

New: Burden Scale for Family Caregivers in 20 European languages

With this scale, valid assessment of subjective burden among family caregivers is possible all over Europe using the same questionnaire.

1. Background

The burden experienced by family caregivers is the most important caregiver-related variable in care at home of a chronically-ill person. The extent of subjective burden has significant impact on the emotional and physical health of the family caregiver, and even influences the mortality of spouse caregivers. It affects the way the family caregiver deals with the care-receiver and determines the time of institutionalization.

2. Burden Scale for Family Caregivers BSFC

We are asking you for information about your present situation. The present situation comprises your caregiving deduced from the illness of your family member (or friend).

The following statements often refer to the type of your assistance. This may be any kind of support up to nursing care.

**Please draw an “X” for the best description of your present situation.
Please answer every question!**

	strongly agree	agree	disagree	strongly disagree
1. I feel fresh and rested in the morning.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. My life satisfaction has suffered because of the care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I often feel physically exhausted.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. From time to time I wish I could “run away” from the situation I am in.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I miss being able to talk with others about the care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I have enough time for my own needs and interests.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Sometimes I feel that the person I am caring for is using me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Away from the caring situation I can switch off.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please turn to next page

	strongly ag- ree	agree	disagree	strongly disagree
9. It's easy for me providing the necessary nursing care (washing, feeding etc).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Sometimes I don't really feel like "myself" as before.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. The care I give is acknowledged by others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Since I have been a caregiver my financial situation has decreased.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. I feel like being forced into this caregiving situation.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. The wishes of the person I am caring for are reasonable in my opinion.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. I feel I have a handle on the care situation.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. My health is affected by the care situation.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. I am still capable of feeling really joyful.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. I have had to give up future plans because of the care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. It doesn't bother me if outsiders are aware of the sick person's situation.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. The care takes a lot of my own strength.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. I feel torn between the demands of my environment (such as family) and the demands of the care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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	strongly agree	agree	disagree	strongly disagree
22. I feel I have a good relationship with the person I am caring for.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. I have problems with other family members due to the care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. I feel I should take a break.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. I am worried about my future because of the care I give.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. My relationships with other family members, relatives, friends and acquaintances are suffering as a result of the care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. I feel sad because of the fate of the person I am caring for.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. I can take care of other daily obligations to my satisfaction in addition to the caregiving.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Thank you very much!

3. Evaluation

The responses to the 28 statements of the BSFC are rated according to the following scheme:

a) For the statements numbered **1, 6, 8, 9, 11, 14, 15, 17, 19, 22 and 28** the rating is as follows:

Response:	Points:
Strongly agree	0
Agree	1
Disagree	2
Strongly disagree	3

b) For the remaining statements numbered **2, 3, 4, 5, 7, 10, 12, 13, 16, 18, 20, 21, 23, 24, 25, 26 and 27** the rating is reversed:

Response:	Points:
Strongly agree	3
Agree	2
Disagree	1
Strongly disagree	0

4. Interpretation of the sum score

The interpretation of the BSFC score depends on the disease causing the need for care. If this is dementia, the interpretation is made according to Table 1. For all other diseases, that is when dementia is not involved, Table 2 applies.

The assignment of the BSFC score to the categories

a) **not or mildly** burdened

b) **moderately** burdened

c) **severely or very severely** burdened

is made depending on the risk of psychosomatic symptoms, which

in a) is **not** increased,

in b) is increased

in c) is **strongly** increased.

Table 1: Interpretation of the BSFC score for caregivers of individuals with **dementia**

BSFC Score	Subjective burden categories	Risk of psychosomatic symptoms	Sample percentage (N = 1236)
0 – 35	none to mild	not at risk ^{a)}	33.8 %
36 – 45	moderate	increased risk ^{b)}	25.3 %
46 –84	severe to very severe	at very high risk ^{c)}	40.9 %

a) if the BSFC score ranges from 0 to 35, the extent of overall physical symptoms (Gießen Symptom List GBB-24) corresponds to the expected value in the “normal population”, that is, 50% of those caregivers have a percentile rank (PR) of physical symptoms ≤ 50 and the other 50% a PR > 50 .

b) if the BSFC score ranges from 36 to 45, 74% of those caregivers have an above-average extent of physical symptoms (PR > 50).

c) if the BSFC score ranges from 46 to 84, 90% of those caregivers have an above-average extent of physical symptoms (PR > 50).

Table 2: Interpretation of the BSFC score for caregivers of individuals **without dementia**

BSFC Score	Subjective burden categories	Risk of psychosomatic symptoms	Sample percentage (N = 591)
0 – 41	none to mild	not at risk ^{a)}	61.4 %
42 - 55	moderate	increased risk ^{b)}	24.4 %
56 –84	severe to very severe	at very high risk ^{c)}	14.2 %

^{a)} if the BSFC score ranges from 0 to 41, the extent of overall physical symptoms (Gießen Symptom List GBB-24) corresponds to the expected value in the “normal population”, that is, 50% of those caregivers have a percentile rank (PR) of physical symptoms ≤ 50 and the other 50% a PR > 50 .

^{b)} if the BSFC score ranges from 42 to 55, 74% of those caregivers have an above-average extent of physical symptoms (PR > 50).

^{c)} if the BSFC score ranges from 56 to 84, 90% of those caregivers have an above-average extent of physical symptoms (PR > 50).