



Unmet Social Needs

Survey results from the German Stroke Foundation

**Christian Voigt, Rebecca Pries, Christina Franzisket,
Michael Brinkmeier, Markus Wagner**

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Background

Why did we ask?

Stroke can lead to long-term consequences and impairments in all areas of life [1].

[1] Chen, T.; Zhang, B.; Deng, Y.; Fan, J.-C.; Zhang, L.; Song, F. (2019): Long-term unmet needs after stroke: systematic review of evidence from survey studies. *BMJ open*, 9(5):e028137. DOI: 10.1136/bmjopen-2018-02813.

Social health and participation restrictions caused by stroke are known to contribute to more depression, reduce quality of life and deteriorate physical recovery after stroke [2].

[2] Northcott, S.; Moss, B.; Harrison, K.; Hilari, K. (2016): A systematic review of the impact of stroke on social support and social networks: associated factors and patterns of change. *Clinical rehabilitation*, 30(8):811-31. DOI: 10.1177/0269215515602136.

However, insufficient information is available to the extent of (unmet) needs of German stroke survivors.

„Thank you, that you have not forgotten about us“

Survey participant quote

The Survey

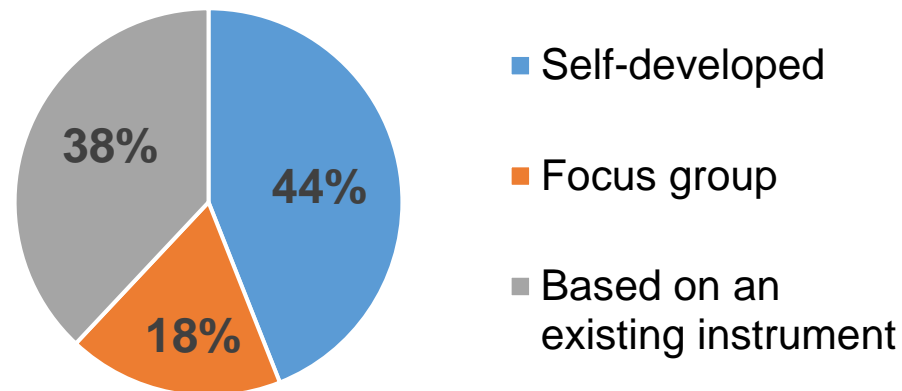
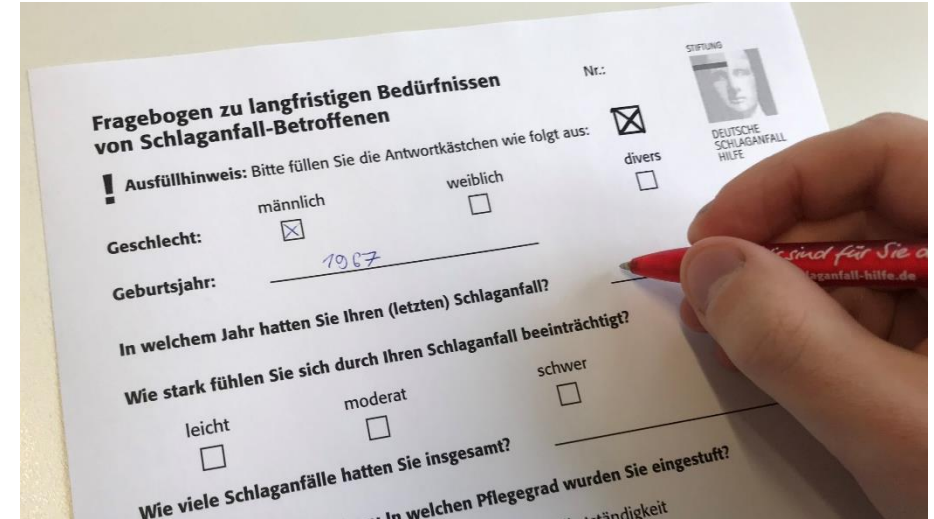
How did we develop the questionnaire?

Screening of existing tools like


- Longer-term Unmet Needs after Stroke (LUNS)
- Post Stroke Checklist (PSC)
- Greater Manchester Stroke Assessment Tool (GM-SAT)

SSO experience + Focus group with stroke survivors

Origin of the questions

Fragebogen zu langfristigen Bedürfnissen von Schlaganfall-Betroffenen

Nr.: 

Ausfüllhinweis: Bitte füllen Sie die Antwortkästchen wie folgt aus:

Geschlecht: männlich weiblich

Geburtsjahr: 1967

In welchem Jahr hatten Sie Ihren (letzten) Schlaganfall?

