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Adaptation and validation of the Caregiver Burden Inventory in Spinal Cord Injuries (CBI-SCI)

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(Article begins on next page)

1 Title: Adaptation and validation of the Caregiver Burden Inventory in Spinal Cord Injuries (CBI-SCI)

2 Running title: Adaptation and validation of the CBI-SCI

3

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28 Abstract:

29 Design: Validation cross-sectional study.

30 Objectives: Even though caregiver burden (CB) represents a well-recognised concern among
31 caregivers of people with a spinal cord injury (SCI), there are no specific questionnaires designed for
32 its evaluation. This study aimed to assess the psychometric properties of the Caregiver Burden
33 Inventory in Spinal Cord Injury (CBI-SCI), which was modified from its original version, and specifically
34 its construct and reliability.

35 Setting: Multicentre study in four urban spinal units across Italy. The CBI-SCI was administered to
36 family caregivers in outpatient clinics.

37 Methods: CBI-SCI was administered in a toolset composed of a sociodemographic questionnaire, the
38 Family Strain Questionnaire-Short Form (FSQ-SF), the Short Form-36 (SF-36) and the Modified Barthel
39 Index (MBI). The CBI-SCI construct validity was assessed through an exploratory factor analysis. The
40 internal consistency of the questionnaire was examined using Cronbach's alpha (α) coefficient for the
41 total scale and its subscales. Concurrent validity was evaluated performing Pearson's correlation
42 coefficient with all instruments included in the toolset.

43 Results: The CBI-SCI was administered to 176 participants from February 2016 to September 2017.
44 Factor analysis highlighted the five-factored structure of the questionnaire. The total scale
45 Cronbach's α was 0.91 ($p < 0.001$). All the five subscales of CBI-SCI showed an acceptable internal
46 consistency, ranging from 0.76 to 0.91 ($p < 0.001$). Pearson's correlation coefficients of the CBI-SCI
47 with all the administered instruments were statistically significant ($p < 0.001$), showing congruent
48 relations.

49 Conclusion: The CBI-SCI, due to its validity and reliability, may represent a valuable instrument to
50 evaluate the CB longitudinally in SCI.

51

52 Introduction:

53 The care of people with a spinal cord injury (SCI) requires great energy on the part of their
54 family caregivers to maintain the disease-related health status and the well-being of care recipients
55 as well as to preserve their status in the community (1). These elements may produce severe
56 psychological distress and anxiety to both parties, which generate a significant burden on caregivers
57 with, in certain cases, repercussions for the person they care for (2). Despite the fact that caregiver
58 burden (CB) is a concept that is widely used to express the weight carried by caregivers due to their
59 assumption of the caregiver role (3), there is no existing International Classification of Diseases (ICD-9
60 or ICD-10) code that describes it.

61 CB is defined by Zarit and colleagues as, “The extent to which caregivers recognise that
62 caregiving has hurt their emotional, social, financial, physical and spiritual functioning” (4). This
63 definition is useful in understanding how CB may be perceived as a multidimensional experience that
64 affects many aspects of the everyday life of caregivers (5). In particular, a recent literature review
65 highlighted how, over several decades, issues related to the physical, mental and social aspects of
66 caregiver health are affected by SCI, impacting on the QOL of family caregivers (1). Moreover, the
67 cost of illness and the necessity of reducing hours or leaving work to assist with the activities of daily
68 living (ADLs) may subject caregivers to financial deprivation and consequently to social isolation,
69 even though other features can be emotionally rewarding such as saving family resources or
70 confirming family ties with the assisted people (6). In this regard, there is an amount of research
71 focused on caregivers’ quality of life (QOL), on mental or physical issues, and on the impact of respite
72 programs for this population (7,8). Conversely, to date, there are few studies that specifically
73 consider the evaluation of CB in SCI.

