

ORIGINAL ARTICLE

Impact of health-related stigma on psychosocial functioning in cancer patients: Construct validity of the stigma-related social problems scale

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Abstract

Objective: The aim of this study was to evaluate the validity of Stigma-related Social Problems scale (SSP) in a cancer population.

Materials and methods: The SSP was sent to 1,179 cancer patients. Mean age was 67.9 year and 43% were women. Tests of internal consistency reliability, construct validity, item-scale convergent validity, ceiling and floor effects and known-group validity were conducted.

Results: The response rate was 62%, and the final sample comprised 728 patients. Reliability coefficients were high for both subscales (Cronbach's alpha = 0.94). Exploratory factor analyses confirmed the unidimensionality and homogeneity of the scales. Item-scale correlations for both scales indicated satisfactory item-scale convergent validity. The proportion of subjects scoring at the lowest possible score level was 26% for the *Distress* scale and 28% for the *Avoidance* scale, while ceiling effects were marginal (<1%). The proportion of missing items was low, ranging from 1.4% to 1.5%. Known-group validity tests confirmed that the scales could capture expected differences between subgroups.

Conclusions: The SSP scale is a feasible instrument with sound psychometric properties that is validated in a study on 728 cancer patients. The instrument can be used to identify cancer patients at risk for psychosocial disturbances and thus in need of support.

KEYWORDS

cancer, stigma, stigma-related social problems scale, validation

1 | INTRODUCTION

Stigma can be described as an internalised sense of shame about having an unwanted condition, along with fear of discrimination due to imputed inferiority or unacceptability (Goffman, 1990). Stigma

can affect social relationships and psychological and behavioural responses and may lead to adverse health outcomes. Health-related stigmatisation can be defined as a process by which a person is associated with negative properties due to his or her illness (Pachankis et al., 2018). Various signs and symptoms of disease are associated

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with health-related stigma, and patients may experience distress that strongly affects their quality of life (Browne, Ventura, Mosely, & Speight, 2013; Earnshaw & Quinn, 2012). Stigma is identified in several cancer diagnoses, for example, head and neck cancer (Threader & McCormack, 2016), lung cancer (Williamson et al., 2018), and prostate cancer (Ettridge et al., 2018). Cancer diagnoses related to certain behaviours or conditions, such as smoking and alcohol abuse (Matejcic, Gunter, & Ferrari, 2017; Mons, Gredner, Behrens, Stock, & Brenner, 2018), may be perceived as having been caused by the individual's lifestyle (Butt, 2008) and can therefore be more stigmatising and cause internalised feelings of guilt (Weiss et al., 2017). Among breast and prostate cancer patients, stigmatisation is additionally influenced by the loss of the female or male identity or sexual functioning and can cause severe distress and withdrawal from social relationships (Fang, Lin, Chen, & Lin, 2015; Lin, Burri, & Pakpour, 2016; Ou et al., 2019; Phelan et al., 2013).

Stigma is related to psychological distress, which may lead to social isolation if one avoids participating in social activities due to fear of being rejected or negatively valued (Fang, Cheng, & Lin, 2018; Pachankis, 2007). Social isolation is associated with depression, and individuals at risk of psychosocial disturbances need to be identified and offered appropriate treatment and support (Werner-Seidler, Afzali, Chapman, Sunderland, & Slade, 2017).

Instruments for measuring stigma mostly focus on how the person perceives stigma by others, such as the Explanatory Model Interview Catalogue (Lebel et al., 2013) or the degree of anticipated stigma, as measured by the Chronic Illness Anticipated Stigma Scale (Earnshaw & Quinn, 2012). There are disease-specific instruments, such as the Cataldo Lung Stigma Scale (Chambers et al., 2015), that contain different subscales measuring consequences of living with the disease, such as shame, discrimination, social isolation, disclosure and negative self-image or attitudes. Other instruments measuring health-related quality of life (HRQoL) focus on aspects of physical and mental health, such as physical and social functioning and mental well-being (Fayers & Machin, 2016), but do not include items concerning the impact of stigma on social life. There is a lack of generic instruments for measuring the impact of health-related stigma on psychosocial functioning in a diverse cancer population. However, the similarity of the consequences of stigma for different conditions indicates that it is possible to use a generic measure to assess the effects of stigma on psychosocial functioning (Van Brakel, 2006). The Stigma-related Social Problems (SSP) scale was constructed to measure the impact of health-related stigma on psychosocial functioning in people with different diseases and disorders. The instrument was validated in a general population sample, and normative Swedish reference data are available for comparison (Ohlsson-Nevo & Karlsson, 2019).

