

Health related quality of life and mental health in long term survivors with brain tumor, Hodgkin's or non-Hodgkin's lymphoma: A registry based study in Schleswig-Holstein, Germany, based on adults

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Background & Aims

Prognosis of most cancer diseases has improved during the last decades leading to a growing cohort of long term cancer survivors. Not only diagnosis and treatment of cancer but also long term effects of treatment and comorbidity may impact health related quality of life and mental health. Patients have access to health care specialists during the time span of diagnosis and treatment and during aftercare – and thus, have the ability to talk about perceived problems or changes if needed. Afterwards it might be harder to jump the hurdle and get into contact with a psychologist for example (Fig. 1).

We aimed to investigate health related quality of life and mental health in a large cohort of adult cancer survivors with brain tumors (BT), Hodgkin's (HL) and non-Hodgkin's lymphoma (NHL) and aimed to assess whether there is a need for lowering the hurdle to get into contact with health care professionals.

Methods

We included 1035 subjects with a diagnosis of BT (9%; ICD-10 C71, D33.0-33.2), HL (22.5%; C81) or NHL (68.5%; C82-84) 5-15 years ago and notification to the epidemiological cancer registry Schleswig-Holstein. They were asked to participate in a population based survey targeted on endocrine late effects, quality of life and mental health. For the latter purposes, SF-36 (V1.0; analyzed: t-score, standardized to U.S. population 1990) and WHO-5 were included in the study questionnaire.

Results

Of all potential participants, 558 subjects (54%) took part whereas 72 subjects had deceased and 62 actively refused participation. Their mean age at tumor diagnosis was 52.7 +/- 14.6 yrs and mean time of follow-up was 9.6 +/- 3 yrs (Tab. 1).

All – except 10 survivors [NHL n=8; HL=1; BT=1] – had contact to health care professionals during the last 12 months (Tab. 2). Adjusted for age and sex, no statistical significant difference was seen between survivors of the three tumor groups regarding their likelihood of having contact to physicians.

72% of all subjects reported a satisfying or good wellbeing during the last 2 weeks, while the presence of a clinical manifest depression was highly likely in 13% of all subjects (Fig. 2). Adjusted for age and sex, survivors of BT patients were three times more likely (OR=3.1; 95% CI: 1.3-7.6) to have low WHO-5 scores being indicative for depression compared to HL (ref.) and NHL patients (OR=1; 0.5-2). Of all 65 patients with low WHO-5 scores, only 13 had contact to a psychiatrist or psychologist.

In contrast, mean SF-36 scores for the mental component scale did not differ between the groups, but was considerably low (~30 points). Compared to HL and NHL patients, BT patients had higher scores for vitality, social functioning, general mental health, but not for role limitations caused by emotional problems (Fig. 3).

Summary and Conclusion

Our study is the largest population based survey on endocrine function, health related quality of life and mental health in adult cancer survivors in Germany. With limitations of a questionnaire approach our data support reduced mental health in long term survivors of brain tumors, Hodgkin's and non-Hodgkin's lymphoma. Only few of them sought help at a psychiatrist or psychologist during the last 12 months. Further efforts have to be undertaken to lower the hurdle of getting in contact with those health care professionals.



Further information:

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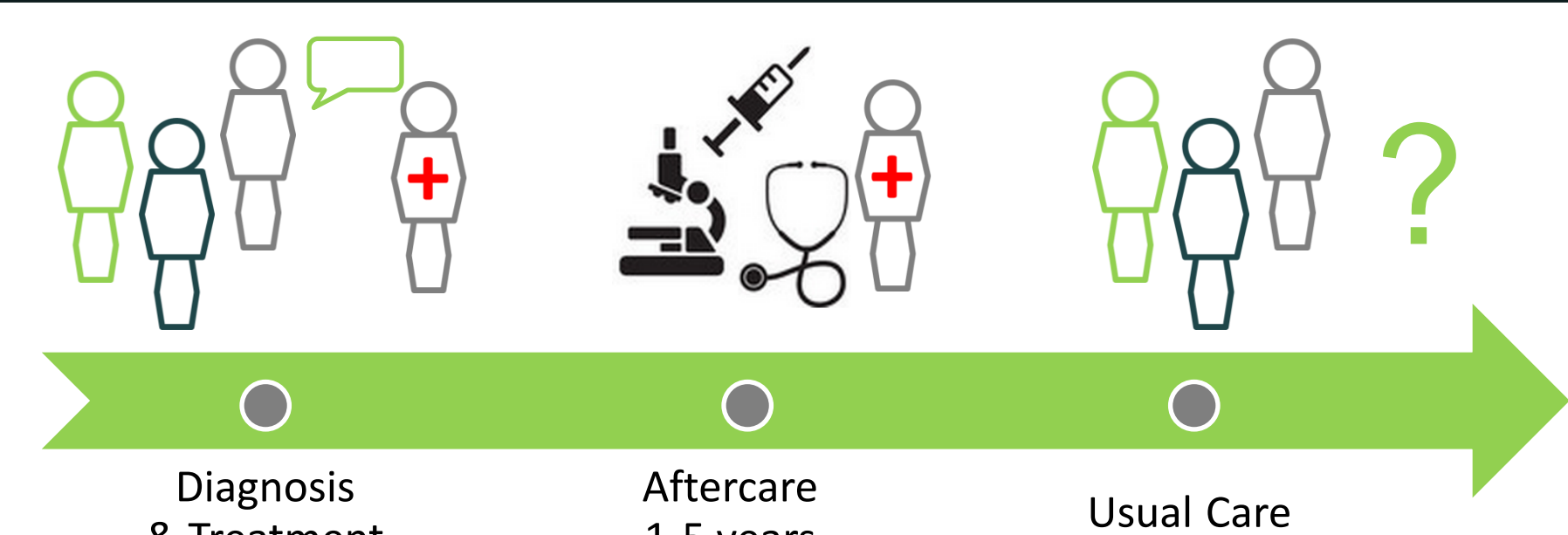


