

## FINAL REPORT – *SHORT FORM*

### **Long-term consequences of cancer and its treatment and satisfaction with health services – Predictors of physical and mental health in long-term survivors**

Period	1 March 2014 – 31 August 2017
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Funding	SWISS BRIDGE Foundation

## **Project Outline**

### ***Structure and Design***

Design	Cross-sectional cohort study
Sample	– Cohort I (5 years after cancer diagnosis): N=660 – Cohort II (10 years after cancer diagnosis): N=342 – Qualitative responses: N=380
Recruitment	Clinical Cancer Registry at the Cancer Center Leipzig
Data collection	questionnaires sent by post (if desired the questionnaire can also be completed online at the computer)

### ***Purpose of the Study***

To address the lack of knowledge with regard to the physical and mental long-term consequences of cancer and its impact on health services planning, we aim to identify physical and psychosocial symptom distress 5 and 10 years after a cancer disease and its impact on health care services utilization and supportive care needs in long-term cancer survivors. We further aim to identify predictors of physical and mental health contributing to quality of life in survivors. The main objective of the study is to analyze the frequency and impact of physical and mental long-term consequences of cancer on health care services utilization and services needs including treatment confidence, quality of life and satisfaction with care. We also aim to contribute to improving current knowledge about patient information and access to follow-up care facilities.

## ***Research Questions***

1. Which physical, psychological and social limitations do long-term cancer patients experience 5 and 10 years after cancer diagnosis, respectively?
2. What is the utilization of oncological and psychosocial health care facilities and services 5 and 10 years after cancer diagnosis, respectively?
3. How satisfied are long-term survivors with oncological and psychosocial support services as well as with information about health and treatment 5 and 10 years after cancer diagnosis, respectively?
4. Are there differences between long-term cancer survivors 5 and 10 years after a cancer diagnosis and the general population with regard to physical and psychosocial symptoms?

## ***Instruments***

<b>Primary Outcomes</b>	<b>Instrument</b>
Physical long-term consequences <ul style="list-style-type: none"> <li>• Comorbid conditions</li> <li>• Physical symptoms</li> </ul>	Comorbidity assessment instrument (Bayliss et al. 2005) EORTC QLQ-C30 – Symptom-Scales (European Organisation for Research and Treatment of Cancer Quality of life questionnaire – Core 30, Aaronson et al. 1993)
Quality of life	EORTC quality of life questionnaire (EORTC QLQ-C30)
Fatigue	Brief-Fatigue-Inventory (BFI-9)
Utilization of psycho-oncological health care facilities and services	SCNS (Supportive Care Needs Survey, Short-Form, Lehmann et al. 2012) / additional Items
level of information about disease, treatment, and support and satisfaction with information	Items from the Info-Modul of the EORTC (EORTC QLQ-INFO25) / additional Items
<b>Secondary Outcomes</b>	
Psychological distress <ul style="list-style-type: none"> <li>• Depression</li> <li>• Anxiety</li> <li>• Fear of progression</li> </ul>	NCCN distress thermometer Patient Health Questionnaire (PHQ-9) General Anxiety Disorder-scale (GAD-7) PA-F (Fear of progression- Questionnaire, Waadt et al. 2011)
Resilience	RS-11 (Resilience Scale – german version, Wagnild und Young 1993, Schuhmacher 2004)
Social support	OSS (Oslo Social Support Scale, Dalgard et al. 2006)

## Main Findings

The aim of our study was to identify physical and psychosocial long-term consequences of a cancer disease and treatment and its impact on supportive care needs, health care services utilization, satisfaction with received information and quality of life. Therefore we recruited adult cancer patients who were diagnosed with cancer 5 or 10 years before via the local cancer registry in Saxony in a cross-sectional cohort study. In addition, gender- and age-matched European reference values of the general population are used to compare quality of life. The study received research ethics committee approval by the University of Leipzig (Az. 070-14-10032014).