The present study is part of a larger project, the Mid-Sweden Cancer Rehabilitation Survey, with a purpose to investigate HRQoL, stigma and cancer rehabilitation needs for people diagnosed with, and treated for, cancer in the Region of Örebro County, Sweden. The specific aim of the present study was to evaluate the validity of the SSP in a cancer population.

2 | MATERIALS AND METHODS

2.1 | Study design

The study used a descriptive cross-sectional design. A postal survey was conducted in Region Örebro County.

2.1.1 | Sample

A total of 1,179 patients who received a cancer diagnosis between 2 November 2015 and 31 October 2016 were identified through quality registers based on the Swedish register Information Network for Cancer. The final sample comprised of 28 different cancer diagnoses.

2.1.2 | Procedure

A nine-page questionnaire comprising demographic questions: the Cancer Rehabilitation Inventory, the SSP, the EORTC QLQ-C30, and the informational module INFO25, was distributed along with an information letter and a prepaid response envelope via regular mail in April 2017 to 1,179 persons. If the questionnaire was not returned after five weeks, a reminding letter and a new questionnaire were sent out.

2.1.3 | Questionnaire

Stigma-related Social Problems scale (SSP)

The SSP is a generic instrument developed to measure the impact of health-related problems on psychosocial functioning (Ohlsson-Nevo & Karlsson, 2019). The instrument comprises 20 items on a four-point response scale and measures two domains: *Distress* (10 items) and *Avoidance* (10 items). *Distress* is measured by asking the respondents to rate whether they feel bothered (embarrassed, inhibited, uncertain) because of their health condition (physical or mental) in various social activities and situations. *Avoidance* is measured by asking if they try to avoid the same social activities and situations. The SSP items cover a broad range of social activities. Item responses are summed to scale scores and transformed into scales of 0 to 100. A higher score indicates more psychosocial dysfunction. A scale score < 20 indicates *no or very mild limitations*, a score between 20 and 39 indicates *mild impairment*, a score from 40 to 59 indicates *moderate impairment* and a score ≥ 60 indicates *severe impairment*. The instrument has been psychometrically validated, and reference data from the Swedish population are available (Ohlsson-Nevo & Karlsson, 2019).

2.1.4 | The EORTC QLQ-30

The EORTC QLQ-C30 measures generic HRQoL and comprises 30 items with 4-point response alternatives, *not at all, a little, quite a lot*

and *very much*, for most of the questions except the last two questions where a response scale from 1 to 7 is used to describe health and quality of life.

The EORTC QLQ-C30 contains five functional subscales (physical functioning, role functioning, emotional functioning, cognitive functioning and social functioning), nine symptom subscales and a global health status scale. The symptom scales include a three-item scale measuring fatigue, two two-item scales measuring pain and nausea and vomiting, and six single-item scales measuring dyspnea, insomnia, appetite loss, constipation, diarrhoea and financial impact.

The psychometric properties of the EORTC QLQ-C30 have been previously evaluated in different languages and clinical settings (Aaronson et al., 1993; Bjordal et al., 2000; Kobayashi et al., 1998; Singer et al., 2009; Yun et al., 2004).

The Role functioning and Social functioning scales were used for testing criterion validity of the SPP.

2.2 | Statistical and psychometric methods

Mean and standard deviation (SD) are presented for continuous variables, frequency and proportion for categorical variables. Significance testing between two groups was performed with Student's *t* test for continuous data and the Mann–Whitney U-test for ordinal data. Comparisons of differences between three groups or more were analysed with one-way ANOVA and the Kruskal–Wallis test. Tukey's post hoc test was used for testing of differences between group means. Correlations were analysed with Spearman's rank correlation coefficient (ρ).

The magnitude of group differences was estimated by calculation of the effect size (ES). ES makes it possible to interpret the importance of a group difference and facilitates comparison across different measures. Effect size is calculated as the mean difference between groups, divided by the pooled standard deviation (Fayers & Machin, 2016). ES was interpreted according to Cohen: trivial = <0.2 , small = 0.2 to <0.5 , moderate = 0.5 to <0.8 and large = ≥ 0.8 (Fayers & Machin, 2016).

The SSP scores in the present study are compared with the scores obtained in a general population (Ohlsson-Nevo & Karlsson, 2019). When measuring HRQoL, a difference of five to 10 points on a 100-point scale has been considered to be of clinical importance (Fayers & Machin, 2016).

SAS 9.4 was used for exploratory factor analysis, and IBM's Statistics for Windows version 22 was used to perform other statistical analysis.

2.2.1 | Reliability

Cronbach's alpha coefficients were calculated for estimating the internal consistency reliability. A coefficient of 0.70 is considered

adequate for group data, although 0.80 is desirable. An alpha of 0.90 is recommended for individual assessment (Fayers & Machin, 2016).