Wie stark fühlen Sie sich durch Ihren Schlaganfall beeinträchtigt?

leicht moderat schwer

Wie viele Schlaganfälle hatten Sie insgesamt?

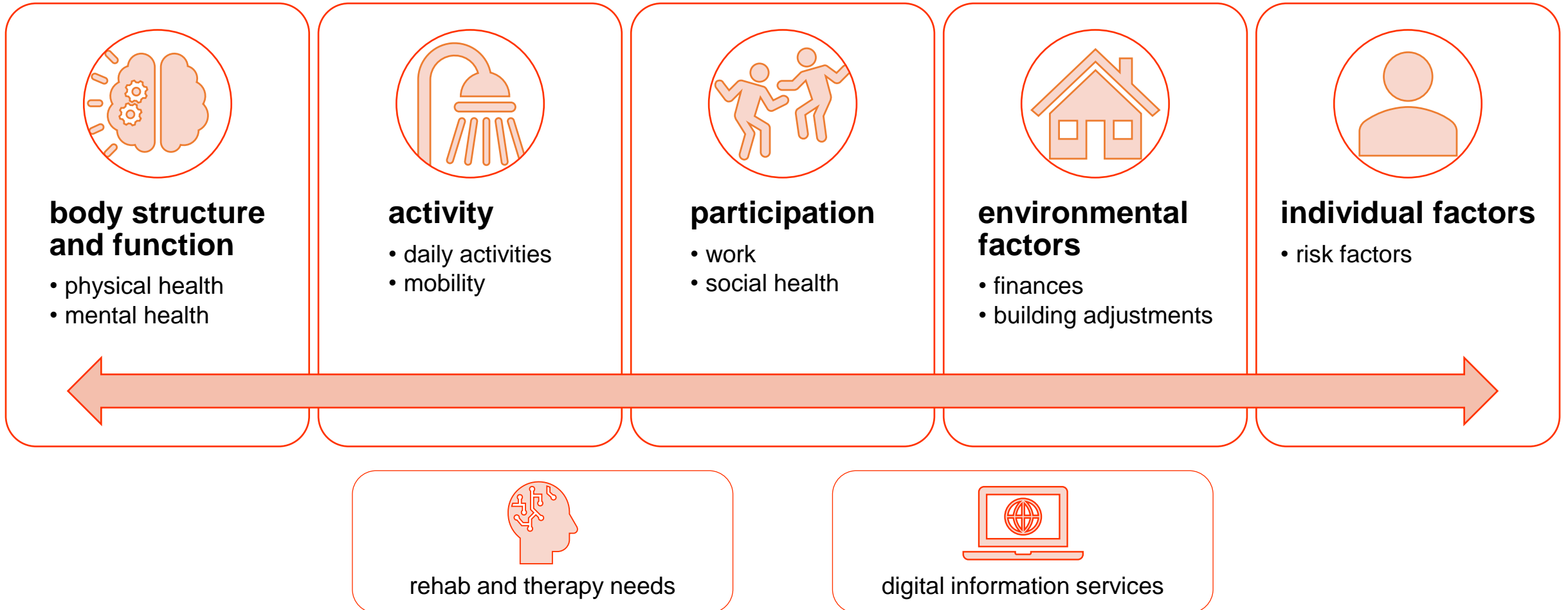
In welchem Pflegegrad wurden Sie eingestuft?

- 11 topics, social health included
- 39 questions assessed unmet needs
- 3-level response scale

Sent to 3,375 stroke survivors (database of the German Stroke Foundation) in May 2021

Survey Topics

What did we ask (ICF orientation)?