1,002 patients (53% male, mean age=67 years) were included in the final analysis (5-year-cohort: N=660; 10-year-cohort: N=342). The main diagnoses were prostate (26%) and breast cancer (22%). Regardless of the time of diagnosis, cancer survivors reported a significant lower health-related quality of life with a lot of physical symptoms in comparison with the population. The most common symptoms were fatigue, sleep disturbances, and pain. The mostly reported comorbid conditions were hypertension, osteoarthritis, back pain, and polyneuropathy (prevalence between 45% and 66%). Survivors reported on average 5 comorbidities, 23% had 7 or more comorbidities. Survivors with fewer comorbid conditions reported better quality of life. Type and prevalence of long-term and late effects differ with disease-related factors (e.g., cancer type, treatment) and characteristics of the patient (e.g., age, sex, comorbidity). Female survivors had a lower quality of life and a significant higher level of morbidity than male survivors. Breast and gynecological cancer survivors reported the highest and prostate cancer survivors had the lowest comorbidity burden. The prevalence of comorbid conditions increases with age and in patients with metastasis or recurrence.

About one in three cancer survivors are psychologically distressed with no differences between the both cohorts (Depression: ~16%; Anxiety: ~8%). Depression and anxiety were higher than in the population. Five years after cancer diagnosis, survivors had significantly higher fear of progression-values than 10 years after diagnosis. Survivors were most worried about what will become of the family; they have been nervous prior to doctor's appointment or periodic examinations and have been afraid of relying on strangers for activities of daily living. Higher fear of progression was related to female gender, younger age, and disease progression. In both cohorts, there was also a significant positive association between fear of progression and depression and anxiety. Regarding received information about disease, treatment, and support services, cancer survivors reported information deficits in several areas. About 40% of the survivors reported they didn't get information about coping with disease effects, only 50% had been informed about support offers. 15% of the cancer survivors perceived the received information as not understandable.

Five years after diagnosis cancer survivors expressed more support needs than 10 years after diagnosis. The greatest need for support they called in the areas fear of recurrence / progression, fixed contact person and physical problems. One on four survivor wanted support for his burdened relatives, for behavioral changes that increase well-being and with regard to his future worries. On the other hand, only 10% received support from a psychologist or psychotherapist. The need for support is particularly high among those 25% of cancer survivors who experienced little support from their social environment.

**In comparison to the general population, long-term cancer survivors show:**

- lower quality of life (especially role function (everyday activities and leisure), physical functioning, and social functioning)
- higher physical symptom burden (especially pain, insomnia, dyspnoe)
- higher fatigue (35-42% of the survivors showed moderate to high fatigue symptomatology)
- higher psychological distress (depression and anxiety)

**Predictors for good quality of life**

- male gender
- low disease stage without metastases or recurrence
- less invasive cancer treatments (especially chemotherapy, radiotherapy; particularly relevant in the 5 year cohort)
- low level of morbidity

**Predictors for good physical health**

- male gender
- younger age
- less invasive cancer treatments (especially hormone therapy; particularly relevant in the 5 year cohort)
- no second cancer disease
- high quality of life

## Sample

1,002 patients were included in the final analysis (postal participation: n=758 / online participation: n=244). The patients who completed the questionnaires online were younger (M=62.1 years;  $p<0.001$ ) and the percentage of male patients was higher (60.2% male;  $p=0.008$ ) than in the group of patients who participated by mail (M=68.2 years; 50.5% male).