2.2.2 | Validity

The Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy and Bartlett's test of sphericity were used to determine whether the data were suitable for factor analysis (Tabachnick & Fidel, 2014). Exploratory factor analysis (principal factors) was employed for testing the unidimensionality and homogeneity of the two SSP scales. Item responses for the scales were analysed separately. Squared multiple correlations were used for computing prior communality estimates, and the eigenvalues-greater-than-one rule (Kaiser's criterion) was used for extracting factors. Items that load on a given factor should have high factor loadings and a loading of at least 0.40 were considered sufficient, a limit value that is often used in the development and validation of patient-reported measures (Cappelleri et al., 2014). To test the stability and generality of the two factors, subgroup analyses were performed for gender and age.

The discriminant validity of the *Distress* and *Avoidance* scales, that is, whether the two scales measure two different aspects of stigma-related social problems, was tested in the total population as well as in gender, age, level of education and occupation subgroups. The degree of association was calculated using the correlation coefficient between the scales.

Item-scale convergent validity was assessed by calculating the correlation (corrected for overlap) between each item and its own subscale. A correlation of 0.40 or greater was considered satisfactory for item-scale convergent validity (Ware, 1994).

Criterion validity was assessed by testing the relationship between the SSP scales and two of the EORTC QLQ-C30 scales: (a) the Role Functioning scale and its two items, item 6, "During the past week, were you limited in doing either your work or other daily activities?" and item 7, "During the past week, were you limited in pursuing your hobbies or other leisure time activities?" and (b) the Social Functioning scale and its two items, item 26, "During the past week, has your physical condition or medical treatment interfered with your family life?" and item 27, "During the past week, has your physical condition or medical treatment interfered with your social activities?" Correlations were interpreted as low (<0.30), moderate (0.30 – 0.60) or strong (>0.60) (Revicki, Rentz, Luo, & Wong, 2011).

The proportions of subjects scoring at the highest (ceiling effect) and lowest (floor effect) possible scale levels were calculated. A floor or ceiling effect was defined as 15% or more of the sample scoring at the lowest or highest scale level (McHorney, Ware, Lu, & Sherbourne, 1994).

Known-group analysis was performed for testing the sensitivity and ability of the scales to capture anticipated differences between groups, such as differences between men and women, between age groups and between levels of education.

3 | RESULTS

The final sample consisted of 728 patients (response rate = 62%), who had received their cancer diagnoses 6 to 18 months prior to the survey.

3.1 | Sample characteristic

Characteristics of the study population are given in Table 1. Women constituted 43.4% of the sample and men 56.6%. The mean age was 67.9 years (range 25–96 years), and the median age was 70 years. There were 27.8% professionally active, and 64.3% received old age pension.

3.2 | Psychometric properties of the SSP

3.2.1 | Reliability

In the total sample, the internal consistency reliability coefficient (Cronbach's alpha) was 0.94 for both the *Distress* and the *Avoidance* scales. In all subgroup analyses by gender, age, education and occupation, Cronbach's alpha coefficients were between 0.91 and 0.96 for the *Distress* scale and between 0.90 and 0.95 for the *Avoidance* scale (Table 2).

3.2.2 | Construct validity

The Bartlett's test of sphericity was significant ($p < .000$) for the *Distress* and *Avoidance* items, and the KMO index of sampling adequacy was 0.96 for both measures, indicating that data were suitable for factor analysis. Exploratory factor analysis confirmed the construct validity of the SSP and the homogeneity of the *Distress* and *Avoidance* scales. Eigenvalues for the first factor were 6.5 (*Distress*) and 6.1 (*Avoidance*), while eigenvalues for the second factor were 0.4 and 0.5 respectively. Factor loadings ranged between 0.68 and 0.88 for the *Distress* scale and between 0.64 and 0.86 for the *Avoidance* scale. The common variance explained by the *Distress* and *Avoidance* factors was 96.5% and 94.6% respectively. The *Distress* and *Avoidance* factors were reproduced in gender and age subgroups, and eigenvalues were above 5.7 for the first and below 0.7 for the second factor, in all subgroup tests.

3.2.3 | Item-scale convergent validity

Item-scale correlations for both the *Distress* and the *Avoidance* scales indicated satisfactory item-scale convergent validity ($r \geq .40$) (Table 2). In the total sample, correlations ranged between .77 and .87 for the *Distress* scale and between .74 and .87 for the *Avoidance*

scale. In all subgroup analyses, item-scale correlations exceeded the minimum desired level of .40.

3.2.4 | Inter-scale correlation

The correlation between the *Distress* and *Avoidance* scales was .81 in the total sample and above .70 in all age groups except for the age group 40–49 years, who had a correlation of .66. In subgroups based on education, occupation or gender, the correlations were between .68 and .93.