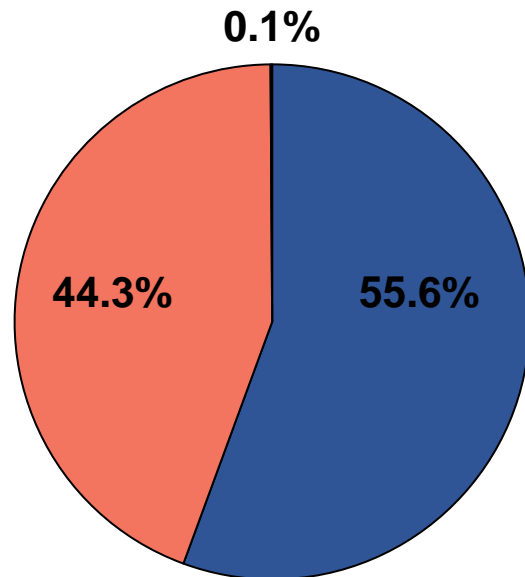


Participants

Gender and Age

979 completed questionnaires,
response rate: 29%

gender distribution



■ male (n=541) ■ female (n=431) ■ diverse (n=1)

Age	minimum	maximum
Time of Survey	16 y	97 y
Stroke onset	0 y (birth)	93 y

Average Age	male	female	total
Survey (n=917)	67.6 (SD=16.3)	63.5 (SD=18.9)	65.9 (SD=17,6)

Participants

Needs related to degree of impairment

Degree of impairment (Self assessment)

Light	Moderate	Severe
33.7%	39.9%	26.4%

No statistical gender difference

Proportion of respondents with no need or at least one need

Impairment	No need	At least 1 need
Light	12.2%	87.8%
Moderate	1.7%	98.3%
Severe	0%	100%

Needs Assessment

How to differentiate Needs and unmet Needs?

Example item: „Since my stroke, I often feel sad or depressed.“

**Yes and I would like
additional help and
support**

**Yes, but I am receiving
enough help and
support**

No

Unmet Need

Need

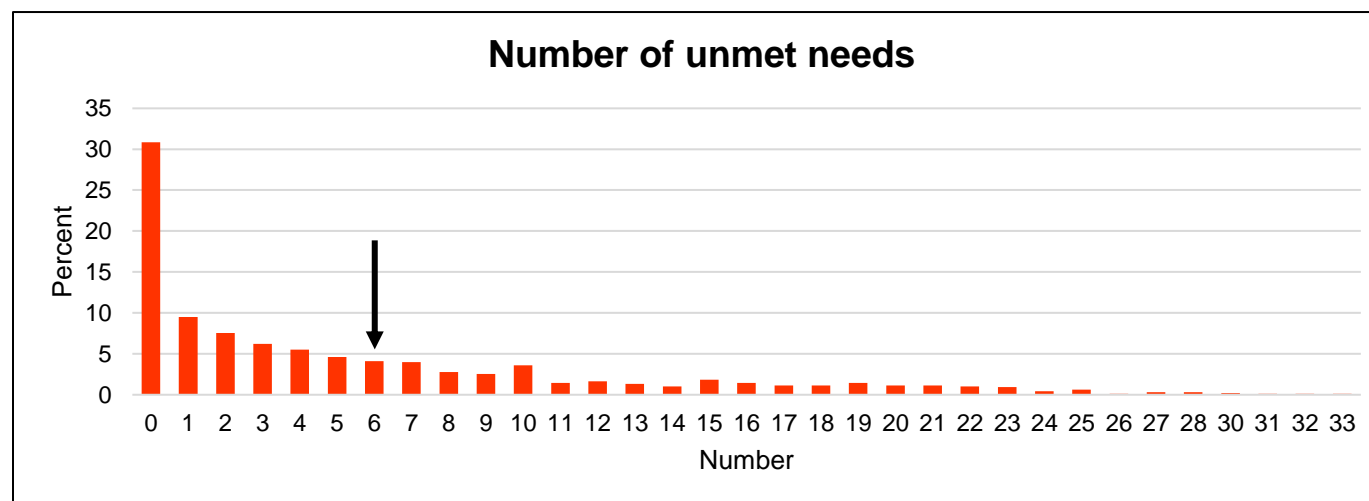
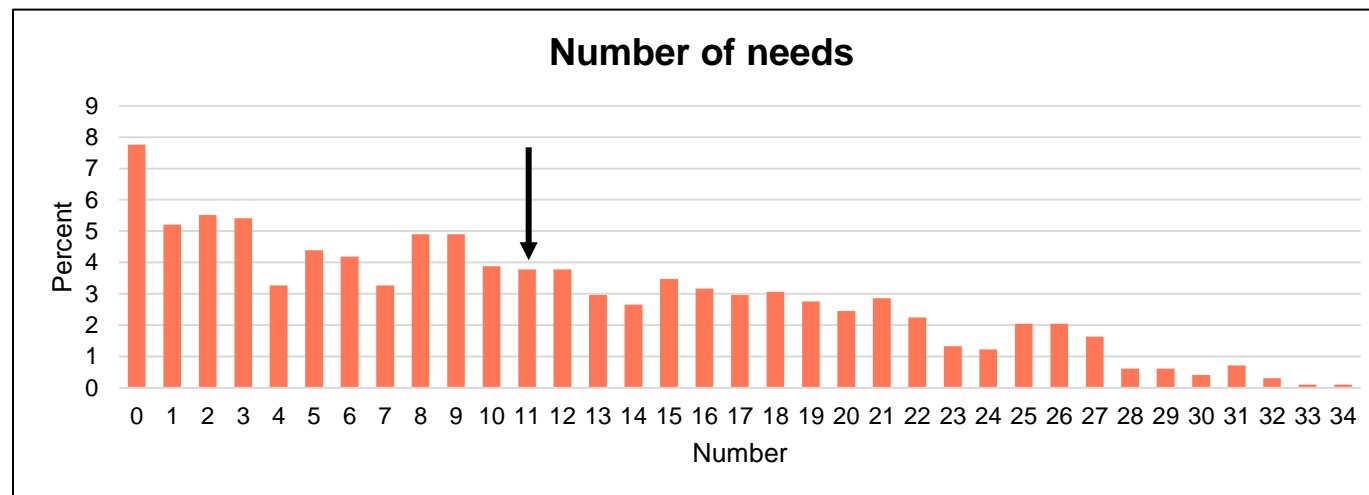
No Need