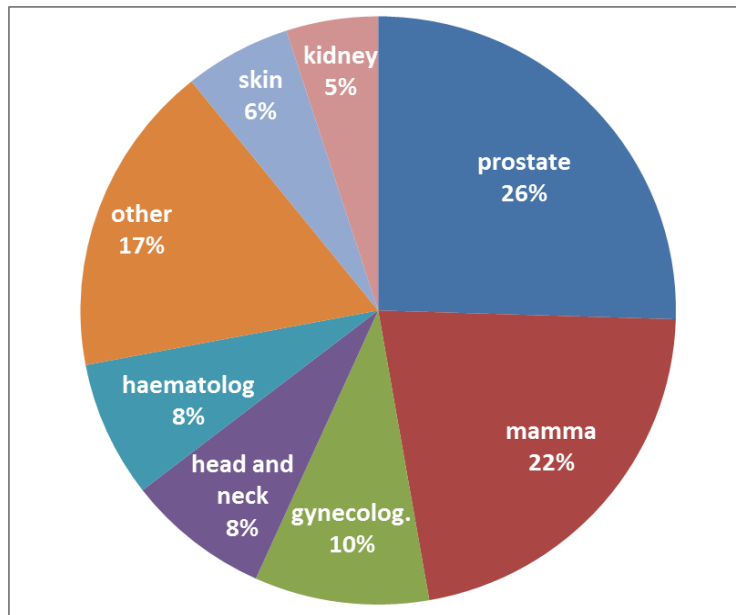
Table below shows social and medical characteristics for all participants separated for the two cohorts (5 and 10 years post diagnosis). In the cohort 10 years post diagnosis survivors were older ( $p=0.010$ ), had a higher household income ( $p=0.018$ ) and were more likely diagnosed with haematological cancer and less likely diagnosed with breast cancer ( $p<0.001$ ) compared to the 5-year-cohort.

*Sample characteristics for both cohorts 5 and 10 years post cancer diagnosis*

		Total sample	5y post cancer diagnosis cohort	10y post cancer diagnosis cohort	<i>p</i>
		N (%)	n (%)	n (%)	
		1002 (100)	660 (65.9)	342 (34.1)	
Age, M (SD)		66.7 (10.5)	66.3 (10.5)	67.6 (10.4)	<i>0.052</i>
	18-49 years	69 (6.9)	49 (7.4)	20 (5.8)	<i>0.010</i>
	50-70 years	468 (46.7)	325 (49.2)	143 (41.8)	
	71-85 years	465 (46.4)	286 (43.3)	179 (52.3)	
Sex	male	530 (52.9)	350 (53.0)	180 (52.6)	<i>0.947</i>
Marital situation	married	719 (72.0)	469 (71.4)	250 (73.3)	<i>0.893</i>
	single	64 (6.4)	45 (6.8)	19 (5.6)	
	divorced	110 (11.0)	75 (11.4)	35 (10.3)	
	widowed	105 (10.5)	68 (10.9)	37 (10.5)	
Employment status	employed	204 (20.4)	136 (21.0)	68 (20.4)	<i>0.847</i>
	retirement pension	665 (67.7)	436 (67.2)	229 (68.8)	
	disability pension	92 (9.2)	63 (9.7)	29 (8.7)	
	unemployed/ housewife	20 (2.0)	13 (2.0)	7 (2.1)	
Medical data*	cancer recurrence	106 (11.1)	63 (10.1)	43 (13.1)	<i>0.193</i>
	metastases	104 (10.9)	75 (12.0)	29 (8.9)	<i>0.156</i>
	second cancer disease	192 (19.6)	123 (19.1)	69 (20.6)	<i>0.611</i>
Treatment	surgery	874 (91.9)	583 (92.7)	291 (90.4)	<i>0.258</i>
	chemotherapy	363 (49.1)	241 (49.1)	122 (49.2)	<i>0.977</i>
	radiotherapy	577 (68.9)	382 (68.5)	195 (69.9)	<i>0.693</i>
	hormone therapy	190 (28.4)	137 (30.1)	53 (24.7)	<i>0.168</i>
Number of treatments	0-1	359 (36.1)	237 (36.2)	122 (36.0)	<i>0.214</i>
	2-3	529 (53.2)	338 (51.6)	191 (55.8)	
	>=4	106 (10.7)	80 (12.2)	26 (7.7)	