74 To assess the CB, different instruments have been developed over several decades to provide
75 a valid and reliable measurement of this phenomenon (4,9–12). Despite the various questionnaires
76 assessing CB that have been used in caregivers of people with SCI (7,8,13–17), the Caregiver Burden

77 Inventory (CBI), which was largely used in different caregiver populations (18–21), has demonstrated
78 to be suitable in evaluating the effects of the burden in its entirety. Unlike the other questionnaires,
79 such as the Zarit Burden Interview (ZBI) (4,13,14), the Caregiver Burden Scale (CBS) (7) or the Burden
80 Assessment Scale (BAS) (15), the CBI has, in fact, a multidimensional more definite structure, that is
81 capable of identifying the elements characterising the CB directly attributable to the individual
82 reaction to this condition, rather than to the related socioeconomic or environmental factors. This
83 self-reported questionnaire was developed in 1989 (9) and is composed of five subscales assessing
84 the impact of the burden on different domains: time-dependent burden (T/dep-B), evaluating strain
85 caused by restriction of individual personal time; developmental burden (Dev-B), indicating the sense
86 of failing about one's intentions and hopes; physical burden (Phys-B), assessing the bodily strain and
87 physical disorders; social burden (Soc-B), produced by striving to achieve the roles connected to the
88 caregiver's job or family; and emotional burden (Emot-B), referring to any shaming or humiliation
89 caused by the assisted people. All subscales except Phys-B include five items with scoring ranging
90 from 0 (strongly disagree) to 4 (strongly agree), and an overall score ranging from 0 to 20 for each
91 dimension. Since Phys-B incorporates four items, a correction factor of 1.25 was applied to allow
92 comparisons with the other subscales. Thus, the total score of CBI was assessed starting from a
93 minimum of 0, showing no burden, to a maximum of 100, indicating the highest achievable burden
94 level.

95 The CBI has been subjected to an Italian, cross-cultural validation by Marvardi in 2005 (22),
96 revealing interesting characteristics. Since the instrument is designed explicitly for caregivers of
97 people with dementia and behavioural disorders, it does not seem to be completely appropriate in
98 the field of SCI, in which assisted individuals are not affected by cognitive impairments. For this
99 reason, it was considered appropriate to modify the original CBI to fit SCI caregivers, and a new
100 version called the Caregiver Burden Inventory in Spinal Cord Injury (CBI-SCI) was specifically
101 developed (Supplementary file 1).

This study aimed to assess the psychometric properties of the CBI-SCI, such as its construct (including the factorial structure and concurrent validity) and reliability (internal consistency).

Methods:

Participants:

A cross-sectional design was used to conduct the study. The sample size was determined based on a criterion of at least seven participants for each item, as detailed in the quality criteria for the evaluation of validation studies included in the COSMIN® checklist (23). Between February 2016 and September 2017, 176 family caregivers of people with SCI who attended the outpatient clinics of the Città della Salute e della Scienza Hospital of Turin, IRCCS Fondazione Santa Lucia of Rome, Cannizzaro Hospital of Catania and Careggi Hospital of Florence were enrolled in a consecutive sample. The definition of family caregiver adopted in this study is an individual, related by blood or partnership, who provides informal assistance to the relative with SCI. We included in the study: (i) family caregivers of individuals with traumatic or non-traumatic SCI, (ii) discharged at least six months ago, (iii) understood the Italian language and (iv) aged 18 or older. Formal caregivers, who are paid to assist, or individuals with cognitive disorders were excluded.

Instrument adaptation:

People with a SCI have some needs that have to be responded to quickly by their caregivers, and their advanced problem-solving skill imposes high emotional strain. Thus, caregivers of people with SCI are not embarrassed by their relatives' behaviours, but rather stressed by their condition and their constant attention needs, even concerning the built environment. For these reasons, during the modification process, three items of the original CBI version were changed. A group composed of four healthcare professionals examined the scale. Since they had more than ten years' experience in SCI, AC, PM and SM identified and proposed the items that had to be changed. Subsequently, MC, who was an expert in psychometrics, provided technical advice on the process.

Specifically, the original Item 3, “I have to watch my care receiver constantly”, was changed to “I have to maintain a high level of attention”; the initial Item 20, “I feel embarrassed over my care receiver’s behaviour”, was modified to “I feel embarrassed about my care receiver’s condition”; the original Item 23, “I feel uncomfortable when I have friends over”, was changed to “I feel uncomfortable when I have friends over or when we go out”.