Similar to Greater Manchester Stroke Assessment Tool (GM-SAT)

General results

Number of needs and unmet needs

- 92.2% have various needs since the stroke
- On average: 11 different needs
- 69.2% of respondents would like to have more support.
Most common: rehabilitation, memory/concentration, therapies
- On average: 6 different support needs



General results

Needs and unmet needs according to time since stroke

Proportion of respondents with at least one need or unmet need

Time since stroke	At least 1 need	At least 1 unmet need
0-4 years	90.1%	68.6%
5 and more years	94.2%	69.1%

Needs are still present 5 or more years after the stroke.

Across all respondents, the average time since the stroke was 9.2 years ($SD=8.4$)

Gender specific results

Needs and unmet needs by gender

Proportion of respondents with at least one need or unmet need

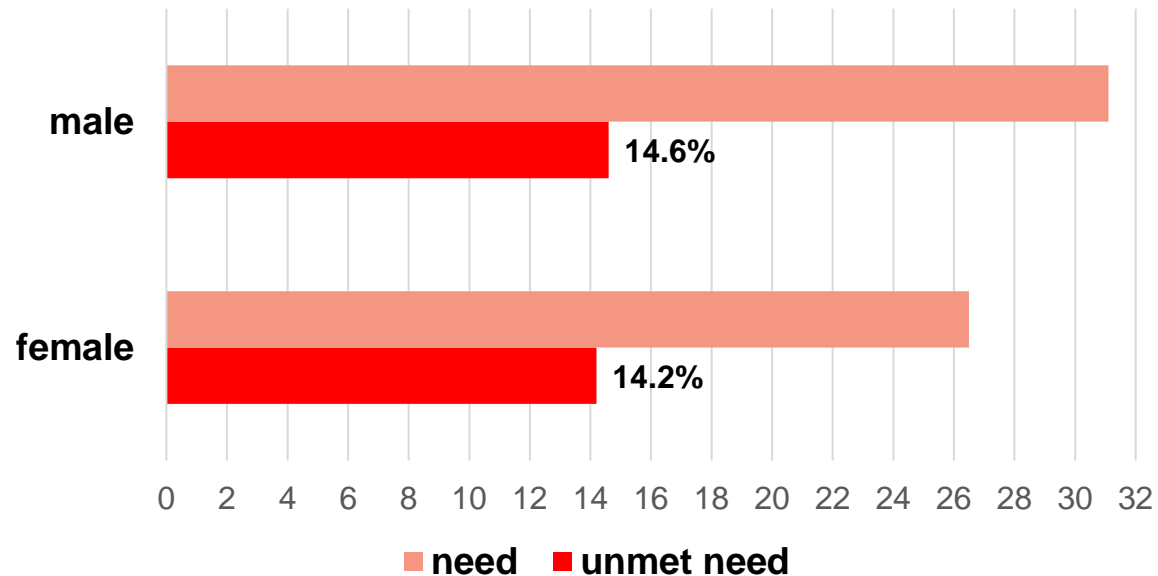
Gender	At least 1 need	At least 1 unmet need
male	91.7 %	67.3 %
female	92.8 %	71.5 %