3.2.5 | Criterion validity

Moderate correlations were found between the *Distress* scale and the EORTC QLQ-C30 Social functioning scale ($\rho = -0.55, p < .01$) and the Role Functioning scale ($\rho = -0.50, p < .01$). The correlation between the *Distress* scale and items 6, 7, 26 and 27 were moderate ($\rho = 0.46-0.56$). The strongest correlation was found between item 27 *During the past week, has your physical condition or medical treatment interfered with your social activities?* and the *Distress* scale ($\rho = 0.56, p < .01$).

The correlation between the *Avoidance* scale and the EORTC QLQ-C30 Social functioning scale was moderate ($\rho = -0.50, p < .01$) as was the correlation with the Role functioning scale ($\rho = -0.47, p < .01$). The correlation between the *Distress* scale and items 6, 7, 26 and 27 was moderate (.41–.50).

3.2.6 | Floor and ceiling effects

The proportion of respondents scoring at the lowest possible scale level (floor effect) was 26.4% for the *Distress* scale and 28.6% for the *Avoidance* scale. Evaluation of floor effects for individual items showed that about half of the sample (46%–63%) answered “not at all bothered” (floor effect) on the *Distress* items, while 52.5%–63% answered that they did not avoid participating in these activities (floor effect). The proportion scoring at the highest possible level (ceiling effect) was marginal, 0.5% and 1.1% respectively (Table 3).

3.2.7 | Completeness of data

In the total sample, the proportion of missing items was low for both scales, ranging between 1.4% and 1.5%. In the subgroups, missing items accounted for 0%–3.5% for both scales, except for item 10 (being physically intimate), with 0%–6.0% missing.

A scale score was calculated for respondents who completed at least half the items in a scale. The percentage of respondents for whom scale scores were computable was 98.5% for the *Distress* scale and 98.6% for the *Avoidance* scale.

TABLE 1 Characteristics of the study sample

Characteristics	No (%)
Total	728
Gender	
Female	316 (43.4)
Male	412 (56.6)
Age (years)	
Mean (SD)	67.9 (12.3)
Median (IQR)	70.0 (14)
Range	25–96
Age group category	
20–29	5 (0.7)
30–39	19 (2.6)
40–49	40 (5.5)
50–59	86 (11.8)
60–69	213 (29.3)
70–79	251 (34.5)
80+	114 (15.7)
Country of birth	
Sweden	636 (87.4)
Other Nordic country	34 (4.7)
Other European country	29 (4.0)
Outside of Europe	16 (2.2)
Missing	13 (1.8)
Education	
Mandatory	227 (31.2)
High school	187 (25.7)
University/higher education	215 (29.5)
Other	85 (11.7)
Missing	14 (1.9)
Occupation	
Employed	165 (22.7)
Own company	37 (5.1)
Parental leave	1 (0.1)
Student	3 (0.4)
Job seeker	9 (1.2)
Old age pension	468 (64.3)
Long-term sickness	22 (3.0)
Other	10 (1.4)
Missing	13 (1.8)
Diagnosis	
Prostate	170 (23.4)
Breast	120 (16.5)
Colorectal	96 (13.2)
Urologic ^a	81 (11.1)
Skin	67 (9.0)
Blood ^b	51 (7.0)

(Continues)

TABLE 1 (Continued)

Characteristics	No (%)
Lung	39 (5.4)
Upper gastro-intestinal ^c	30 (4.1)
Gynaecologic ^d	27 (3.7)
Head/neck	26 (3.6)
Other ^e	21 (2.9)

Abbreviations: SD, Standard deviation; IQR, Interquartile range.

^aBladder, testicular, penis cancers.^bKLL, KML, AML, lymphoma, myeloma.^cPancreatic, liver/gallbladder, ventricular, oesophageal cancers.^dCervical, endometrial, ovarian, vaginal and vulvar cancers.^eBrain tumour, thyroid sarcoma.

3.3 | Mean values of the Distress scale

The mean (SD) *Distress* score in the total sample was 25.4 (27.2) on the 0–100 scale (Table 4). In the total sample, 53% reported no or very mild (score < 20), 16% mild (score 20–39), 10% moderate (score 40–59) and 14% severe (score ≥ 60) distress.

Women reported more distress than men ($p < .001$) (Table 4).

In the age groups, the mean *Distress* score ranged between 21.5 and 36.6 (Table 4). Moderate or severe distress was reported by 17% in the age group 20–39 years, 22% in the age group 40–49, 25% in the age group 50–59 years, 29% in the age group 60–69 years, 28% in the age group 70–79 and 29% in the oldest age group (≥80 years). The oldest age group reported significantly more distress than those between 60 and 69 years ($p < .000$) and those aged 70–79 years ($p < .001$).

