


Impact of health-related stigma on psychosocial functioning in the general population: Construct validity and Swedish reference data for the Stigma-related Social Problems scale (SSP)

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Felt stigma is an internalized sense of shame about having an unwanted condition, along with fear of discrimination. 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 performance of the SSP scale was tested in 3,422 subjects from the general population (Mid-Swed Health Survey) and in subgroups according to gender, age, occupation, and education. The homogeneity and construct validity of the *Distress* and *Avoidance* scales were confirmed by exploratory factor analysis and the two factors were accurately reproduced across gender and age subgroups. The internal consistency reliability was high for both the *Distress* and *Avoidance* scales. Reliability coefficients were above the 0.90 standard for the *Distress* scale in all subgroups and for the *Avoidance* scale in most subgroups. The SSP scale is an instrument with sound psychometric properties that can be used to identify psychosocial disturbances.

KEYWORDS

construct validity, instrument, psychosocial, stigma, survey

1 | INTRODUCTION

Stigma occurs when society labels a person as tainted and less desirable compared with others (Goffman, 1990). Felt stigma is an internalized sense of shame about having an unwanted condition, along with fear of discrimination due to imputed inferiority or unacceptability. When discrimination actually occurs, it is referred to as “enacted stigma.” Felt and enacted stigma can occur when a person’s appearance differs from the norm of normality. Stigma can affect several factors, such as social relationships, stress, psychological, and behavioral responses, that may lead to adverse health outcomes. The factors mediate the relationship between stigma and

health outcomes. Stigmatizing conditions are common and affect a large portion of the general population. Examples of stigmatized status include minority sexual orientation, disability, and minority race/ethnicity (Hatzenbuehler, Phelan, & Link, 2013). Various illnesses and symptoms of disease are associated with health-related stigma and people living with chronic illnesses may experience distress that strongly affects their quality of life (QoL) (Browne, Ventura, Mosely, & Speight, 2013; Earnshaw, Quinn, & Park, 2012). Known stigmatizing diseases include severe obesity (Puhl & Heuer, 2009), psoriasis (Hrethorow, Salomon, Matusiak, Reich, & Szepletowski, 2012), epilepsy, mental illness, and head and neck cancer (Threader & McCormack, 2016).

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Conditions without visible attributes can also be stigmatizing as they are associated with certain behaviors or conditions, such as smoking, alcohol abuse (Lebel & Devins, 2008), or sexually transmitted infections, such as human immunodeficiency virus (HIV). Others may perceive that the person has caused the disease through their way of living (Butt, 2008).

Felt and enacted stigma are related to psychological distress that can be limiting and lead to social isolation as a person hesitates to participate or altogether avoids participating in social activities, fearing rejection or negative evaluation (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).

Most instruments for measuring stigma focus on how the person perceives stigma from others, such as the Explanatory Model Interview Catalogue (EMIC) (Lebel et al., 2013; Phelan et al., 2013), or the degree of anticipated stigma, as measured by the Chronic Illness Anticipated Stigma Scale (CIASS) (Earnshaw et al., 2012). There are also a number of disease-specific instruments, such as the Cataldo Lung Stigma Scale (Chambers et al., 2015) and the HIV stigma scale (Berger, Ferrans, & Lashley, 2001; Wiklander et al., 2013), which consist of several subscales measuring different consequences of living with the disease, such as shame, social isolation, discrimination, disclosure, and negative self-image or attitudes. Instruments measuring health-related quality of life (HRQoL) focus on different aspects of physical and mental health, such as physical and social functioning and mental wellbeing (Fayers & Machin, 2009), but do not include items on the impact of stigma on social life. There is no validated generic instrument available for measuring the impact of health-related stigma on social functioning. The similarity of the consequences of stigma across different conditions suggests that it would be possible to use a generic measure to assess the impact of stigma on social functioning (Van Brakel, 2006).

One advantage of generic instruments is that reference data for the general population can be obtained. With normative reference data the impact of stigmatizing health problems on social behavior can be evaluated for different health conditions and comparisons can be made across subgroups within the general population. Generic instruments also have the advantage that patients with different health problems can be compared, and that comparison across subgroups in the general population is possible. There is a need for a brief generic instrument that can be used for screening and evaluation in health care, in order to capture persons who are stigmatized and to evaluate the effects of prevention and treatment efforts.