Fig. 1: Tumor patient's contact with health care professionals

Tab. 1: Description of our study population according to subgroup

	Hodgkin's lymphoma	Non-Hodgkin's lymphoma	Brain tumor
Contacted	233	709	93
Active refusal of participation	2 (0.9%)	59 (8.3%)	1 (1.1%)
Moved away	34 (14.6%)	46 (6.5%)	14 (15.1%)
Deceased	7 (3.0%)	53 (7.5%)	12 (12.9%)
Crude participation	117 / 233 (50.2%)	398 / 709 (56.1%)	43 / 93 (46.2%)
Participation among eligibles	117 / 192 (60.9%)	398 / 610 (65.2%)	43 / 67 (64.2%)
Sex			
female	46 (39.3%)	176 (44.2%)	22 (51.2%)
male	71 (60.7%)	222 (55.8%)	21 (48.8%)
Age (years)			
at diagnosis	42 (SD 15)	57 (SD 12)	44 (SD 13)
at survey	52 (SD 15)	66 (SD 12)	53 (SD 13)

Tab. 2: Proportion of survivors with contact to physicians during the last 12 months

	Hodgkin's lymphoma	Non-Hodgkin's lymphoma	Brain tumor
General physician	89.7	83.8	93.0
Ophthalmologist	30.8	51.5	41.9
Oncologist	38.5	46.0	23.3
Dermatologist	19.7	33.3	23.3
Internist	12.0	32.6	20.9
Neurologist	14.5	13.6	65.1
Psychiatrist / psychologist	9.4	5.8	18.6
Urologist	12.8	21.2	11.6
Else	24.8	25.0	48.8
Gynecologist*	76.1	64.2	68.2