Among occupational groups, the mean *Distress* scores ranged between 22.0 and 36.5 (Table 5). Moderate or severe distress was reported by 22% of the professionally active participants and by 27% of those receiving old age pension. The group on sick leave reported the highest mean *Distress* score (36.5), and this group had the highest proportion of severe to moderate distress (36%). A significantly higher *Distress* score was observed for those with old age pension compared with the professionally active group ($p = .004$).

3.4 | Mean values of the Avoidance scale

In the total sample, the mean (SD) *Avoidance* score was 21.9 (24.6) (Table 4). Altogether, 54% reported no or very mild (score < 20), 25% reported mild (score 20–39), 11% moderate (score 40–59) and 9% severe (score ≥ 60) avoidance. None of the subgroups reported mean values in the severe *Avoidance* category (score ≥ 60). The highest mean score was reported by those on sick leave, with a mean of 35.8.

Women reported higher avoidance score than men ($p < .01$) (Table 4). An *Avoidance* score in the severe category was reported by 11% of the women and 7% of the men.

Mean values in all age groups were in the no or very mild category. Moderate or severe avoidance was reported by 17%–23% in all age groups, except ≥ 80 years, where 29% reported severe avoidance.

	Distress		Avoidance	
	<i>n</i> = 716		<i>n</i> = 718	
	Cronbach's alpha	Item-total correlation ^a	Cronbach's alpha	Item-total correlations ^a
Total	0.94	0.72–0.84	0.94	0.63–0.83
Woman	0.95	0.70–0.87	0.94	0.65–0.83
Man	0.94	0.63–0.84	0.93	0.61–0.85
Age group				
20–39	0.91	0.61–0.82	0.90	0.55–0.79
40–49	0.94	0.56–0.86	0.91	0.52–0.83
50–59	0.94	0.70–0.87	0.90	0.53–0.79
60–69	0.94	0.67–0.83	0.94	0.62–0.83
70–79	0.95	0.65–0.87	0.94	0.65–0.84
80+	0.95	0.67–0.87	0.94	0.66–0.86
Education				
Elementary	0.94	0.70–0.87	0.92	0.61–0.82
High school	0.94	0.64–0.87	0.94	0.67–0.83
University	0.95	0.63–0.87	0.95	0.66–0.86
Occupation				
Professionally active ^b	0.93	0.64–0.84	0.91	0.55–0.77
Sickness	0.96	0.70–0.89	0.95	0.59–0.90
Old age pension	0.95	0.66–0.88	0.94	0.65–0.86

^aCorrected for overlap.

^bEmployed + Own company.

Comparisons of age groups showed that the youngest age group reported the lowest mean *Avoidance* score, 13.3 (*SD* 17.6), while the oldest reported the highest mean score, 24.1 (*SD* 26.1). The oldest (≥ 80) reported more avoidance than those aged 60–69 years ($p < .005$).

A significant difference between the occupational groups was found ($p < .001$) (Table 5). The professionally active reported a significantly lower *Avoidance* score than those on sick leave ($p < .005$) as well as those with old age pension ($p < .01$). Among the patients on sick leave, 40% reported moderate to severe avoidance, while the corresponding proportion for those with old age pension was 20%, and 12% among the professionally active.

The most reported distress concerned the items about participating in sport, bathing in public places and engagement in sexual intimacy (15%–16%). The same items represented the highest possible avoidance by 13%–15%.

3.5 | Comparison of the *Distress* and *Avoidance* scales

The mean *Distress* score was significantly higher ($p < .05$) than the *Avoidance* score for the total sample and in 13 of 20 subgroups (Table 4). Patients born outside of Europe and the occupational group “other” were the only subgroups scoring higher in *Avoidance*

than in *Distress* (Table 5). The magnitude of subgroup differences between *Distress* and *Avoidance* was trivial to small (*ES* 0.02–0.22) (Tables 4 and 5).

3.6 | Comparison between cancer patients and reference data

No significant differences in *Distress* or *Avoidance* between the cancer population and the general population were observed in the total samples; however, some differences were noted in the subgroups. Differences of at least five points between the study sample and the general population are described below (Tables 4 and 5).

In most comparisons, the subgroups of cancer patients reported lower dysfunction than the corresponding groups in the general population. The subgroups of cancer patients who reported higher dysfunction than the reference group on both the *Distress* and *Avoidance* scales were those in the age group 40–49 years (Table 4) and those born in another European country (outside of the Nordic countries) (Table 5). Higher *Distress* in the cancer patients was reported in the age group 50–59 years, among the professionally active, and among those with university education, compared with the same groups from the general population.