The Obesity-related Problems (OP) scale is a disease-specific HRQoL instrument developed to measure the impact of obesity on psychosocial functioning. It measures how distressed obese persons are in social situations, i.e., how the stigma of being obese affects their social functioning and behavior (Karlsson, Taft, Sjostrom, Torgerson, & Sullivan, 2003; Lee et al., 2013). Based on the OP scale, a generic

module, the Stigma-related Social Problems (SSP) scale, was developed for measuring the impact of health-related stigma on social functioning in people with different diseases and disorders.

This article reports one of the studies conducted as part of a larger project, the Mid-Swed Health Survey. The purpose of the project was to validate three new instruments, the SSP scale, the RAND 36-item Short Form survey (RAND-36) and World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0), and to collect normative data for these from the general population. The specific aims of this study were to evaluate the validity of the SSP scale in the general population and to present reference data for the general Swedish population.

2 | METHODS

2.1 | Study design

A postal survey was conducted in Region Örebro County, a central region of Sweden with a population of 290,000 inhabitants, 250,000 of whom live in a city or a small town area, and 40,000 in rural areas. The region has one residential city, as well as several small towns, rural and urban areas, i.e., a population structure similar to the population of Sweden.

2.2 | Sample

A random sample of 8,140 persons was extracted from a population register and stratified according to sex and age. The sample size was based on a power set at 80% ($\alpha = 0.05$) to detect a between-group difference of 10 scale points. In September 2015, 4,040 persons were invited to participate in the study. Because of the low response rate (42%), an additional sample of 4,100 persons were invited to participate in March 2016.

2.3 | Procedure

The Mid-Swed Health Survey comprises a nine-page questionnaire including the Swedish version of the three above-mentioned instruments, the SSP scale, RAND-36 and WHODAS 2.0, as well as demographic questions. The questionnaire was distributed along with an information letter and a prepaid envelope via regular mail. After 2 weeks, a thank-you/reminder card was sent to all 8,140 persons. If the questionnaire was not returned after 5 weeks, a reminding letter with a new questionnaire was sent out.

2.4 | Questionnaire

2.4.1 | The Stigma-related Social Problems scale

The SSP scale was constructed to measure the impact of various health problems on psychosocial functioning and comprises 20 items on a 4-point response scale. The responses are aggregated into two domains: *Distress* (ten items) and *Avoidance* (ten items), here referred

to as the “Distress” and “Avoidance” scales. The SSP scale is introduced with the following sentence: “With the questions below, we want to gain knowledge about whether your health condition (physical or mental) is limiting you in social situations.” The following question is used to measure distress: “Do you feel bothered (embarrassed, inhibited, insecure) because of your health condition (physical or mental) in the following activities and situations: ...?” and the response options range from 1 = “Definitely bothered” to 4 = “Definitely not bothered.” The question measuring avoidance is: “Indicate to what extent you try to avoid the following activities and situations because of your health condition (physical or mental): ...” and the response options range from 1 = “Almost always” to 4 = “Never.” The same ten items are used to measure distress and avoidance.

The SSP scale includes items on a broad range of social activities: gatherings in my own home, gatherings in a friend's or relative's home, going to restaurants, participation in community activities, participation in sport, exercise or dance, travelling by public transport, going to the cinema or theatre, trying on and buying clothes, bathing in public places, and sexual relationships/being physically intimate. The instrument takes about 3–5 min to complete. Item responses are aggregated into summated scale scores which are transformed to 0–100 scales. A higher score indicates greater psychosocial dysfunction. A scale score is calculated if the respondent has answered at least half of the ten items in a scale. A person-specific estimate for missing items is based on the mean of those items that are available (Fayers & Machin, 2009). A scale score <20 indicates no, or very mild, limitations; while scores between 20 and 39 indicate mild impairment, scores of 40–59 indicate moderate impairment, and a score ≥ 60 indicates severe impairment.

2.4.2 | The RAND 36-item short form survey

The RAND-36 measures generic HRQoL and comprises 36 items grouped into eight multi-item scales: Physical functioning, Role limitations due to physical problems, Bodily pain, General health, Vitality, Social functioning, Role limitations due to emotional problems, and Mental health. In this study, two items from the Social functioning scale were used for testing criterion validity.