\* based on the self-reports of patients

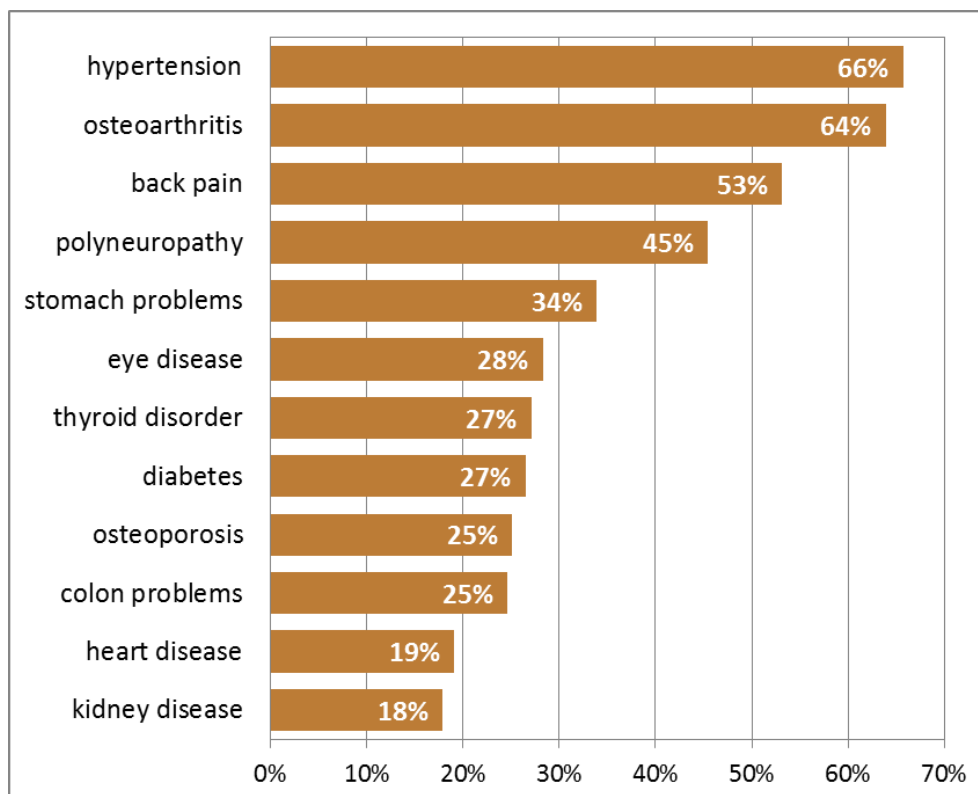
### Diagnoses of the study participants



## Results

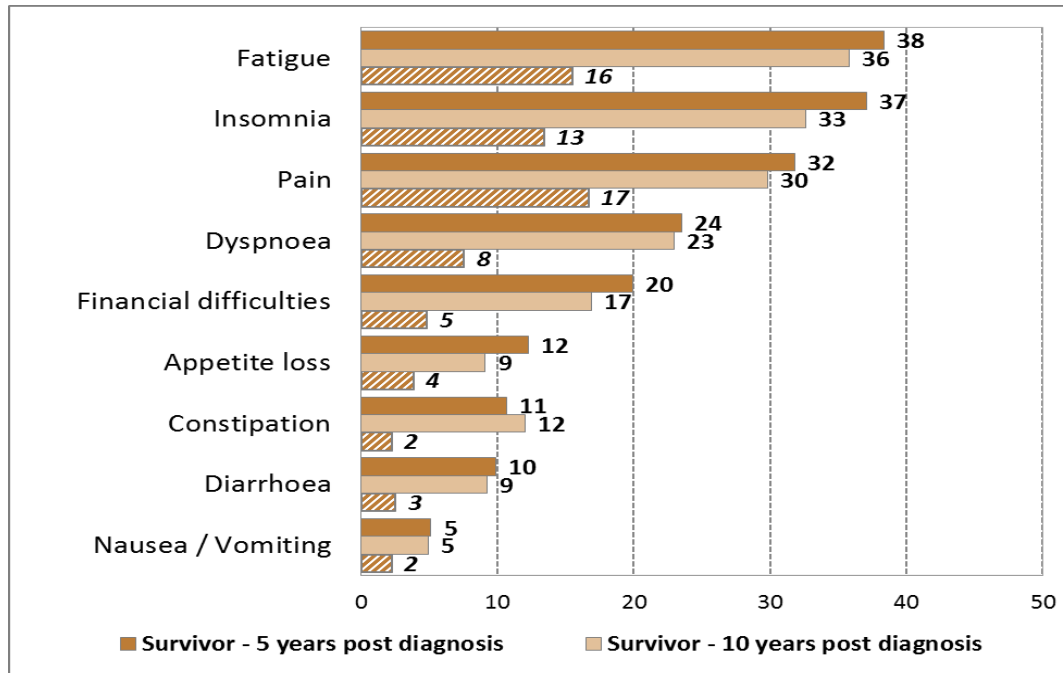
### Comorbid conditions

Survivors reported on average 5 comorbidities (SD=3.2). From the list of 18 comorbid conditions, 23% had 7 or more comorbidities. We found no significant differences in the number of conditions between the two cohorts ( $p=0.219$ ). Breast and gynaecological cancer survivors reported the highest number ( $M=5.2$ ) and prostate ( $M=4.5$ ) and head and neck cancer survivors ( $M=4.2$ ) had the lowest number of comorbid conditions.

