


Home Care in Germany - Between Strain and Strength

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Introduction

- 2,5 million people in Germany are in need of care and assistance
 - 70% are living at home and receiving informal care
 - 2/3 of them are supported by close relatives
- Experts estimate an increase in long term care patients of 29% by 2020 and an increase of 50% by 2030
- Informal care  important pillar of the German health care system
- Future challenge: to maintain the status quo facing demographic trends

Methods

- representative sample of 1,007 informal caregivers aged 18 and older
- Computer Assisted Personal Interviews (CAPI) carried out by FORSA
- validated questionnaire (Burden Scale for Family Caregivers BSFC) supplemented by questions addressing subjective wellbeing and utilization of information / support programs
- quota-sample (incl. statistical weights)

Methods

Definition of family caregivers

- Informal caregiving for people with a registered level of care (“Pflegestufe” 0-3)
- outpatient care / ambulatory setting
- Caregiving is defined as more than domestic care (cooking and housing)

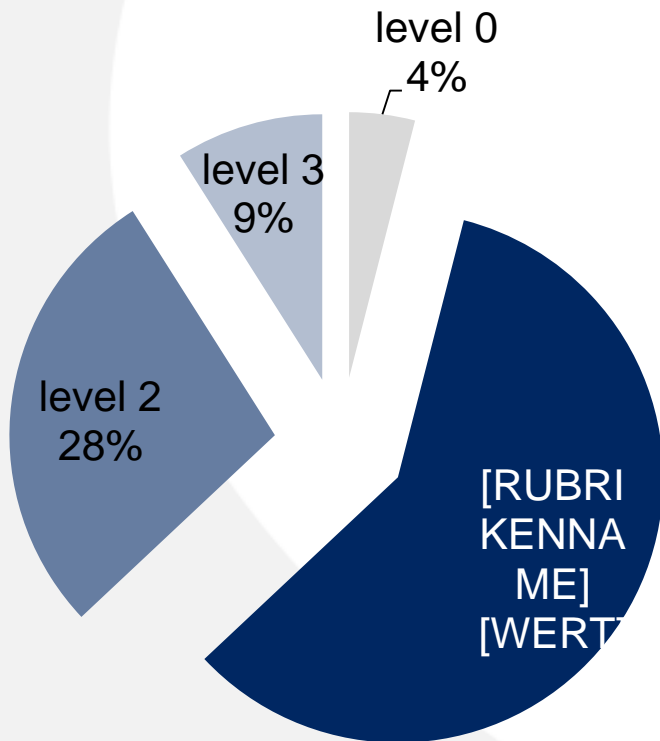
Methods

Burden Scale for Family Caregivers (BSFC) Questionnaire

	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"/>

Results

Sample description

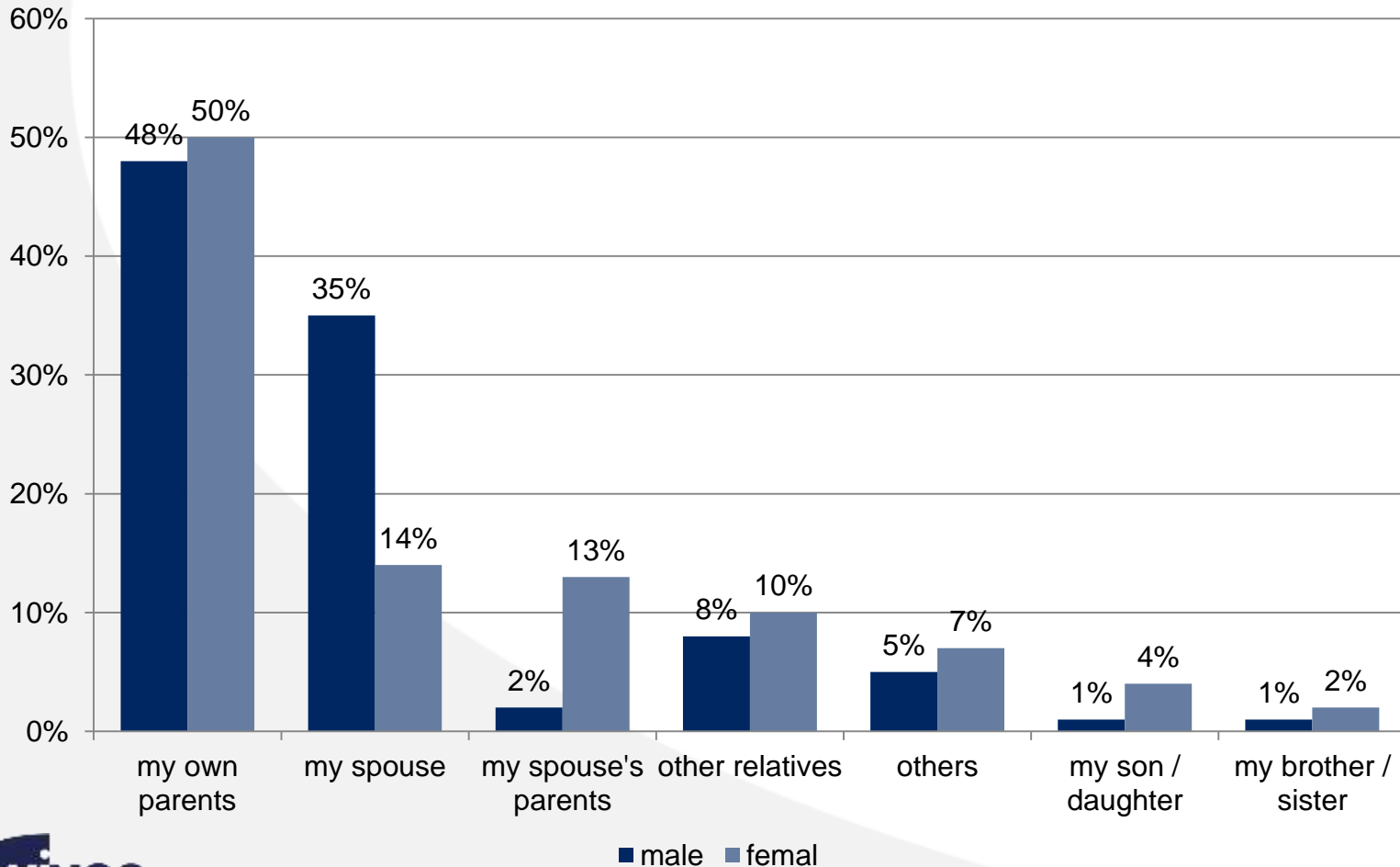


- **sex**: 79% of the respondents were female (21% male respectively).
- **age**: 52 % were aged 50-65, approx. 30% were 18-49 years old and 19% were 65 years and above
- **relationship**: 50% are responsible for the care for their parents, 18% for their spouses and 11% for their spouse's parents.
- **carer's situation**: 63% had time to grow into their duties and responsibilities and 37% were suddenly confronted with them. 30% look after a person suffering from dementia.
- **frequency of care**: about 7 out of 10 (65%) are providing care on a daily basis.