2.5 | Cognitive interviewing

A qualitative pilot test was conducted to evaluate the cognitive understanding of the questionnaire (Patrick et al., 2011). The main purpose was to evaluate whether instructions and questions are easy to understand, to find potentially problematic questions, and to examine the participants' thoughts when answering the questionnaire. A total of six patients, four women and two men, participated. The selection of participants was based on variety in age and sex. The age range was 25–90 years. Data were collected by a structured face-to-face interview conducted by one of the authors. The patients were asked to explain whether the questionnaire was difficult to understand; what the instructions in the questionnaire

asked them to do; whether the content was relevant or upsetting; and whether they felt that there were any areas not covered in the questionnaire. The interviewer encouraged the participants to think aloud while answering each of the questions. The questionnaire was considered easy to understand and answer and was completed, on average, in 3 min.

2.6 | Statistical and psychometric methods

Socio-demographic data are presented as means and standard deviations (SDs) for continuous variables and as frequencies and proportions for categorical variables. The chi-square test was used for testing proportions. Two-group comparisons were performed with Student's *t*-test for continuous data and the Mann–Whitney *U*-test for ordinal data. Comparisons of three groups or more were analyzed with one-way analysis of variance (ANOVA) and the Kruskal–Wallis test. Tukey's post hoc test was used for testing differences between group means. The magnitude of a group difference was determined by calculation of the effect size (ES). This calculation makes it possible to judge the importance of a group difference and facilitates comparison across different measures. Effect size of a between-group difference was estimated by calculating the mean difference, divided by the pooled SD (Fayers & Machin, 2016). We interpreted ESs according to standard criteria proposed by Cohen: trivial (<0.2), small (0.2–<0.5), moderate (0.5–<0.8), and large (≥ 0.8) (Fayers & Machin, 2016). The Kolmogorov–Smirnov test and visual inspection of histograms, quantile–quantile (Q–Q) plots and boxplots were applied to test for normal distribution. We used SAS 9.4 (SAS Institute, Cary, NC) and IBM SPSS Statistics for Windows version 22 (IBM, Armonk, NY) to perform statistical analysis.

2.6.1 | Reliability

Cronbach's alpha coefficients were computed to estimate the internal consistency reliability of scale scores. A coefficient of at least 0.70 is considered adequate for group data, while 0.90 is recommended for individual assessment (Fayers & Machin, 2016).

2.6.2 | Validity

Exploratory factor analysis (principal factors) was employed to test the unidimensionality and homogeneity of the *Distress* and *Avoidance* scales. Item responses were analyzed separately for the two scales. Squared multiple correlations were used for computing prior communality estimates. Factors with an eigenvalue greater than one were extracted (Kaiser's criterion). Items with a minimum loading of 0.40 were considered to contribute to a given factor. To test the stability and generality of the factor structure, subgroup analyses were performed for gender and age.

Item–scale convergent validity was assessed by calculating correlation coefficients between each item and its own subscale. Correlations were corrected for overlap. A correlation of 0.40 or greater was considered adequate for item–scale convergent validity (Ware, 1994).

Criterion validity was assessed by testing the relationship between the SSP scale and RAND-36 Social functioning (Hays & Morales, 2001) and its two items: item 20 ("During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors or groups?") and item 32 ("During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.?)."). Correlations were interpreted as low (<0.30), moderate (0.3–0.60), or strong (> 0.6) (Revicki, Rentz, Luo, & Wong, 2011).

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

The proportions of respondents scoring at the lowest (floor effect) and highest (ceiling effect) possible scale levels were calculated. The floor effect and ceiling effect were defined as 15% or more of the sample scoring at the lowest and highest scale level, respectively (McHorney & Tarlov, 1995).

2.6.3 | Sensitivity

Known-groups analysis was used for testing the scales' sensitivity and ability to capture anticipated differences between groups, such as differences between men and women, age groups, and different educational levels.

3 | RESULTS

The response rate was 42% and the final sample comprised 3,422 participants. The response rate varied from 61% in participants 60 years and older, to 42% in persons aged 40–59 years, and 28% in the 20–39-year age group.