Needs occur equally often in both sexes.

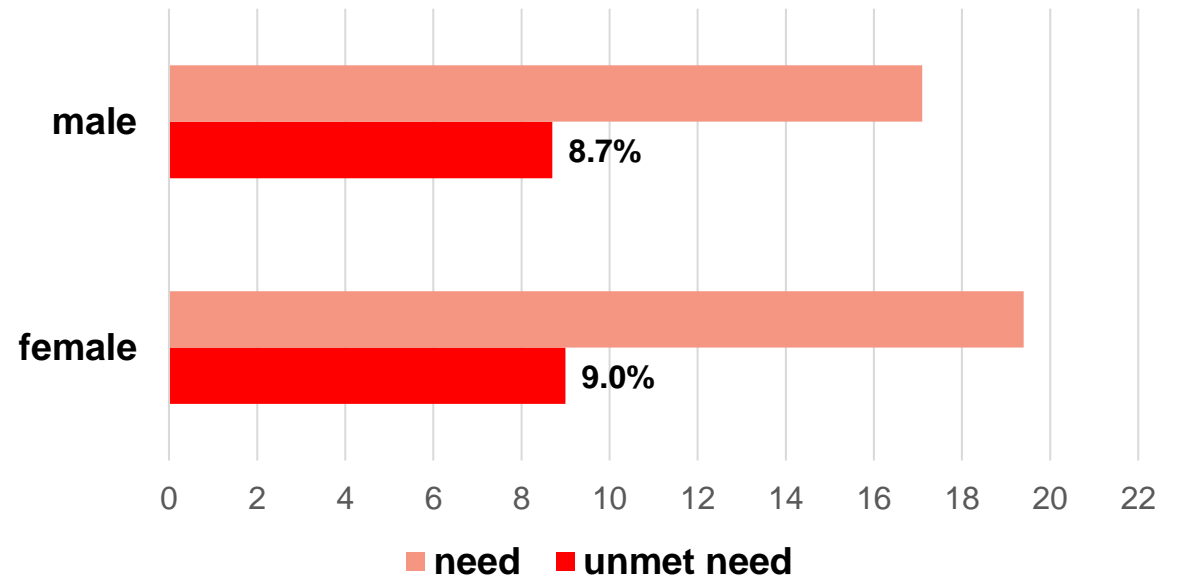
Social Health related results

Contacts and relationships

Difficulties in maintaining contacts or making new ones



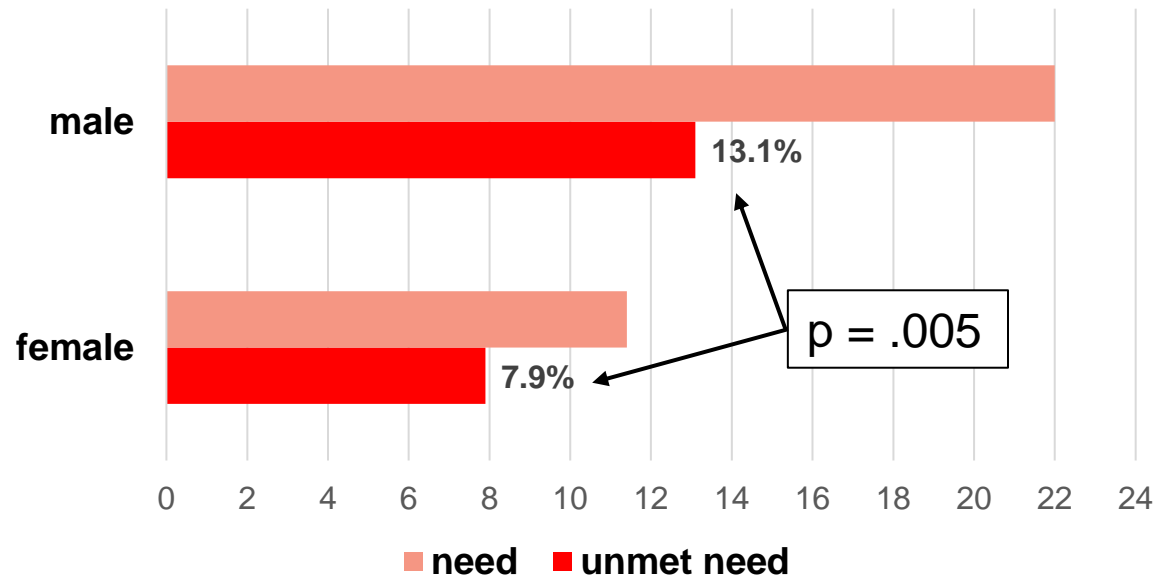
Relationship with my (caring) relatives became more difficult



