

Fear of cancer recurrence among young adult cancer survivors – exploring long-term contributing factors in a large, population-based cohort

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BACKGROUND

Fear of cancer recurrence (FCR) may be debilitating, yet knowledge of FCR among the growing population of long-term young adult survivors (YACS) is scarce.

We explored risk of FCR and associated factors in a nationwide, population-based cohort of YACS.

METHODS

All 5-yr survivors identified by the Cancer Registry of Norway (CRN):

- diagnosed at 19-39 years
- breast cancer (BC), malignant melanoma (MM), colorectal cancer (CRC), leukemia (LEU) and non-Hodgkin lymphoma (NHL)
- during 1985-2009

They completed a mailed, cross-sectional NOR-CAYACS health survey. FCR measured with the Assessment of survivorship concern (ASC)-scale. Group comparisons were performed using ANOVA. Univariate and multivariate linear regression modelling was performed.

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PATIENT CHARACTERISTICS

Table 1. Sample characteristics

	N (%)	MM ¹ (%)	BC ² (%)	CRC ³ (%)	NHL ⁴ (%)	LEU ⁵ (%)
Total	936 (100)	231 (24.7)	359 (38.4)	110 (11.8)	146 (15.6)	90 (9.6)
Gender						
Female	682 (72.9)	163 (70.6)	359 (100)	55 (50)	66 (45.2)	39 (43.3)
Male	254 (27.1)	68 (29.4)	0 (0)	55 (50)	80 (54.8)	51 (56.7)
Education >13 y	547 (58.4)	146 (63.2)	204 (56.8)	70 (63.6)	82 (56.2)	45 (50)
Not living alone	820 (82.2)	206 (89.2)	316 (88)	93 (84.5)	131 (84.5)	74 (82.2)
Living with children	446 (47.6)	119 (51.5)	170 (47.4)	44 (40)	68 (46.6)	45 (50)
Clinical variables						
Treatment modality						
Limited surgery ⁶	216 (23.1)	216 (93.5)	0 (0)	0 (0)	0 (0)	0 (0)
Local treatment: surgery and/or RT ⁷	106 (11.3)	0 (0)	30 (8.4)	69 (62.7)	7 (4.8)	0 (0)
Systemic treatment alone	108 (11.5)	9 (3.9)	2 (0.6)	2 (1.8)	36 (24.7)	59 (65.6)
Systemic treatments + surgery and/or RT	506 (54.1)	6 (2.6)	327 (91.1)	39 (35.5)	103 (70.5)	31 (34.4)
Somatic comorbidity						
1-2 co-morbid somatic conditions	482 (51.5)	482 (50.2)	185 (51.5)	61 (55.5)	74 (50.7)	46 (51.1)
> 2 co-morbid somatic conditions	179 (19.1)	31 (13.4)	67 (18.7)	21 (19.1)	41 (28.1)	19 (21.1)
Pain interfering with normal work	93 (9.9)	18 (7.8)	39 (10.9)	11 (10.0)	16 (11.0)	9 (10.0)
Trouble sleeping	429 (45.8)	87 (37.7)	193 (53.8)	54 (49.1)	67 (45.9)	28 (31.1)
Late effects	559 (59.7)	34 (14.7)	289 (80.5)	56 (50.9)	112 (76.7)	68 (75.6)
Age at survey, mean (SD)⁸	49.1 (7.8)	49.4 (7.9)	49.8 (6.9)	49.1(9.4)	48.3 (8.2)	46.4(7.7)
Age at diagnosis, mean (SD)	32.6 (5.5)	31.2 (5.8)	35.2 (3.6)	33.5 (33.5)	30.3 (5.7)	28.8 (6)
Time since diagnosis, mean (SD)	15.9 (6.6)	17.7 (6.6)	14.0 (5.9)	15.1 (7.4)	17.4 (6.8)	16.9 (5.9)
HADS-A, mean (SD)	4.6 (3.7)	4.0 (3.3)	4.9 (3.8)	4.2 (3.4)	5.0 (16.4)	4.6 (3.7)
Fatigue, mean (SD)	12.9 (4.9)	12.1 (4.2)	13.5 (4.9)	13.0 (5.7)	13.1 (4.8)	12.4 (5.3)
PHQ, mean (SD)	5.1 (4.7)	3.8 (4)	5.8 (4.8)	5.1 (4.5)	5.5 (4.6)	5.0 (5.3)

In total, 936 YACs were included in the study, with an average of 16 years since diagnoses (table 1).