3.1 | Sample characteristics

Characteristics of the study population are shown in Table 1. There were 55% women and 45% men and mean age was 56.8 years (range 20–100 years). A total of 23% had mandatory education (<10 years), 32% had high school education, and 32% had university or higher education. Regarding employment status, the responses showed that 41% were gainfully employed, 40% were on retirement pension, and 5% were students. The great majority (88%) of respondents had been born in Sweden.

3.2 | Psychometric properties of the Stigma-related Social Problems scale

3.2.1 | Reliability

In the total sample, the internal consistency reliability coefficient (Cronbach's alpha) was 0.94 for the *Distress* scale and 0.93 for the

TABLE 1 Characteristics of the study population

Characteristics	No (%)
Total	3422
Sex	
Female	1872 (55)
Male	1550 (45)
Age (year)	
Mean	56.9 (20.1)
Median	60
Range	20–100
Age group category	
20–29	394 (11.5)
30–39	489 (14.3)
40–49	408 (11.9)
50–59	399 (11.7)
60–69	587 (17.2)
70–79	625 (18.3)
80+	520 (15.2)
Country of birth	
Sweden	3011 (88)
Nordic country	111 (3.2)
European country	107 (3.1)
Outside of Europe	161 (4.7)
Missing	32 (0.9)
Education	
Mandatory	806 (23.6)
High school	1109 (32.4)
University/higher education	1102 (32.2)
Other	362 (10.6)
Missing	41 (1.2)
Occupation	
Employed	1417 (41.5)
Own company	208 (6.1)
Parental leave	71 (2.1)
Student	171 (5.0)
In labour market programme	10 (0.3)
Job seeker	74 (2.2)
Old age pension	1370 (40.0)
Activity or sickness compensation	70 (2.0)
Long term sickness	50 (1.5)
Other	165 (4.8)

Avoidance scale. In all subgroup analyses by sex, age, education, and occupation, Cronbach's alpha was between 0.90 and 0.96 for the *Distress* scale and between 0.89 and 0.95 for the *Avoidance* scale (Table 2).

3.2.2 | Construct validity

Exploratory factor analysis confirmed the unidimensionality of the *Distress* and *Avoidance* scales. Eigenvalues for the first factor were 6.2 (*Distress* scale) and 6.0 (*Avoidance* scale), while eigenvalues for the second factor were below 0.4 for both scales. Factor loadings were 0.68–0.85 and 0.67–0.85 for the *Distress* and *Avoidance* scales, respectively (Table 3). The distress and avoidance factors were reproduced in gender and age subgroups. In all subgroup tests, eigenvalues were above 4.9 for the first, and below 0.7 for the second factor.

3.2.3 | Item-scale convergent validity

Item-scale correlations for both the *Distress* scale and the *Avoidance* scale indicated satisfactory item-scale convergent validity ($r \geq 0.40$). In

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

	Distress		Avoidance	
	Cronbach's alpha	Item-total correlation ^a	Cronbach's alpha	Item-total correlation ^a
Total	0.94	0.67–0.82	0.93	0.65–0.82
Sex				
Woman	0.94	0.65–0.83	0.93	0.64–0.82
Man	0.94	0.69–0.82	0.94	0.67–0.83
Age group				
20–29	0.90	0.49–0.75	0.89	0.48–0.76
30–39	0.93	0.58–0.80	0.93	0.55–0.79
40–49	0.94	0.53–0.79	0.93	0.60–0.82
50–59	0.96	0.75–0.86	0.95	0.74–0.86
60–69	0.93	0.65–0.82	0.93	0.65–0.80
70–79	0.93	0.61–0.81	0.92	0.60–0.82
80+	0.93	0.57–0.83	0.93	0.65–0.85
Education				
Elementary	0.94	0.66–0.84	0.93	0.64–0.84
High school	0.93	0.61–0.80	0.93	0.61–0.79
University	0.93	0.65–0.81	0.93	0.64–0.80
Occupation				
Professionally active ^b	0.94	0.60–0.77	0.92	0.61–0.77
Unemployed ^c	0.90	0.41–0.79	0.91	0.56–0.75
Parental leave	0.91	0.40–0.89	0.92	0.55–0.81
Sickness ^d	0.91	0.58–0.80	0.91	0.51–0.82
Student	0.92	0.56–0.81	0.91	0.47–0.76
Old age pension	0.94	0.65–0.84	0.94	0.65–0.84
Other	0.94	0.61–0.82	0.92	0.55–0.81

^aCorrected for overlap.