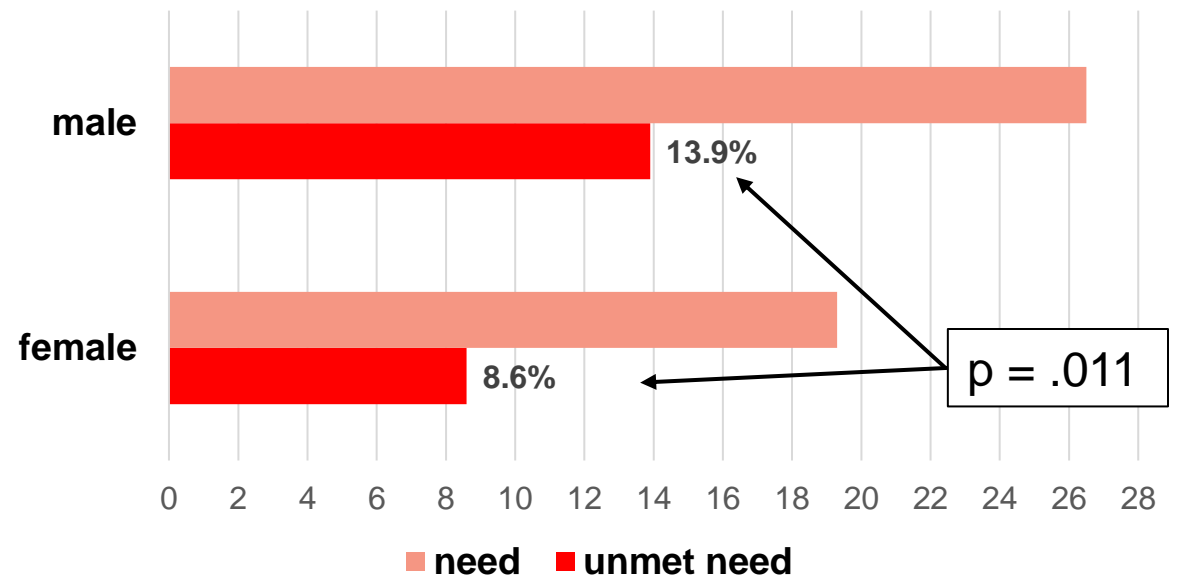
Gender differences in Social Health

Relationships and Communicating

being concerned about the (physical) relationship with their partner



communicating with other people



Summary - Conclusion - Outlook

- Sample not representative (age, gender) and heterogenous (time since stroke, age distribution)
- Questionnaire not validated, self assessment of participants

but

- “Kickstarter” for further explorative analysis, refinement of data pool and future projects
- Confirmation of research that a majority of stroke survivors has long-term needs (independent of age, gender or years living with stroke)
- Similarities, but also differences between genders to maintain social contacts or relationships

Next steps

- More research is needed to develop and establish better long-term stroke support, which includes research on gender specific aspects of health and social care
- **We strive to encourage researchers together with stroke survivors to take next steps with us!**

Take home messages

Quotes from the Participants

„Due to my two strokes I don't have lasting damages, but inspite of that, there is not a single day I don't think about it or am not frightened.“

„I would wish for more help with activities of my daily live.“

„Offers for support and help for long term survivors of stroke are missing. More should be done and reported about this!“

Thank you very much for your attention!