TABLE 2 Internal consistency reliability (Cronbach's alpha) and item-total correlations

TABLE 3 Descriptive statistics and features of the SSP score distribution

	Distress <i>n</i> = (716)	Avoidance <i>n</i> = (718)
Mean (SD) ^a	25.2 (27.2)	21.9 (24.6)
CI 95% ^b	23.2–27.2	20.1–23.7
Median	15.0	16.7
Skewness (SE)	0.964 (0.091)	1.270 (0.091)
Kurtosis (SE)	−0.137 (0.181)	1.047 (0.181)
Range	0–100	0–100
Floor (%) ^c	26.4	28.6
Ceiling (%) ^d	0.5	1.1
Missing (%) ^e	1.5	1.4

Abbreviation: SE = standard error.

^aA higher score indicates more dysfunction.

^b95% confidence interval.

^cPercentage of subjects scoring at the lowest possible scale level.

^dPercentage of subjects scoring at the highest possible scale level.

^ePercentage missing total scale score.

The magnitude of the differences was small, with the exception of those on sick leave, for which the difference was moderate.

4 | DISCUSSION

The validation of the SSP in a diverse oncologic population showed the same robustness as the result of the validation in the general population (Ohlsson-Nevo & Karlsson, 2019). The SSP measures health-related effects of stigma on psychosocial functioning and can be useful in detecting cancer patients at risk for social isolation, which is a potential risk factor for depression (Werner-Seidler et al., 2017) and premature mortality (Umberson & Montez, 2010).

The internal consistency reliability was high for the *Distress* and the *Avoidance* scales. Reliability coefficients were 0.90 or above for both scales in all subgroups, indicating that the instrument can be used for group as well as individual assessment (Fayers & Machin, 2016).

The construct validity of the SSP was confirmed by exploratory factor analysis, and the distress and avoidance factors were reproduced across subgroups according to age and gender. Factor invariability across different samples and subgroups is a good indication of the robustness of a multi-item construct (Gorsuch, 1983). The construct validity of the SSP was further confirmed by item-scale correlations above the adequate level of 0.40 for both scales in all subgroups. The criterion validity of the *Distress* and *Avoidance* scales was tested against the Social functioning and Role functioning items and scales from the QLQ-C30. The correlations were moderate, indicating that the constructs measure a similar domain but different latent variables.

The high completeness of data confirms that the response burden of this short instrument is low. It also indicates that the instrument was easy to understand and well accepted among cancer patients.

Twenty-four per cent of this cancer population suffered from moderate to severe distress, and 20% reported moderate to severe impairment in avoidance. Distress and avoidance measured with the SSP are associated with a person's health problems (Ohlsson-Nevo & Karlsson, 2019). Cancer patients may suffer from diverse symptoms (Reeve et al., 2014), and healthcare services need to identify these patients and offer effective treatment and supportive care to improve the quality of life and prevent social stigma.

As expected, the correlation between the *Distress* and *Avoidance* scales was strong. However, the mean scores of the two scales were significantly different in 14 of 21 subgroup analyses, indicating that the scales measure different aspects of psychosocial dysfunction. In general, the participants reported higher levels of distress but did not avoid social activities to the same degree.

Large standard deviations were observed for the *Distress* and *Avoidance* scales, reflecting a large variation in the study group. Large standard deviations reduce statistical power, which means that larger samples are needed to detect statistically significant differences. Large standard deviations are often observed for patient-reported outcome measures (Juul et al., 2014; Natrah, Ezat, Syed, Rizal, & Saperi, 2012; Velenik, Secerov-Ermenc, But-Hadzic, & Zadnik, 2017), https://www.eortc.org/app/uploads/sites/2/2018/02/reference_values_manual2008.pdf.

Comparison of SSP scores between cancer patients and the general population showed no differences in *Distress* and *Avoidance* between the total samples, indicating that cancer patients are generally not more affected by psychosocial dysfunction than other people are. This corresponds with similar comparisons in studies of HRQoL in cancer populations (Harju et al., 2017). However, our results differ from previous studies, as several subgroups of cancer patients in our study reported less psychosocial dysfunction than people in the general population. Hinz et al. (Hinz et al., 2011) described higher psychological distress among cancer patients, and several studies comparing HRQoL among cancer populations and general populations have reported lower HRQoL in cancer patients (Annunziata et al., 2015; Beekers, Husson, Mols, van Eenbergen, & van de Poll-Franse, 2015; Kim et al., 2014; Yoo et al., 2017). A poorer HRQoL was found among breast cancer patients in Sweden compared with normative data. Important contributing factors were chemotherapy, lack of social support, sick leave and a poor financial situation (Hoyer et al., 2011).