The CBI-SCI was presented to a panel of five healthcare professionals and five caregivers who were experts in the SCI field for at least 5 years. To assess the understandability and to determine its content validity, a 5-point Likert scale ranging from 0 (not consistent) to 5 (strongly consistent) was used independently by the experts. The scale scored 0.83 about its content validity index/average, and the items that compose it reached the 0.78 cut-off value for everyone, showing their validity (24). A pilot study was performed to assess the clarity, comprehensibility and legibility of the CBI-SCI. Data assessed from 12 caregivers, who were not included in the study, obtained a face validity value of 9.43 out of 10, using a 10-point Likert scale ranging from 0 (not consistent) to 10 (strongly consistent). The CBI-SCI was approved as acceptable to apply the following psychometric tests.

Procedure:

Participants were recruited during routine follow-up appointments at the spinal unit’s outpatient clinic. The entire toolset, which required a collection time of almost 15 minutes, was completed in an isolated area to avoid the risk that the closeness of care recipients might modify the responses of their caregivers. The following data were collected:

Sociodemographic information of caregivers and people with SCI

Sociodemographic data were collected using a questionnaire purposely designed for this study. Caregivers’ information covered age, gender, marital status, rapport with the individual with SCI, level of education, employment, cohabitation and economic situation. The same variables were gathered from people with SCI; furthermore, the clinical information of the SCI including the level, the cause and the time since injury were collected.

151 *Functional independence of individuals with SCI*

152 The Modified Barthel Index (MBI) (25) was completed by participants and used to assess the
153 independence level of care recipients. This one-dimensional scale consists of 10 items regarding the
154 person's daily functioning in ADLs. MBI scores vary from 0 (total dependence) to 100 (independence).
155 Even though the Spinal Cord Independence Measure (SCIM) demonstrated a better sensitivity (26),
156 given the aim of the study, the MBI was selected as a reliable tool that is simpler and shorter and
157 could be completed more easily by participants. Kucukdeveci et al. (27) presented excellent internal
158 consistency (Cronbach's alpha [α] = 0.88) and criterion validity (r = 0.76) with the American Spinal
159 Injury Association (ASIA) scores in a SCI population.

160 *Caregiver burden*

161 CB was assessed using the CBI-SCI, a 24-item modified version of the CBI (9).

162 *Psychological health of caregivers*

163 The Family Strain Questionnaire-Short Form (FSQ-SF) is a self-administered one-dimensional
164 questionnaire employed to determine the psychological impact of caregiving. It was developed by
165 Vidotto et al. (28) to evaluate caregiver strain and the potential risks related to emotional and
166 psychophysical disorders. It consists of 30 dichotomic questions progressively indicating four
167 psychological risk areas and the urgency needed for support interventions, respectively: OK,
168 Recommended, Strongly Recommended and Urgent. The highest score obtainable is 30, which
169 suggests a high risk of psychological complications due to the more severe level of strain perceived
170 by caregivers. The FSQ-SF attained satisfactory psychometric properties in a sample of caregivers of
171 people with dementia (28); it has been used for the first time in the field of SCI in this study.

172 *Health status of caregivers*

173 The Short Form-36 (SF-36) was administered to assess the general health perceived by caregivers.
174 This questionnaire was developed in 1992 to be applied in all health conditions and detect

fundamental human values that describe health concepts significant to a person's functional status and well-being (29). It consists of 36 self-administered questions covering eight main domains (vitality, physical functioning, bodily pain, general health, physical role functioning, emotional role functioning, social role functioning and mental health) represented on a 0 to 100 scale; the lower the score, the more impairment in the specific domain. The SF-36 showed very reasonable values of validity and reliability (Cronbach's $\alpha = 0.82$); thus, it is broadly adopted to discriminate, evaluate and anticipate effects in various health conditions, including SCI (30).

Ethical consideration:

The Città della Salute e della Scienza di Torino, Mauriziano Hospital, ASL TO 1 Research Ethics Committee, Turin, Italy, gave the ethics approval (Resolution n° 1002/2016 - #CS/1040); all recruitment centres received the authorisation for participating in the study. Participation was voluntary, and caregivers who met the inclusion criteria and signed the written informed consent were asked to complete a set of structured questionnaires. Anonymity and confidential treatment of data were maintained during all the research processes.

Statistical analysis:

Descriptive statistical analysis (means, standard deviations and frequencies) were used to describe the sociodemographic characteristics of participants, including the clinical information of people with SCI and the results of administered questionnaires.