^bEmployed + own company.

^cLabor market program + job seeker.

^dActivity or sickness comp. + long term sickness.

the total sample, correlations ranged between 0.67 and 0.82 for *Distress* and between 0.65 and 0.82 for *Avoidance* (Table 2). In all subgroup analyses, item–scale correlations exceeded the minimum desired level of 0.40 (Table 2).

3.2.4 | Inter-scale correlation

The correlation between the *Distress* and *Avoidance* scales was 0.79 in the total sample and above 0.76 in all age groups except for the oldest

TABLE 3 Factor loadings and item-scale correlations for the Distress and Avoidance scales

Items	Distress		Avoidance	
	Factor loading	Item-total correlation ^a	Factor loading	Item-total correlation ^a
1. Private gatherings in my own home	0.74	0.70	0.75	0.70
2. Private gatherings in a friend's or relative's home	0.83	0.79	0.82	0.77
3. Going to a restaurant or pub	0.85	0.82	0.84	0.80
4. Going to community activities, courses etc.	0.83	0.81	0.82	0.79
5. Participate in sports, exercise, dance	0.77	0.76	0.75	0.73
6. Travel by public transportation (bus, train, tram, subway)	0.77	0.74	0.74	0.71
7. Going to the cinema, theater, sports event	0.85	0.82	0.85	0.82
8. Trying on and buying clothes	0.76	0.74	0.74	0.72
9. Bathing in public places (beach, public pool etc.)	0.76	0.74	0.74	0.73
10. Sexual relationship, being physically intimate	0.68	0.67	0.67	0.65

^aCorrected for overlap.

(80+ years) who had a correlation of 0.51. In subgroups based on education, occupation and sex the correlations were between 0.67 and 0.84.

3.2.5 | Criterion validity

Moderate correlations were found between the *Distress* scale and RAND-36 item 20 ($r = 0.55$) and item 32 ($r = 0.58$; $p < 0.01$). Likewise, correlations between the *Avoidance* scale and items 20 ($r = 0.50$) and 32 ($r = 0.53$) were moderate ($p < 0.01$). A strong correlation was observed between the *Distress* scale and RAND-36 Social functioning ($r = 0.61$; $p < 0.01$), while a moderate correlation was noted between the *Avoidance* scale and the Social functioning scale ($r = 0.56$; $p < 0.01$).

3.2.6 | Floor and ceiling effects

The proportion of respondents scoring at the lowest possible score level (floor effect) was 25% for the *Distress* scale and 28% for the *Avoidance* scale. The proportion scoring at the highest possible level (ceiling effect) was marginal, 1% and 0.7%, respectively (Table 4).

3.2.7 | Completeness of data

The proportion of missing items was generally low, ranging between 0.8% and 1.5% for the *Distress* scale and between 1.7% and 2.2% for the *Avoidance* scale, except for item 10 (Being physically intimate), with 4.0% (*Distress*) and 4.5% (*Avoidance*) missing data. In the age groups 20–69 years, missing data for item 10 amounted to 1.0–2.6%, while in the older age groups 6.7–13.8% of data were missing. Missing items accounted for 1–2% (except item 10) for both scales in all subgroups (sex, age, occupation, education) except for the oldest group (80+ years), where 2.5–5.6% of items were missing.

TABLE 4 Descriptive statistics and features of the score distribution for the *Distress* and *Avoidance* scales

	Distress <i>n</i> = 3,399	Avoidance <i>n</i> = 3,374
Mean (SD) ^a	25.3 (27.2)	21.0 (24.2)
95% CI	24.4–26.2	20.2–21.8
Median	16.7	13.3
Skewness	1.03	1.3
Range	0–100	0–100
Floor (%) ^b	25.4	27.9
Ceiling (%) ^c	1.0	0.7
Missing (%) ^d	0.7	1.4

CI, confidence interval.

^aHigher score indicates more psychosocial dysfunction.

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

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

^dPercentage of missing total scale score.

A scale score was calculated for respondents who completed at least half of the items in a scale. The percentage of respondents for whom scale scores were computable was 99.3% for the *Distress* scale and 98.6% for the *Avoidance* scale.