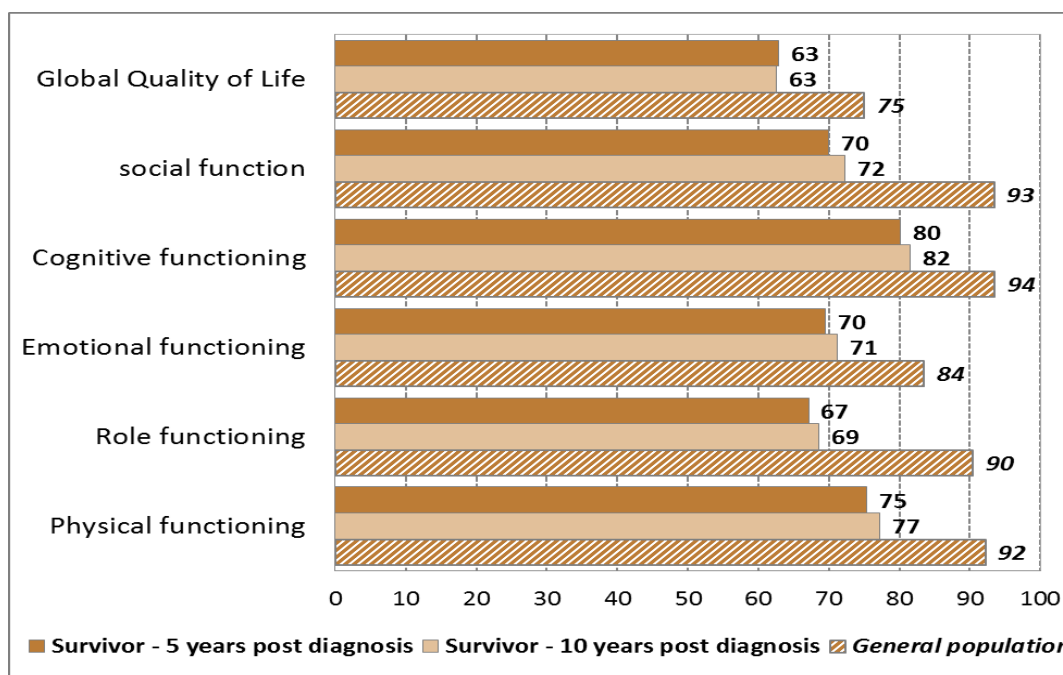


**Health related quality of life**

We found no significant differences in all quality of life dimensions between cancer survivors 5 and 10 years post diagnosis except for appetite loss that was higher in the 5-year-cohort (p=0.04). We compared the patients' quality of life to a representative gender- and age-matched comparison group from six European general population normative studies (male: 52.9%; age group: 60-69 years; N=16,151) (Hinz et al. Acta oncologica 2014). The cancer survivors had significantly lower values in all areas of quality of life than the general population.