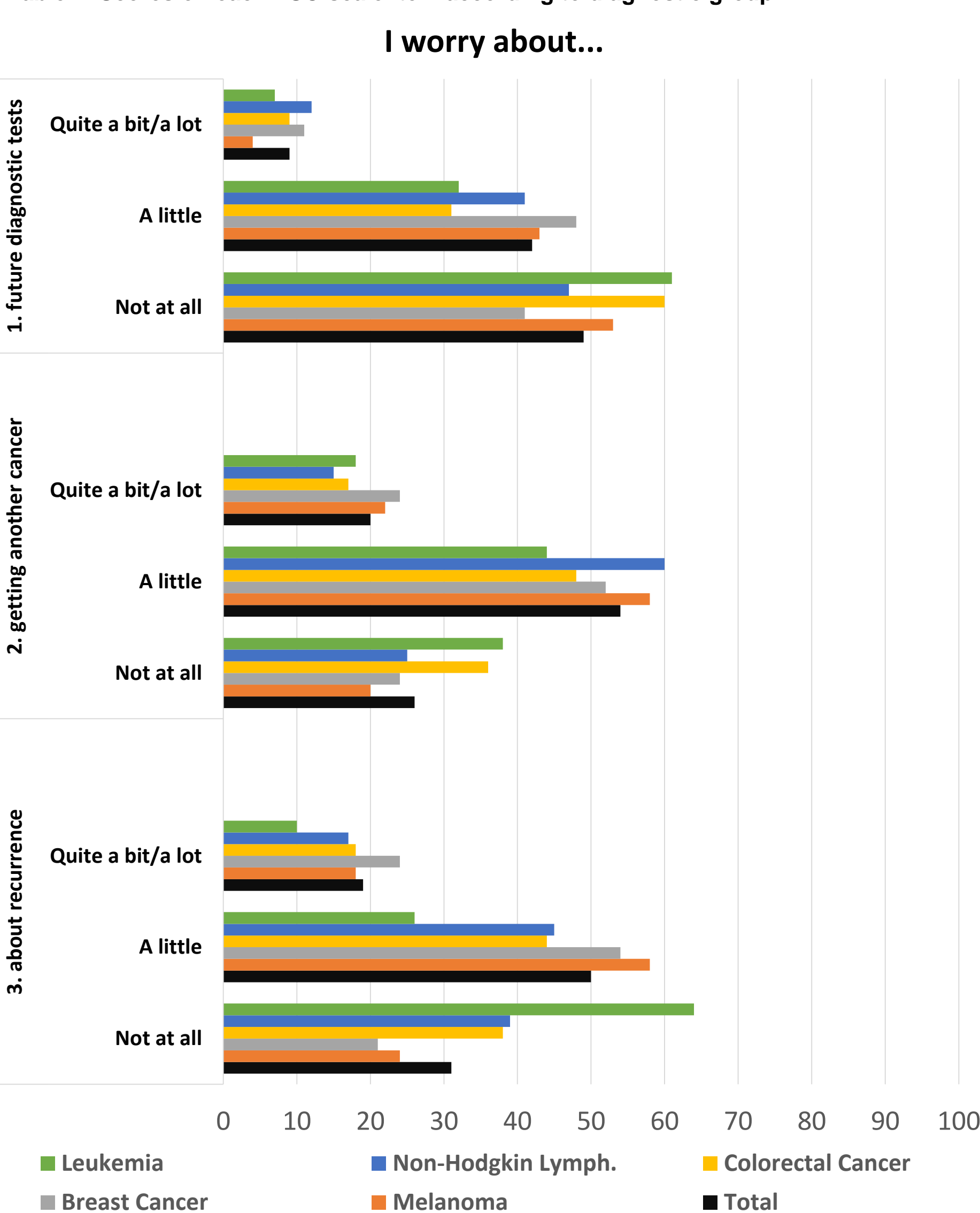
Survivors were primarily female, with higher education, and almost half of the sample had children. BC was the most prevalent cancer form (38.4%), followed by MM (24.7%), NHL (15.6%), CRC (11.8%) and LEU (9.6%).