Results

Relationship between caregiver and person in need of care

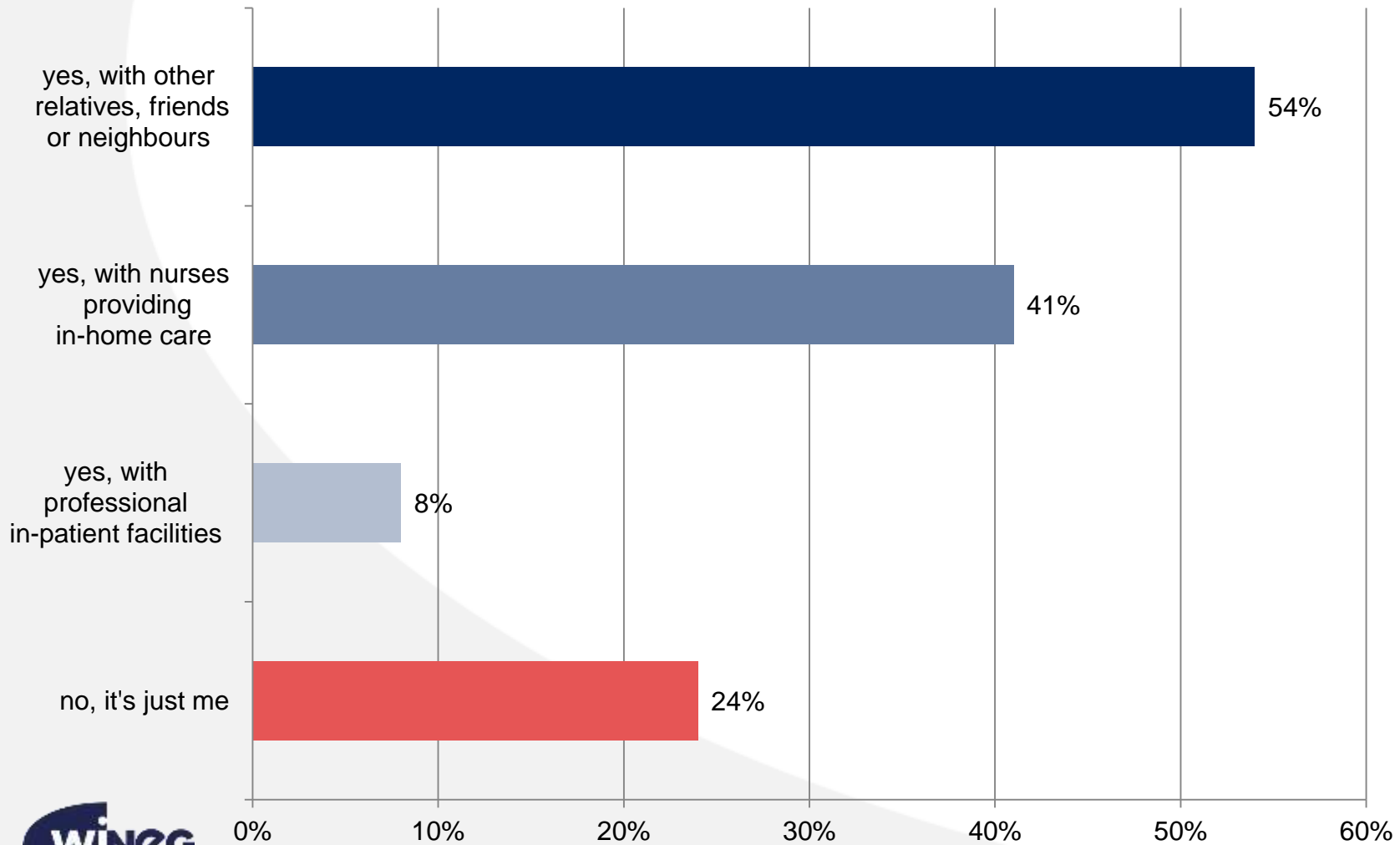
Who do you care for? (male = 210, female = 797)



Results

Informal or professional support:

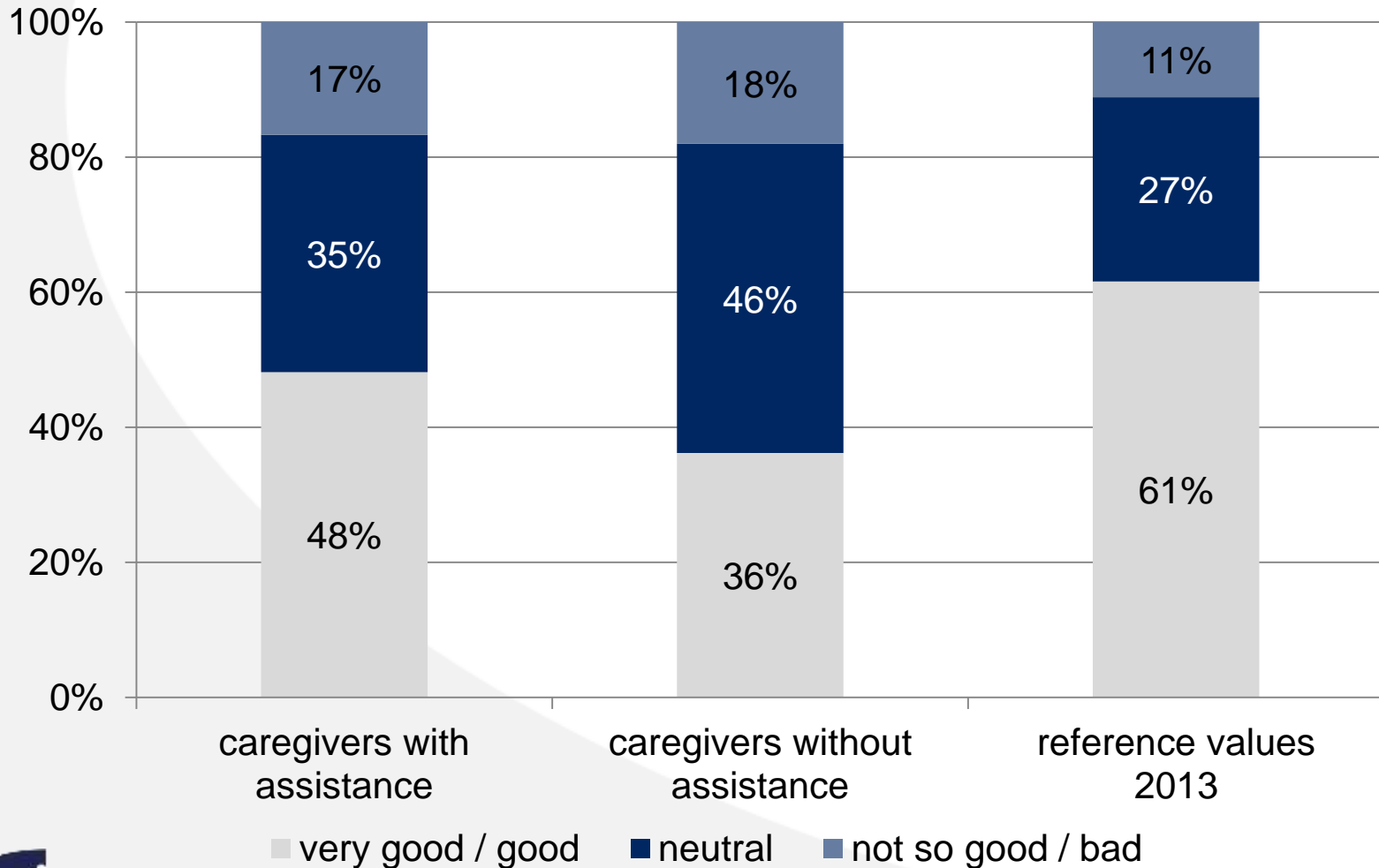
Do you share the workload with somebody? (N=1,007)*