3.3 | Impact of health-related stigma on psychosocial functioning in the general population

3.3.1 | Distress scale

The mean (SD) *Distress* score in the total sample was 25.3 (27.1) on the 0–100 scale. In the total sample, 57% reported no, or very mild (score < 20), 17% mild (score 20–39), 11% moderate (score 40–59) and 15% severe (score ≥ 60) distress.

Sex

No significant difference was found between men (24.7; SD 26.8) and women (25.8; SD 27.4; $p = 0.27$) (Table 5).

Age

Moderate or severe distress was reported by 17–18% in the age groups 20–49 years, 22–28% aged 50–79 years, and 56% in the oldest age group (80+ years). In all age groups, the mean *Distress* score ranged between 17.5 and 48.9 (Table 5). Post hoc test of mean differences showed that participants younger than 70 years reported significantly lower distress compared with the older participants ($p < 0.005$). The lowest mean *Distress* score, 17.5 (21.7), was observed in the age group 40–49 years and the highest mean score, 48.9 (30.0), in the oldest age group (80+ years).

Occupation

The professionally active participants reported significantly lower distress compared with those on sick leave, the unemployed and the retired (Table 5). Those on sick leave had the highest mean *Distress* score, 57.9 (26.8), of all groups, while the lowest mean score was reported by those on parental leave, 15.1 (19.8) (Table 5). Subgroup analyses showed that the youngest age groups (20–49 years), those with university education, the professionally active, those on parental leave, and students reported on average no, or very mild, distress (mean group score < 20).

3.3.2 | Avoidance scale

In the total sample, the mean (SD) *Avoidance* score was 21.0 (24.2). Altogether 61% reported no, or very mild, avoidance (score < 20), while 19% reported mild (score 20–39), 9% moderate (score 40–59) and 10% severe (score ≥ 60) avoidance. None of the subgroups reported mean values in the severe *Avoidance* category (score ≥ 60).

Sex

No significant differences were found between men and women ($p = 0.37$) (Table 5).

TABLE 5 Mean (SD) Stigma-related Social Problems scale values by gender, age, country of birth, education, and occupation

	Distress		Avoidance		ES	p ^a
	Mean (SD)	CI	Mean (SD)	CI		
Total	25.3 (27.1)	24.4–26.2	21.0 (24.2)	20.2–21.9	0.17	< 0.001
Sex						
Women	25.8 (27.4)	24.5–27.0	21.4 (24.2)	20.3–27.0	0.17	<0.001
Men	24.7 (26.8)	23.4–26.1	20.6 (24.2)	19.4–21.9	0.16	<0.001
Ages						
20–29	19.7 (21.4)	17.6–21.9	15.7 (18.6)	13.9–17.6	0.20	<0.001
30–39	18.2 (22.4)	16.2–20.2	16.5 (20.6)	14.1–17.7	0.08	<0.001
40–49	17.5 (21.7)	15.4–19.6	17.5 (20.6)	14.5–18.5	0.00	0.128
50–59	21.2 (26.7)	18.5–23.8	18.8 (23.9)	16.5–21.2	0.09	<0.001
60–69	20.8 (24.2)	18.7–22.7	17.8 (21.8)	16.1–19.4	0.13	<0.001
70–79	27.1 (26.7)	25.0–29.2	22.7 (24.3)	20.7–24.6	0.17	<0.001
80+	48.9 (30.0)	46.3–51.5	37.3 (29.4)	34.7–39.8	0.39	<0.001
Country of birth						
Sweden	24.6 (26.8)	23.7–25.6	20.2 (23.8)	19.3–21.0	0.17	<0.001
Nordic country	34.9 (30.4)	29.2–40.6	25.5 (26.0)	20.6–30.3	0.33	<0.001
Other European country	27.3 (30.4)	21.4–33.1	26.8 (28.3)	21.4–32.3	0.02	0.470
Outside of Europe	29.4 (26.4)	25.3–33.5	29.6 (24.3)	25.8–33.4	–0.01	0.932
Education						
Mandatory	37.7 (30.3)	35.6–39.8	29.1 (27.3)	27.2–31.1	0.30	<0.001
High school	22.0 (24.3)	20.6–24.5	19.2 (22.3)	17.9–20.6	0.12	<0.001
University	17.8 (23.0)	16.5–19.2	15.4 (20.6)	14.2–16.7	0.11	<0.001
Other	30.2 (29.1)	27.2–33.2	25.4 (26.8)	22.7–28.3	0.17	<0.001
Occupation						
Professional active ^b	16.2 (20.1)	16.1–14.1	14.2 (17.8)	13.2–15.1	0.10	<0.001
Unemployed ^c	27.4 (24.2)	22.2–32.7	23.9 (23.0)	13.4–15.3	0.15	<0.025
Parental leave	15.2 (19.8)	10.6–19.9	11.0 (15.4)	7.3–14.7	0.24	<0.001
Sickness ^d	57.9 (26.8)	52.6–63.2	48.8 (27.5)	43.3–54.2	0.34	<0.001
Student	19.6 (25.3)	16.0–50.6	39.4 (21.1)	25.2–53.6	0.85	<0.001
Old age pension	34.5 (30.0)	32.9–36.1	27.5 (27.2)	26.0–28.9	0.25	<0.001
Other	32.1 (32.5)	24.3–39.8	25.6 (27.7)	19.0–32.3	0.21	<0.000