Survivors worried most about:
1.getting another cancer (74%)
2.disease recurrence (69%)
3.future diagnostic tests (51%)

One in five (20%) reported quite a bit or a lot of FCR.

Mean FCR score (SD) was
- Total sample 5.6 (2.0)
- BC 5.9 (2.0)
- MM 5.6 (1.9)
- NHL 5.4 (1.8)
- CRC 5.3 (2.0)
- LEU 4.8 (1.9)

Table 2. Scores on each ASC-scale item according to diagnostic group



RESULTS

The multivariable hierarchical linear regression model (Table 3) explained a total of 43% of the variance in FCR scores.

PTSS was by far the strongest predictor of high FCR scores, uniquely explaining 18% of the variance, followed by being diagnosed with BC and CRC when compared to MM, higher levels of anxiety and living with children.

INTERPRETATION

FCR is frequent, even decades beyond treatment completion, in a large population-based sample of YACS, across a range of cancer diagnoses and among survivors of cancers associated with good prognosis, such as MM.

The need for age-sensitive and comprehensive follow-up care of cancer survivors will become increasingly important as cancer survival rates continue to improve.

FCR is distressing and can negatively impact quality of life, also in the rapidly growing YACS population. Since efficacious therapies are available, the clinical community should, in our view, put forward a stronger focus on FCR in follow-up care.

Table 3 Multivariate hierarchical linear regression (only last block shown)

Block 6 variables	B (95% CI)	Std beta	p
constant	1.57 (-0.32-3.47)		0.10
Gender ¹	-0.02 (-0.27-0.24)	0.00	0.89
Living with children	0.28 (0.07-0.48)	0.07	0.01
Age at survey	-0.01 (-0.03-0.01)	-0.02	0.58
Time since diagnosis	0.00 (-0.02-0.02)	0.00	0.95
Diagnostic group ²			
- BC	0.69 (0.28-1.1)	0.31	<0.01
- CRC	0.55 (0.14-0.95)	0.19	0.01
- NHL	0.40 (-0.01-0.82)	0.15	0.06
- LEU	0.17 (-0.27-0.61)	0.06	0.44
Treatment ³			
- Local treatment	-0.01 (-0.9-0.89)	0.00	0.99
- Systemic treatment only	0.33 (-0.46-1.13)	0.05	0.41
-Systemic treatments and RT and/or surgery	0.03 (-0.79-0.84)	0.01	0.95
Pain	-0.18 (-0.54-0.17)	-0.03	0.31
Trouble sleeping	0.02 (-0.19-0.23)	0.01	0.86
Fatigue	-0.01 (-0.03-0.01)	-0.03	0.41
Late effects	0.18 (-0.07-0.43)	0.05	0.16
Anxiety	0.08 (0.04-0.11)	0.14	<0.01
PTSS	0.21 (0.19-0.24)	0.56	<0.01

Notes: Variables significantly associated with FCR in univariable models were included. 1 ref. female; 2 ref. MM; 3 ref. limited surgery. Block 1 Gender, Living w children, Age at survey (3% variance explained); Block 2 Diagnostic gr, Treatment (2%); Block 3 Trouble sleeping, fatigue (7%); Block 4 Late effects (1%); Block 5 Anxiety (12%); Block 6 PTSS (18%); Total variance explained (43%)

CONCLUSIONS

FCR is prevalent even among long-term YACS, and including survivors of MM with favorable prognoses. Attention to ongoing risks of PTSS and FCR in this growing survivor population is warranted to optimize future survivorship care.