* multiple answers possible

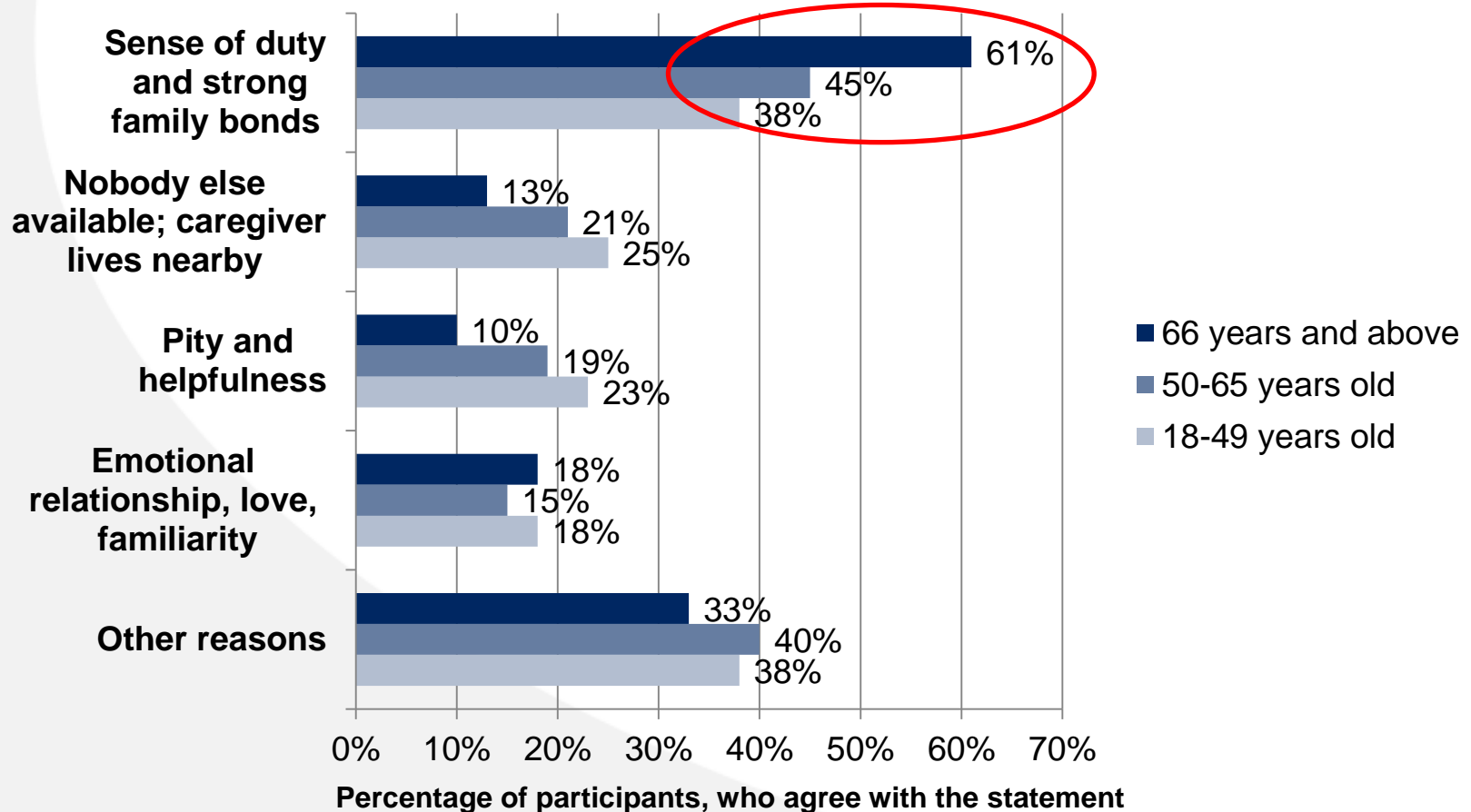
Results

Subjective health status of caregivers vs. general population:
How would you describe your own health status? (N = 765 / 242 / 1,000)