*Symptom scales (EORTC) in both cohorts in comparison to the reference population*



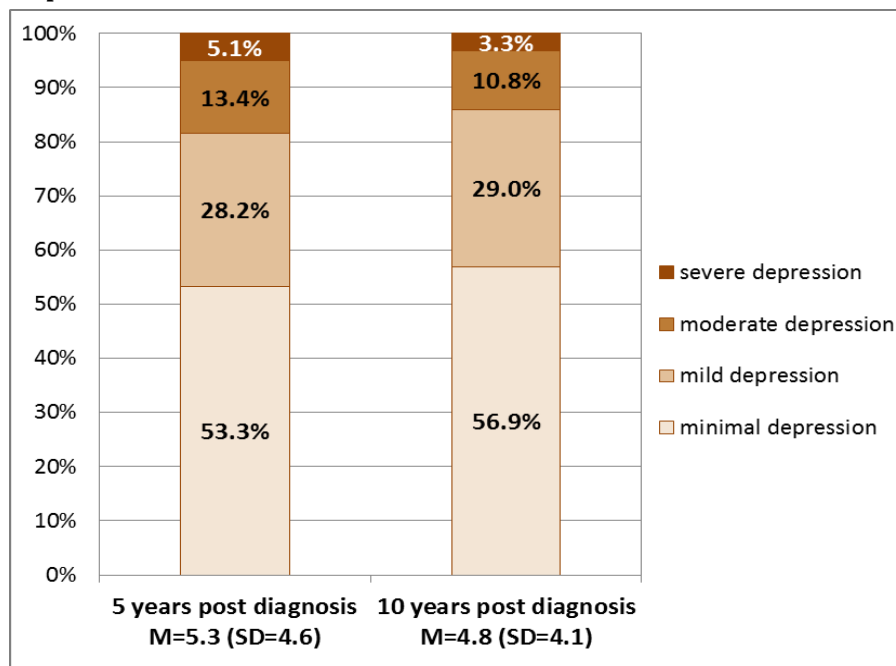
*Functioning scales (EORTC) in both cohorts in comparison to the reference population*

## **Psychological distress**

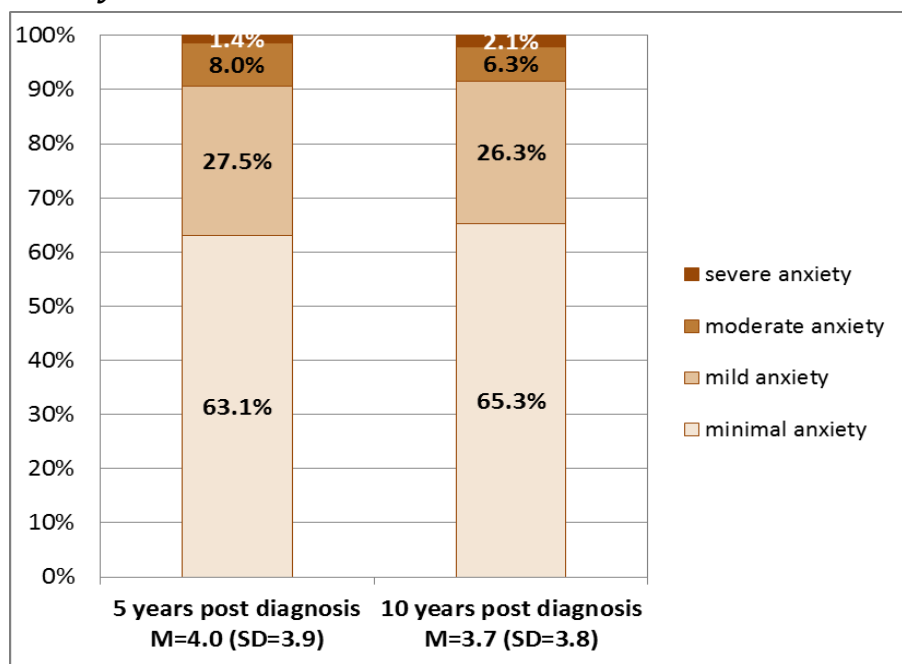
About one in three cancer survivors were psychological distressed with no differences between the both cohorts (Distress-Thermometer, Cutoff  $\geq 5$ ).