The construct validity of the CBI-SCI was evaluated analysing its factorial structure. To this end, an exploratory factor analysis (EFA) was performed. In this study the interest is directed to the dimensions behind the variables, thus to identify latent constructs rather than easily reducing the data. For this purpose, a principal axis factorisation was used with a Promax rotation, assuming that the factors of the scale were correlated. The suitability of the sample for factor analysis was supported by the Kaiser-Meyer-Olkin (KMO) and Bartlett's tests. A KMO test threshold value of 0.80 was considered satisfactory to indicate the sampling was adequate, while a significance level < 0.05

on Bartlett's test suggested the homogeneity of item variances (31,32). The factors that reach an eigenvalue ≥ 1 were considered to be retained, and a minimum factor loading coefficient of 0.30 was accepted to maintain each item in the scale (33).

The reliability and validity of the scale were assessed for the total scale and each dimension extracted by factor analysis. Total CBI-SCI and internal consistency reliability of its subscales were tested by computing Cronbach's α coefficient, values of 0.70 and above were considered as satisfactory (34).

The concurrent validity of the CBI-SCI was assessed correlating the total score with scores of other questionnaires, specifically MBI, FSQ-SF and the eight subscales of SF-36, using the Pearson product-moment correlation: a value of ± 0.30 was considered to be a weak correlation, a value of ± 0.50 was considered a moderate correlation and a value of ± 0.70 was considered a strong correlation (34).

Statistical analysis of all data collected was carried out using the SPSS statistical package (version 22; IBM SPSS Statistics, Armonk, NY). Level of significance was set at $p < 0.05$.

Results:

The mean age of family caregivers was 56.2 years (SD ± 14.6), only 30 (17%) were males, and one-quarter of them ($n = 44$, 25%) were parents of the individual with SCI. Almost the entire sample ($n = 139$, 79%) lived with the assisted person, and around half of them ($n = 86$, 49%) lived in an urban area. Almost half of the sample ($n = 95$, 54%) had been in the caregiving role for more than three years, and a third of them ($n = 59$, 33%) declared that they do not have any significant income from work or government assistance. The mean age of people with SCI was 51.9 years (SD ± 17.9), and eighty-nine (51%) of the sample consisted of tetraplegics. The most common cause of SCI is traumatic ($n = 142$, 81%), within which road accidents were the 46% ($n = 80$). The time since the injury was mostly greater than three years ($n = 100$, 58%), and more than half ($n = 108$, 62%) were married. The sociodemographic characteristics of participants are presented in Table 1.

224 *Construct validity*

225 The normality and the sphericity measures on the CBI-SCI were performed through the KMO and
226 Bartlett's sphericity tests. The KMO test reached a value of 0.867, and the Bartlett's test provided a
227 value of 2510.33 ($df = 276$, $p = 0.000$). Due to this these results, the sample was considered
228 acceptable for factor analysis, that confirmed the five-factored structure of the original scale. Table 2
229 shows the factor loadings for each item.

230 *Reliability*

231 Table 3 summarises the Cronbach's α values of the entire CBI-SCI and each of its subscales, their
232 means and standard deviations. The total scale Cronbach's α coefficient was found to be 0.91. All five
233 subscales of the CBI-SCI showed acceptable Cronbach's α scoring, which varied between 0.76 and
234 0.91.

235 *Concurrent validity*

236 All Pearson correlations between CBI-SCI and other administered instruments were statistically
237 significant ($p < 0.001$), as shown in Table 4. The FSQ-SF obtained the highest r value ($r = 0.63$; $p <$
238 0.001), indicating a moderate direct correlation with the burden level perceived by participants. All
239 other correlations were negative, showing an inverse effect between variables. Particularly, CB
240 showed a moderate correlation with General Health ($r = -0.50$; $p < 0.001$) and Social Role Functioning
241 ($r = 0.58$; $p < 0.001$) on the subscales of SF-36.

242 Discussion:

243 This study assessed the psychometric properties of the CBI-SCI in an Italian family caregivers
244 sample. The modified scale was evaluated positively for its content validity by a panel of experts,
245 who identified the presence of the desired features in the included items. Furthermore, the face
246 validity calculated during the preliminary testing showed an excellent value concerning the clarity,
247 comprehensibility and legibility of the questionnaire (33).

