1)	14	(12.7)
Skin cancer	7	(1.2)	3	(3.0)	3	(0.8)	1	(0.9)
Bladder and/or kidney cancer	7	(1.2)	0	(0.0)	5	(1.3)	2	(1.8)
Other	12	(2.1)	4	(4.0)	7	(1.9)	1	(0.9)
Missing, n (%)	71	(10.9)	22	(18.2)	32	(7.9)	17	(13.4)
EORTC QLQ C-30: Symptoms[d], n[e] (%)								
Pain	423	(64.7)	67	(55.4)	268	(66.0)	88	(69.3)
Fatigue	574	(87.8)	110	(90.9)	355	(87.4)	109	(85.8)
Nausea/Vomiting	81	(12.4)	17	(14.1)	40	(9.9)	24	(18.9)
Dyspnoea	336	(51.4)	48	(39.7)	205	(50.5)	83	(64.4)
Insomnia	531	(81.2)	92	(76)	344	(84.7)	95	(74.8)
Appetite	238	(36.4)	36	(29.8)	134	(33.0)	68	(53.5)
Constipation	259	(39.6)	50	(41.3)	149	(36.7)	60	(47.2)
Diarrhea	270	(41.3)	49	(40.5)	158	(38.9)	63	(49.6)

YAC: Young Adults with Cancer (18–39 years); MAC: Middle-aged Adults with Cancer (40–64 years); EC: Elderly with Cancer (≥65 years); EORTC QLQ C-30: European Organization for Research Treatment of Cancer Quality of Life Questionnaire Core 30.

[a]Flexjob is a Danish labour market political initiative aimed to provide a job for citizens, who are not able to perform an ordinary job, and not sick enough to go into early retirement.

[b]Working part time: working under 37 hours a week.

[c]Working: working full time which in Denmark is 37 hours.

[d]For all symptoms only one answer is missing.

[e]Number of participants experiencing symptoms according to Johnsen et al [27]: Symptoms scores >33.3= “no symptom” and ≤33.3=”yes symptom” on the EORTC QLQ C-30.

Table 2. EORTC QLQ C-30 functioning scores for each age group (n=654).

Age groups	Physical functioning[a] Means (95% CI)	Social functioning[a] Means (95% CI)	Role functioning[a,b] Means (95% CI)	Cognitive functioning[a] Means (95% CI)
YAC	81.7 (79.3;84.1)	64.9 (60.1;69.7)	58.0 (53.5;62.5)	56.7 (51.9;61.5)
MAC	76.3 (74.8;77.9)	62.8 (60.2;65.4)	56.7 (54.3;59.2)	57.2 (54.6;59.8)
EC	71.9 (69.0;74.8)	65.7 (61.7;69.8)	62.1 (57.8;66.3)	69.7 (65.2;74.1)

Age groups	Physical functioning	Social functioning	Role functioning	Cognitive functioning
YAC, n (%)				
No problem	102 (84)	40 (33)	27 (22)	36 (30)
Moderate problem	18 (15)	58 (48)	61 (50)	47 (39)
Severe problem	1 (1)	23 (19)	33 (27)	38 (31)
MAC, n (%)				
No problem	290 (71)	135 (33)	87 (21)	113 (28)
Moderate problem	109 (27)	168 (41)	190 (47)	179 (44)
Severe problem	7 (2)	103 (25)	128 (32)	114 (28)
EC, n (%)				
No problem	71 (56)	37 (29)	32 (25)	60 (47)
Moderate problem	51 (40)	66 (52)	62 (49)	49 (39)
Severe problem	5 (4)	24 (19)	33 (26)	18 (14)

YAC: Young Adults with Cancer (18–39 years); MAC: Middle-aged Adults with Cancer (40–64 years); EC: Elderly with Cancer (≥65 years); EORTC QLQ C-30: European Organization for Research Treatment of Cancer Quality of Life Questionnaire Core 30. SD: Standard Deviation; CI: Confidence Interval.

[a]Score ranges from 0–100, A higher score represents higher functioning and health-related quality of life.

[b]One missing answer.

≤ 33.3: Severe activity limitations and participation restrictions, ≤ 66.7: moderate activity limitations and participation restrictions, > 66.7: no activity limitations and participation restrictions.

Table 3. Multiple linear regression analyses of the differences in functioning between the age groups.

Age groups	Crude Physical functioning [95% CI] (n=654)	Adjusted Physical functioning [95% CI] (n=645)[b]	p value	Crude Social functioning [95% CI] (n=654)	Adjusted Social functioning [95% CI] (n=645)[b]	p value	Crude Role functioning [95% CI] (n=653)[a]	Adjusted Role functioning [95% CI] (n=644)[ab]	p value
YAC	ref	ref		ref	ref		ref	ref	
MAC	-5.33 (-8.47 ; -2.18)	-3.90 (-6.84 ; -0.95)	0.009	-2.07 (-7.40 ; 3.27)	-1.14 (-6.28 ; 4.00)	0.664	-1.24 (-6.34 ; 3.87)	0.94 (-3.85 ; 5.74)	0.700
EC	-9.75 (-13.61 ; -5.89)	-7.63 (-11.29 ; -3.96)	0.000	0.87 (-5.67 ; 7.42)	3.05 (-3.36 ; 9.45)	0.351	4.08 (-2.17 ; 10.34)	7.11 (1.13 ; 13.08)	0.020

Age groups	Crude Cognitive functioning [95% CI] (n=654)	Adjusted Cognitive functioning [95% CI] (n=645)[b]	p value
YAC	ref	ref	
MAC	0.43 (-4.90 ; 5.77)	1.25 (-3.94 ; 6.44)	0.636
EC	12.94 (6.39 ; 19.48)	13.82 (7.35 ; 20.29)	0.000

YAC: Young Adults with Cancer (18–39 years); MAC: Middle-aged Adults with Cancer (40–64 years); EC: Elderly with Cancer (≥65 years); CI: Confidence Interval.

[a]One missing answer.[b] Nine missing answers on the confounder of gender.