Regarding depression and anxiety, there were no significant differences between the cohorts ( $p=0.138$  /  $p=0.232$ ). Depressive symptomatology of the cancer survivors was significantly higher than in the general population (PHQ-9 Sumscore:  $M=2.91$ ). Anxiety symptomatology of the cancer survivors was also significantly higher than in the general population (GAD-7 Sumscore:  $M=2.95$ ).

### ***Depression***



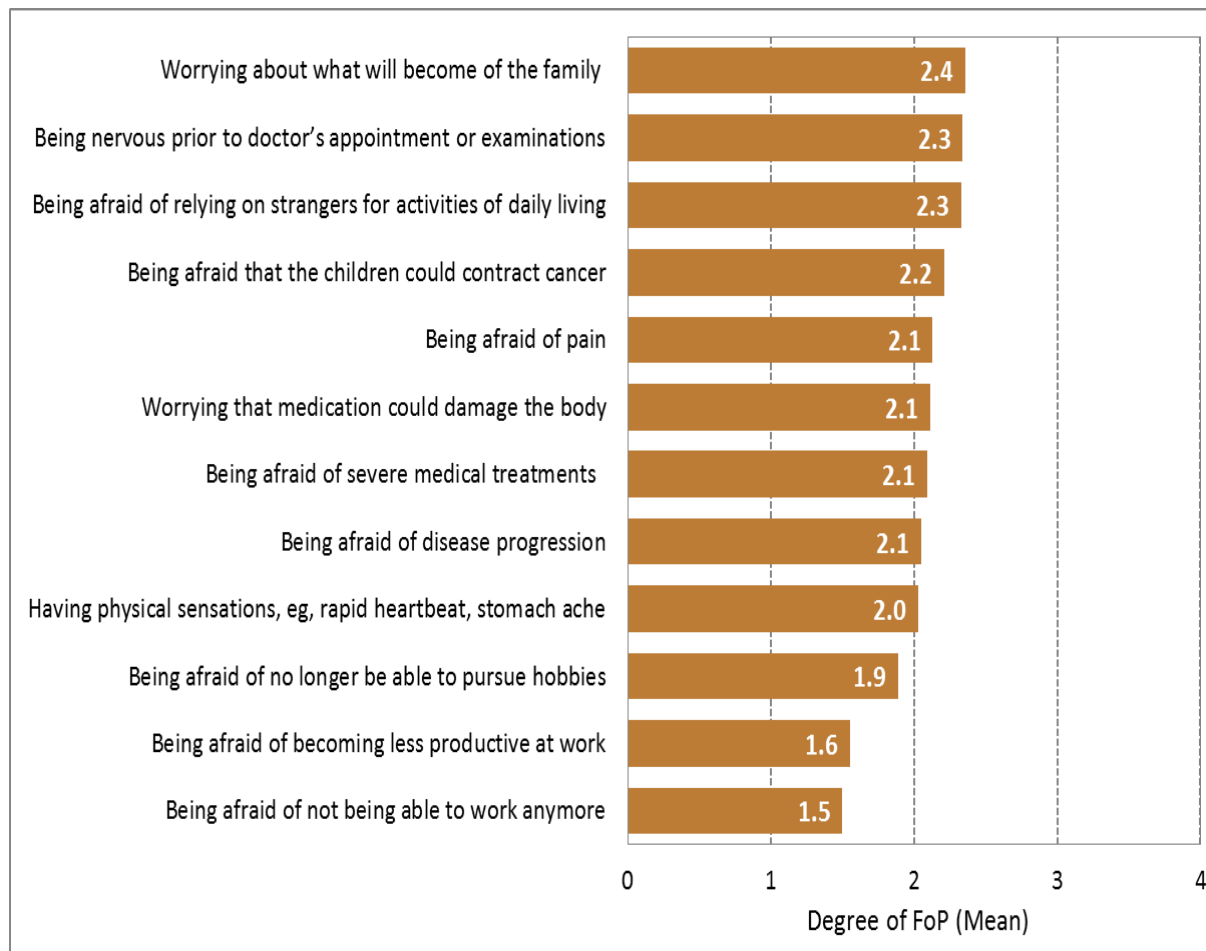
### ***Anxiety***





### ***Fear of progression***

Five years after cancer diagnosis, survivors had significantly higher fear of progression-values than 10 years after diagnosis.