It might be that the social support by designated contact nurses stipulated for all cancer patients in Sweden and the other healthcare personnel involved in the care (Westman, Kirkpatrick, Ebrahim, Henriksson, & Sharp, 2018) has been successful in supporting cancer patients. A possible explanation for the lower distress and avoidance in the oldest cancer patients compared with the corresponding group in the reference population may be that elderly people in the general population live more isolated lives than cancer patients of

TABLE 4 Mean (SD) values by gender and age

	CANCER PATIENTS (n = 728)				SWEDISH REFERENCE DATA (n = 3,399)							
	Distress		Avoidance		Distress		Avoidance		ES ^e	ES ^f		
	Mean (SD)	CI	Mean (SD)	CI	Mean (SD)	CL	Mean (SD)	CL				
Total	25.4 (27.2)	23.2-27.2	21.9 (24.6)	20.1-23.7	0.12	0.00	25.3(27.1)	24.4-26.2	21.0(24.2)	20.2-21.9	0.004	0.03
Sex												
Women	28.7 (29.1)	25.5-32.0	24.4 (26.0)	21.5-27.3	0.16	0.00	25.8 (27.4)	24.5-27.0	21.4 (24.2)	20.3-27.0	0.10	0.12
Men	22.5 (25.4)	20.2-25.0	20.0 (23.2)	17.8-22.3	0.11	0.00	24.7 (26.8)	23.4-26.1	20.6 (24.2)	19.4-21.9	0.08	0.02
P ^g	0.00		0.01									
Ages												
20-39	22.9 (21.9)	13.7-32.2	20.3 (19.7)	12.0-28.6	0.13	0.44	19.0(21.9)	16.9-21.05	16.1(19.6)	14.0-17.6	0.18	0.21
40-49	28.7 (26.7)^a	20.8-36.6	23.3 (23.1)^a	16.0-30.7	0.22	0.01	17.5 (21.7)	15.4-19.6	17.5(20.6)	14.5-18.5	0.47	0.26
50-59	26.9 (27.9)^a	20.9-32.8	21.3 (23.5)	16.2-26.3	0.22	0.00	21.2 (26.7)	18.5-23.8	18.8 (23.9)	16.5-21.2	0.21	0.10
60-69	21.5 (25.2)	19.1-25.7	18.8 (21.8)	15.8-21.7	0.11	0.00	20.8 (24.2)	18.7-22.7	17.8 (21.8)	16.1-19.4	0.03	0.04
70-79	22.4 (26.2)	19.1-25.7	21.1 (25.4)	17.9-24.3	0.05	0.18	27.1 (26.7)	25.0-29.2	22.7 (24.3)	20.7-24.6	0.18	0.06
80+	36.6 (31.4)^b	30.7-42.5	29.9 (28.3)^b	24.6-35.2	0.22	0.00	48.9 (30.0)	46.3-51.5	37.3 (29.4)	34.7-39.8	0.44	0.26
P ^g	0.001		0.21									

Note: Numbers in bold text indicate 5-10 points difference compared with the Swedish reference values.

ES = Effect size, SD = standard deviation, CI = Confidence interval.

^aCancer patients had 5-10 points higher dysfunction scores than reference values.

^bCancer patients had 5-10 points lower dysfunction scores than reference values.

^cES of the difference between Distress and Avoidance scores in cancer patients.

^dTest of significant differences between Distress and Avoidance (Student's T test).

^eES of the differences in Distress between patient and reference data.

^fES of the differences in Avoidance between patient and reference data.

^gANOVA.