CI, confidence interval; ES, effect size of the difference between mean scores for Distress and Avoidance.

^aTest of significant differences between *Distress* and *Avoidance* (Student *T*-test).

^bEmployed and self-employed.

^cLabor market program and job-seeker.

^dActivity or sickness compensation and long term sickness.

Age

Mean values in all age groups were in the no, or very mild, category, except for the oldest (80+ years). Moderate or severe avoidance was reported by 15% aged 50–69 years and by more than 20% of 70–80+ year-olds. Comparisons of age groups showed that the youngest age group reported the lowest mean *Avoidance* score, 15.7 (18.6), while the oldest reported the highest mean score, 37.3 (29.4). Multiple comparisons showed that the oldest group differed significantly from all other age groups ($p < 0.0001$). More stigma-related avoidance was generally related to older age although the 50–59-year-olds reported (non-significantly) more avoidance compared with the 60–69-year-olds; still, this was significantly lower than that reported by the oldest (80+ years).

Occupation

Those on sick leave reported the highest mean *Avoidance* score, of 48.8 (27.5), while the lowest score, 14.2 (17.8), was observed for the professionally active group.

3.4 | Comparison of the Distress and Avoidance scales

The mean *Distress* score was significantly higher ($p < 0.04$) than the *Avoidance* score for the total sample and for most subgroups based on sex, age, level of education, and occupation (Table 5). The magnitude of subgroup differences was trivial to large (ES 0.00–0.85). Mean *Distress* and *Avoidance* scores were roughly equal in the 40–49-year age group ($p = 0.128$), in people born in Europe but outside the Nordic countries ($p = 0.470$), and in those born outside Europe ($p = 0.932$). Students were the only group reporting higher *Avoidance* than *Distress* scores ($p < 0.001$) (Table 5).

4 | DISCUSSION

The SSP scale was developed as a brief generic tool for assessing the impact of health-related stigma on psychosocial functioning. The purpose of the present study was to evaluate the psychometric

properties of the SSP scale and present reference data for the general Swedish population. The performance of the SSP scale was tested in a large general population sample and in subgroups by gender, age, occupation, and education. The homogeneity and construct validity of the *Distress* and *Avoidance* scales was confirmed by exploratory factor analysis and the two factors were accurately reproduced across subgroups according to gender and age. Factor invariability across different samples and subgroups is generally a good indication of the robustness of a multi-item construct (Gorsuch, 1983).

The internal consistency reliability was high for both the *Distress* scale and the *Avoidance* scale. Reliability coefficients were above the 0.90 standard for the *Distress* scale in all subgroups and for the *Avoidance* scale in most subgroups. A reliability of 0.90 or higher indicates that a measure is applicable for both group and individual assessments (Fayers & Machin, 2016). The psychometric performance of the SSP scale is consistent with results obtained for the OP scale, from which the SSP scale was developed (Karlsson et al., 2003).