*Fear of progression- Questionnaire, Single-Items (0=never/ 4=very often)*

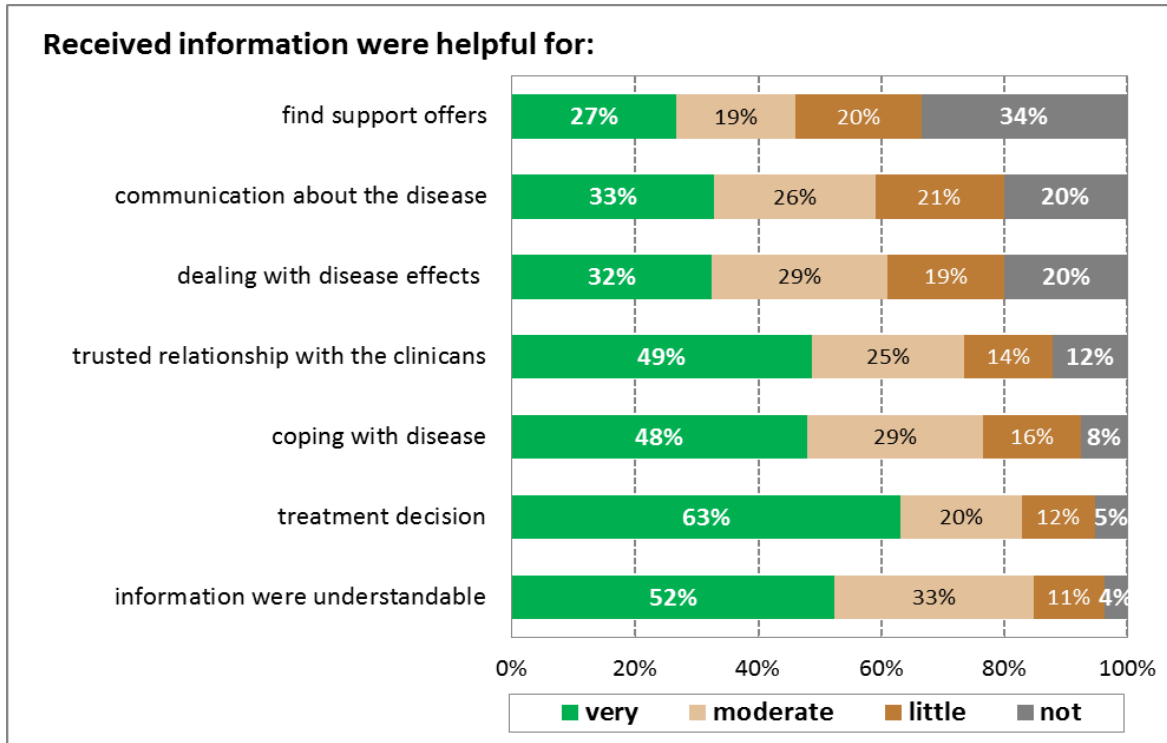
Fear of progression depended on demographic factors, cancer site, and psychological distress. Higher fear of progression was related to female gender, younger age, and disease progression. High values for fear of progression had patients with breast, gynaecological, kidney, and haematological cancer (M=27.9–25.1). Prostate cancer survivors showed lowest fear of progression values (M=20.6).

In both cohorts, there was also a significant positive association between fear of progression and depression and anxiety.

Our findings indicate the need to identify patients, who are suffering from high levels of Fear of progression, and to develop and provide appropriate interventions for patients who are experiencing clinically relevant Fear of progression.

**Information received and satisfaction with information**

We assessed the self-perceived level of information about disease, treatment, and support in cancer survivors and their satisfaction with this information:



**Support needs, utilization and social support**