TABLE 5 Mean (SD) by country of birth, education and occupation

	CANCER PATIENTS (n = 728)						SWEDISH REFERENCE DATA (n = 3,399)					
	Distress			Avoidance			Distress			Avoidance		
	Mean (SD)	CI	ES ^a	Mean (SD)	CI	p ^b	Mean (SD)	CL	ES ^c	Mean (SD)	CI	ES ^d
Country of birth												
Sweden	24.8 (27.2)	22.7–27.0	0.13	21.5 (24.5)	19.6–23.4	0.00	24.6 (26.8)	23.7–25.6	0.007	20.2 (23.8)	19.3–21.0	0.05
Other Nordic countries	27.7 (29.4)^j	17.1–38.3	0.19	22.5 (26.5)	12.9–32.0	0.10	34.9 (30.4)	29.2–40.6	0.24	25.5 (26.0)	20.6–30.3	0.11
Other European countries	35.4 (27.7)^h	24.9–45.9	0.12	32.1 (28.4)^h	21.3–42.9	0.47	27.3 (30.4)	21.4–33.1	0.28	26.8 (28.3)	21.4–32.3	0.19
Outside of Europe	22.1 (20.8)^j	11.0–33.2	-0.11	24.4 (20.0)ⁱ	13.7–35.0	0.65	29.4 (26.4)	25.3–33.5	0.31	29.6 (24.3)	25.8–33.4	0.23
p ^e	0.52			0.48								
Education												
Mandatory	27.6 (27.4)^j	23.9–31.2	0.14	24.1 (24.2)^j	20.8–27.2	0.01	37.7 (30.3)	35.6–39.8	0.35	29.1 (27.3)	27.2–31.1	0.19
High school	24.1 (26.5)	20.5–27.7	0.08	22.0 (24.9)	18.8–25.5	0.02	22.0 (24.3)	20.6–24.5	0.08	19.2 (22.3)	17.9–20.6	0.12
University	22.9 (27.0)^h	19.0–26.9	0.12	19.8 (25.2)	16.1–23.4	0.01	17.8 (23.0)	16.5–19.2	0.20	15.4 (20.6)	14.2–16.7	0.19
Other	26.5 (29.1)	20.1–32.8	0.19	21.5 (24.4)	16.2–26.8	0.01	30.2 (29.1)	27.2–33.2	0.13	25.4 (26.8)	22.7–28.3	0.15
p ^e	0.54			0.98								
Occupation												
Professionally active ^f	22.0 (23.8)^h	18.6–25.3	0.22	17.3 (19.7)	14.5–20.0	0.00	16.2 (20.1)	16.1–14.1	0.26	14.2 (17.8)	13.2–15.1	0.16
Sickness leave ^g	36.5 (33.6)^j	21.6–51.4	0.02	35.8 (30.0)^j	22.4–49.0	0.82	57.9 (26.8)	52.6–63.2	0.70	48.8 (27.5)	43.3–54.2	0.45
Old age pension	26.6 (28.3)^j	24.0–29.3	0.11	23.6 (26.0)	21.2–26.0	0.00	34.5 (30.0)	32.9–36.1	0.27	27.5 (27.2)	26.0–28.9	0.15
p ^e	0.00			0.00								

Note: Numbers in bold text indicate 5–10 points difference compared with the Swedish reference values.

ES = Effect size, SD = standard deviation, CI = Confidence interval.

^aES of the difference between Distress and Avoidance scores in cancer patients.

^bTest of significant differences between Distress and Avoidance (Student's T test).

^cES of the differences in Distress between patient and reference data.

^dES of the differences in Avoidance between patient and reference data.

^eANOVA.

^fEmployed + Own company.

^gActivity or sickness compensation + Long-term sickness.

^hCancer patients had 5–10 points higher dysfunction scores than reference values.

ⁱCancer patients had 5–10 points lower dysfunction scores than reference values.

the same age. Elderly people are generally at risk for involuntary social isolation, due to reduced social network and decreased economic resources. Furthermore, there are indications that the impact of social support is stronger in cancer patients than in the general population (Yoo et al., 2017).

The group of patients in our study who reported higher social dysfunction compared with the corresponding groups from the general population comprised mainly younger persons, those with university education and professionally active patients and may indicate that their social lives are more limited to work and family due to the impact of the cancer diagnosis.

A major strength of this study is that the performance of the SSP was tested in a larger cancer population than similar validation studies of other instruments (Arraras et al., 2010; Guzelant et al., 2004; Lim, Miller, Kaambwa, & Koczwara, 2017; Lui, Gallo-Hershberg, & DeAngelis, 2017; Rucci et al., 2018; Villoria & Lara, 2018; Yung et al., 2018). A large sample size makes it possible to perform psychometric analyses across subgroups, which is important for confirming the general applicability of a measure (McHorney et al., 1994).

4.1 | Study limitation

A study limitation is the low response rate of 62%. Similar rates have been reported in other health surveys (Abel, Saunders, & Lyratzopoulos, 2016; Feigelson et al., 2017; Ohlsson-Nevo & Karlsson, 2019). Other limitations are that test–retest reliability was not performed and the absence of data on marital status.

4.2 | Clinical implications

The overall positive results of the validation of the SSP in this clinically diverse population of cancer patients support the psychometric properties of the SSP scale. Our findings suggest that the SSP scale is a reliable and valid instrument for measuring the impact of health-related stigma in a cancer population and tailor adequate support to cancer patients with social dysfunctions.

5 | STATEMENT

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration. The Regional Ethical Review Board of Uppsala approved the study (reference number Dnr 2016/287).

The patients got written information about the study in the regular mail and were informed to return the instruments if they agreed to participate in the study.

This article does not contain any studies with animals performed by any of the authors.

CONFLICT OF INTEREST

The authors have no conflict of interest to disclose.

ETHICAL APPROVAL

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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