Factor analysis and Promax rotation were used to explore the construct validity of the CBI-SCI. Marvardi (22) identified that the Italian version of the original CBI showed a four dimension structure, with the items related to Dev-B and Phys-B investigating the same dimension of burden. Nevertheless, in this study, five factors were identified in the CBI-SCI, which could explain the total variance of 66%, as proposed in the original CBI version developed by Nolan and Guest (9,35). Furthermore, the three items that were changed did not modify the original dimensions that composed the instrument. The internal consistency of the CBI-SCI showed a Cronbach's α value of 0.91, and all subscales obtained values consistently > 0.70 , which are comparable with the ones obtained by the original CBI version in different populations (9,35).

Moreover, correlations identified between CBI-SCI and all the subscales of the SF-36, as well as with the MBI and the FSQ-SF, used to test the concurrent validity of the instrument were entirely significant and congruent in their correlations. These findings strengthen the validity of the CBI-SCI, as previous research identified the relation between burden and QOL in caregivers of different populations (36,37). Also, the positive correlation of the modified tool with the FSQ-SF agrees with prior studies, which identified the strain of caregiving affecting the psychological well-being of relatives of people with SCI (8,16). Despite evidence that the level of independence of care recipients affects only the physical health of caregivers and is not a predictor of CB (15), a significant negative correlation is found between CBI-SCI and MBI in the current sample.

Caregivers are essential to maintaining the well-being of people with SCI, as well as to maintain their social participation in the community. The caregivers' efforts may cause severe psychological distress and create a significant burden, especially on those who are not ready to take on this role (38). In this regard, the CBI-SCI explores different elements that previous research on caregivers of individuals with SCI identified as distinctive in this population. Caregivers of people with SCI are subjected to a reduction of their personal time, due to the need to assist relatives in their ADLs; thus, they spend a high number of hours assisting (17,38). Moreover, the financial constraints and the difficulties in choosing alternative solutions which may derive from this situation are

predictors of developing burden and lead them to social isolation (15). Caregivers of people with a SCI are frequently exposed to a physical burden, due to the nature of the daily activities they perform (7); assisting their relatives is frequently linked to pain and poor physical health, which are associated with negative outcomes such as the occurrence of depression (15). Moreover, a longer duration of caregiving is associated with a poorer QOL (38).

All the previous domains are measured in the CBI-SCI by its dimensions. To our knowledge, no specific questionnaires were previously developed and, given the importance of assessing subjective CB, the findings of this study suggest the applicability of this tool to the global evaluation of caregivers in SCI. The administration of the CBI-SCI at regular intervals could provide the opportunity to profile an individual's burden trend for each respondent and to identify caregivers who are more at risk. This multidimensional portrait could be helpful in tailoring intervention programs directed to specific burden dimensions of caregivers.

Despite its strengths, such as the sample size, which is large for a validation study (39), this study has several limitations. In fact, the study was conducted in a specific geographical area, and the use of a cross-sectional design limits the results of the concurrent validity of the CBI-SCI. Particularly, a longitudinal design is recommended to test the predictive validity of questionnaires, since the empirical evidence supports the suitability of the CBI's original version. Because of its adequate reliability (9,35) and given the maintenance of the structure despite the changes in three items, it was not considered necessary to perform a test-retest assessment of the modified tool.

Future studies are needed to understand the relationship between CB in SCI and the sociodemographic and psychological characteristics of caregivers, in addition to functional independence and clinical information of their relatives. A more in-depth comprehension of this topic is fundamental for the development of healthcare policies in support of families and to compare CB across different illness.

299 Conclusion:

300 The study findings support the validity and reliability of the CBI-SCI as an instrument to assess the
301 burden for caregivers of individuals with a SCI. The present version, modified explicitly for SCI, may
302 represent a valuable tool for research in this field as well as to longitudinally evaluate the difficulties
303 experienced by caregivers. The possibility to identify the level of burden perceived by caregivers of
304 people with a SCI is fundamental to guide healthcare professionals in determining the needs of
305 caregivers and to plan appropriate interventions.

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308 e della Scienza Hospital of Turin, IRRCs Fondazione Santa Lucia of Rome, Cannizzaro Hospital of
309 Catania and Careggi Hospital of Florence for dedicating their time to this study.

310 Conflicts of Interest:

311 This research received no specific grant from any funding agency in the public, commercial, or not-
312 for-profit sectors. The authors report no conflicts of interest.