* Only women were considered

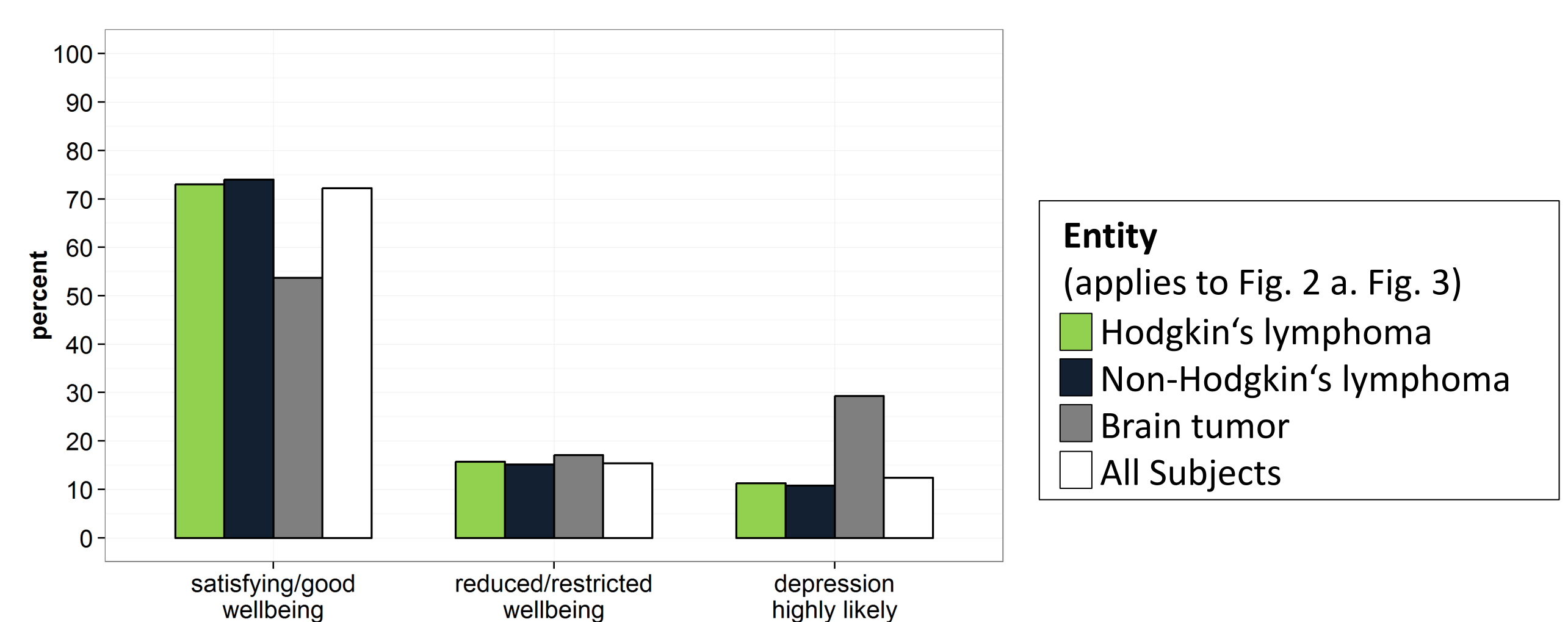


Fig. 2: WHO-5 scores according tumor subgroups

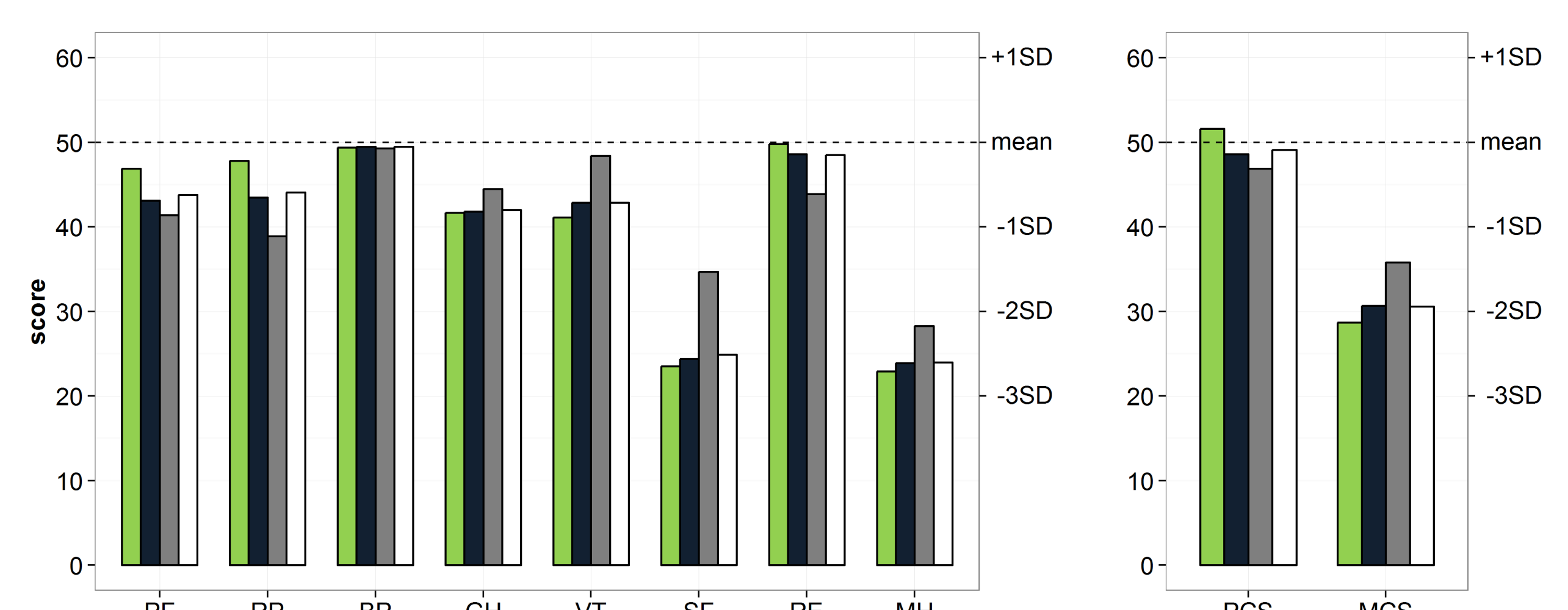


Fig. 3: SF-36 scores according tumor subgroups

Note: All summary measures use norm-based scoring (mean = 50, standard deviation = 10, U.S. gen. pop. norm, 1990). SF-36 domains: PF = Physical Function; RP = Role Physical; BP = Bodily Pain; GH = General Health; VT = Vitality; SF = Social Function; RE = Role Emotional; MH = Mental Health; PCS = Physical Component Summary; MCS = Mental Component Summary.