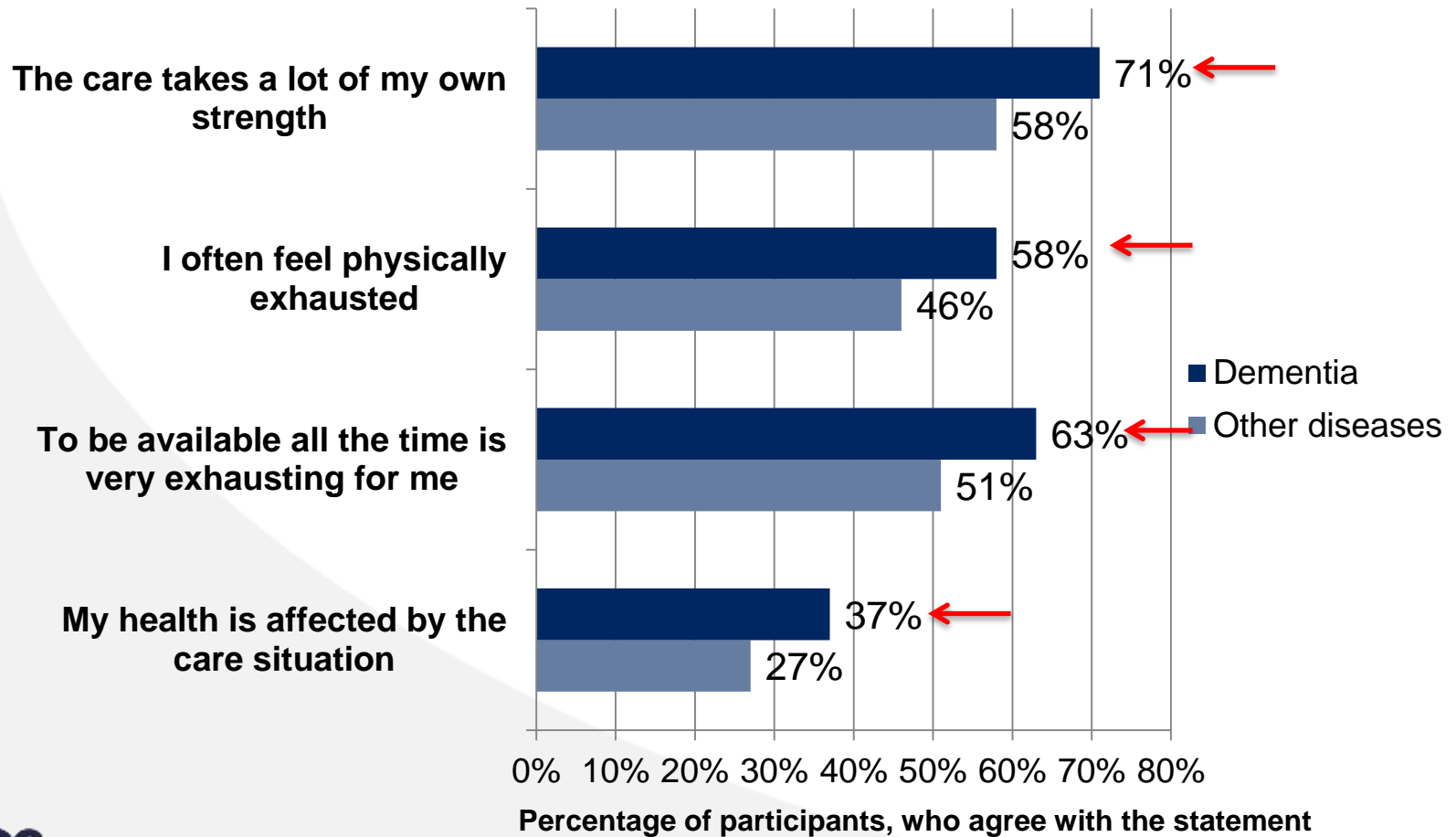
Results

What are the reasons for you to carry out caregiving tasks?
sorted by age groups (N=1,007) *



Results

Single items of the Burden Scale for Family Caregivers (BSFC) differentiated for dementia and other diseases (N=1,007)



Results

Which of the following health care services do you know or use?
(N=1,007) *

	Percentage of participants, who <u>know</u> the service	Percentage of participants, who <u>do use</u> the service
Mobile home care services	100 %	58 %
Outpatient <u>day</u> care services	92 %	20 %
Short-term nursing home care (available over max. 28 days)	91 %	25 %
Outpatient <u>night</u> care services	74 %	7 %
Single care training for family caregivers at home	50 %	17 %
Group training for family caregivers	58 %	14 %
Counseling ("Pflegerstützpunkte")	55 %	14 %
Self-help group	69 %	16 %

Results

Positive aspects:

BSFC statements with highest levels of agreement (>75%)

	% of respondents who agree
I feel I have a good relationship with the person I am caring for.	95%
I feel I have a handle on the care situation.	91%
It doesn't bother me if outsiders are aware of the sick person's situation.	87%
The wishes of the persons I am caring for are reasonable in my opinion.	85%
It's easy for me providing the necessary nursing care.	84%
I am still capable of feeling really joyful.	83%
I feel sad because of the fate of the person I am caring for.	78%
The care I give is acknowledged by others.	76%

Summary and Conclusion

- Family Caregivers in Germany are mainly women aged 50 to 59 years
 - With regard to the increasing employment rate of women and the increasing number of elderly people in need it is not possible to maintain informal care to the present extent
 - There is a strong need for adapted “care arrangements”
- Lower sense of duty and family relationship in the younger generation of family caregivers
 - Care is a future challenge not only for policy makers but for the society as a whole
 - TK-pilot project: integration of community-based care and services
- Persons who care for people with dementia report higher levels of burden
 - Despite the overall situation is really demanding, carers reported a lot of positive aspects: more than 3/4 say they have a handle on the situation and others acknowledge their efforts
- Many health care services are not used frequently or not even known
 - There is a strong need for low threshold support programs
 - TK: improved communication with family caregivers

Thank you for your attention!



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Backup

Burden Scale for Family Caregivers

Calculation of BSFC-Score

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

Burden Scale for Family Caregivers

Interpretation of BSFC-Score

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).