Floor effects were observed, but no ceiling effects, which was expected in a general population sample mainly consisting of people without chronic diseases or other serious health problems. The proportion scoring at the lowest possible scale level is most likely reduced in studies in different groups with stigmatized health conditions. The proportions of missing items were low, indicating that the questionnaire was well accepted by the respondents. Most of the missing responses were responses to item 10, which asks about stigma-related distress and avoidance of sexual intimacy. A reluctance to answer questions about intimacy is a well-known obstacle when collecting self-report data (Knowles, Haigh, McLean, & Phillips, 2015).

The associations between the SSP scales and RAND-36 Social functioning scale and items were moderate to strong, indicating satisfactory criterion validity.

The SSP scale showed sensitivity and the ability to detect relevant differences between subgroups based on age, occupation and socio-economic status (SES). As expected, the highest mean *Distress* scores were observed among those on sick leave and in the oldest age group (80+ years). Also, respondents with low education reported higher distress compared with those with high education. The professionally active and those on parental leave reported lower distress compared with the unemployed. Differences in SES have consistently been associated with health disparities and the results of the present study are in line with previous research of social determinants of health differences (Marmot, Friel, Bell, Houweling, & Taylor, 2008).

General population data for the SSP scale were presented, which enables norm-based comparisons and interpretation of scores across diverse patient populations. However, the low response rate among the youngest indicates that the sample may not be fully representative of young adults and these norm values should therefore be used with caution.

As expected, the correlation between the *Distress* and *Avoidance* scales was strong ($r_s = 0.79$), indicating that the scales measure the same underlying latent variable. However, from a clinical perspective it

is essential to measure both aspects of psychosocial dysfunction. In fact, significant differences between mean values of the two scales were observed in 23 out of 26 subgroup analyses, which supports that the scales measure different aspects of psychosocial functioning. As expected, the participants generally reported higher levels of distress but did not avoid social activities to the same degree. However, the student group reported significantly higher *Avoidance* than *Distress* scores, which is a different scoring pattern compared with all other subgroups. The reasons why students showed a different response pattern is unclear. A possible explanation is that students avoid activities for reasons other than distress, e.g., financial reasons.

Items included in the SSP scale were selected from the OP scale which contains a broad range of social activities that may be difficult for a stigmatized person to participate in. The SSP scale covers social activities in the private sector as well as ordinary activities in public life and community life. Some questions are about activities that include body exposure, which may be especially unpleasant for people with health-related stigma. The purpose of the selected items is to measure the impact of health-related stigma on interpersonal interactions and relationships, as well as the consequences for the individual regarding participation in social and community activities. It is important to note that it is not necessary to include all possible aspects for measuring a latent variable; it is sufficient to select a smaller number of the most important items to achieve effective construct validity (Fayers & Machin, 2016).

The large sample size ($n = 3,422$) is a major strength of this study, making it possible to repeat the psychometric analysis in several subgroups. Validation of instruments across study populations and subgroups is essential for confirming the general applicability of a measure (McHorney, Lu, & Sherbourne, 1994; Puhl & Heuer, 2009). A weakness of the study is the low response rate (42%). However, participants 60 years and older had a response rate of 61%, while the youngest groups had a response rate of 28%. A low response rate, especially in younger age groups, has been reported in other health surveys (Jacobsen et al., 2018; Waller Lidstrom, Wennberg, Lundqvist, Forsen, & Waller, 2017). However, all age groups in the present study included at least 400 subjects and the three oldest age groups included more than 500 subjects in each group. It was not possible to answer the survey on the web, which may be a reason for the low response rate among younger adults.

5 | CONCLUSIONS

The SSP scale is a short instrument with sound psychometric properties that can be used as a generic tool to identify individuals with different diseases and health problems at risk of psychosocial disturbances. Findings of the present study suggest that the SSP scale is a reliable and valid instrument for measuring the impact of health-related stigma on psychosocial functioning in the general population. In future research, we plan to evaluate the validity and usefulness of the SSP scale in populations suffering from different stigmatizing conditions and diagnoses.

6 | IMPLICATION

The SPP scale can be used to measure health-related stigma in different groups with stigmatizing conditions. The instrument is especially useful as a screening tool to identify persons at risk or when measuring the effect of interventions aimed at improving social stigma.


CONFLICT OF INTEREST

The authors have no conflict of interest to disclose.

COMPLIANCE WITH ETHICAL STANDARDS

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. The study was approved by the Regional Ethical Review Board of Uppsala (reference number 2015/071).

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