313 Authors' contributions

314 AC was responsible for designing and writing the study protocol, and for submitting the study to the
315 ethical committee. He was also responsible for writing the report, coordinating the recruiting centres
316 and interpreting results.

317 MC was responsible for the database managing, analysing data and interpreting results. He
318 contributed to writing the report.

319 PM and SF were responsible for designing and writing the study protocol. They provided feedback on
320 the report.

321 GS, LC, BB and SM were responsible for recruiting the participants and managing the data. They
322 provided feedback on the report.

323 LG and EV provided feedback on the report.

324 Supplementary file 1: contains the final version of the CBI-SCI, an instrument to assess the burden for
325 caregivers of individuals with a SCI.

326

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Table 1

Sample Characteristics (N=176)

Variable	N (%)	Mean	SD
Age of caregivers (years)		56.2	14.6
Females	146 (83%)		
Married/Partner	95 (54%)		
Education of caregivers			
Primary School	22 (13%)		
Middle School	56 (32%)		
High School	80 (45%)		
University	17 (10%)		
Unemployed	59 (33%)		
Age of people with SCI (years)		51.9	17.9
Males	139 (79%)		
Unmarried	60 (34%)		
Education of people with SCI			
Primary School	24 (14%)		
Middle School	56 (33%)		
High School	83 (47%)		
University	10 (6%)		
Active Workers	35% (61)		

Legend: SD Standard Deviation

Table 2

Factor loadings for the 24 items in the Caregiver Burden Inventory in Spinal Cord Injury (CBI-SCI)

Item	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Name of factors
1. My care receiver needs my help to perform many daily tasks	0,92					Time-dependent burden
2. My care receiver is dependent on me	0,94					
3. I have to maintain a high level of attention	0,75					
4. I have to help my care receiver with many basic functions	0,96					
5. I don't have a minute's break from my caregiving chores	0,49					
6. I feel I am missing out on life		0,73				Developmental burden
7. I wish I could escape from this situation		0,80				
8. My social life has suffered		0,84				
9. I feel emotionally drained due to caring for my care receiver		0,60				
10. I expected that things would be different at this point in my life		0,84				
11. I'm not getting enough sleep			0,47			Physical burden
12. My health has suffered			0,74			
13. Caregiving has made me physically sick			0,94			
14. I'm physically tired			0,35			
15. I don't get along with other family members as well as I used to				0,48		Social burden
16. My caregiving efforts aren't appreciated by others in my family				0,81		
17. I've had problems with my marriage				0,57		
18. I don't do as good a job at work as I used to				0,49		
19. I feel resentful of other relatives who could but do not help				0,68		
20. I feel embarrassed about my care receiver's condition					0,83	Emotional burden
21. I feel ashamed of my care receiver					0,75	
22. I resent my care receiver					0,54	
23. I feel uncomfortable when I have friends over or when we go out					0,66	
24. I feel angry about my interactions with my care receiver					0,48	

Table 3

Cronbach's alpha coefficients, means and standard deviations of CBI-SCI and its subscales

	Cronbach's alpha	Mean	SD
Time-dependent burden	0,91	13,91	5,48
Developmental burden	0,88	9,79	5,87
Physical burden	0,87	10,10	5,88
Social burden	0,76	5,15	4,62
Emotional burden	0,76	1,93	2,90
Total CBI-SCI	0,91	41,05	18,10

Legend: SD Standard Deviation

Table 4

Correlation between CBI-SCI and administered questionnaires

Questionnaire	<i>p</i> value	Pearson's <i>r</i>
Modified Barthel Index (MBI)	0,000	- 0,45
Family Strain Questionnaire - Short Form (FSQ-SF)	0,000	0,63
SF-36 Subscale - Vitality	0,000	- 0,45
SF-36 Subscale - Physical functioning	0,000	- 0,35
SF-36 Subscale - Bodily pain	0,000	- 0,48
SF-36 Subscale - General health	0,000	- 0,50
SF-36 Subscale - Physical role functioning	0,000	- 0,49
SF-36 Subscale - Emotional role functioning	0,000	- 0,45
SF-36 Subscale - Social role functioning	0,000	- 0,58
SF-36 Subscale - Mental health	0,000	- 0,52