

# Medical Care Situation and Stigmatization of People with ME/CFS in Germany

Dr. Laura Froehlich

## People with ME/CFS are medically underserved

- Barriers to accessing medical care
    - Geographical and financial hurdles
  - Satisfaction with medical care
    - Specialists are scarce
    - GPs have knowledge gaps about ME/CFS
    - Health professionals often attribute ME/CFS symptoms to psychological factors
- **Goal 1:** Investigate medical care situation of people with ME/CFS in Germany

## People with ME/CFS report stigmatization

- **Stigmatization:** perceived discrimination due to having ME/CFS
- Delegitimizing experiences by physicians, family members and acquaintances
- Stigmatization associated with lower physical, mental, and social functioning
- **Goal 2:** Investigate the role of causal attributions in stigmatization
- **Causal attributions:** perceived reasons for stigma
  - Controllability: other people believe that people with ME/CFS are responsible for their condition
  - Instability: other people believe that ME/CFS is changeable/ one can recover

## Survey among people with ME/CFS in Germany

Symptoms & Functional +  
Social Status

DSQ SF/ PEM, SF 36, NeuroQoL (Satisfaction with Social Roles and Activities)

Medical Care Access

Medical services utilized in last 6 months in regard to ME/CFS  
Barriers to access  
Satisfaction with medical care

Causal attributions

Responsibility (e.g., „people blame me for my illness“)  
Instability (e.g., „people see my illness as changeable“)

Stigmatization

NeuroQoL SSCI-8 (stigma scale for chronic illnesses, e.g., „Because of my illness, some people avoided me“)



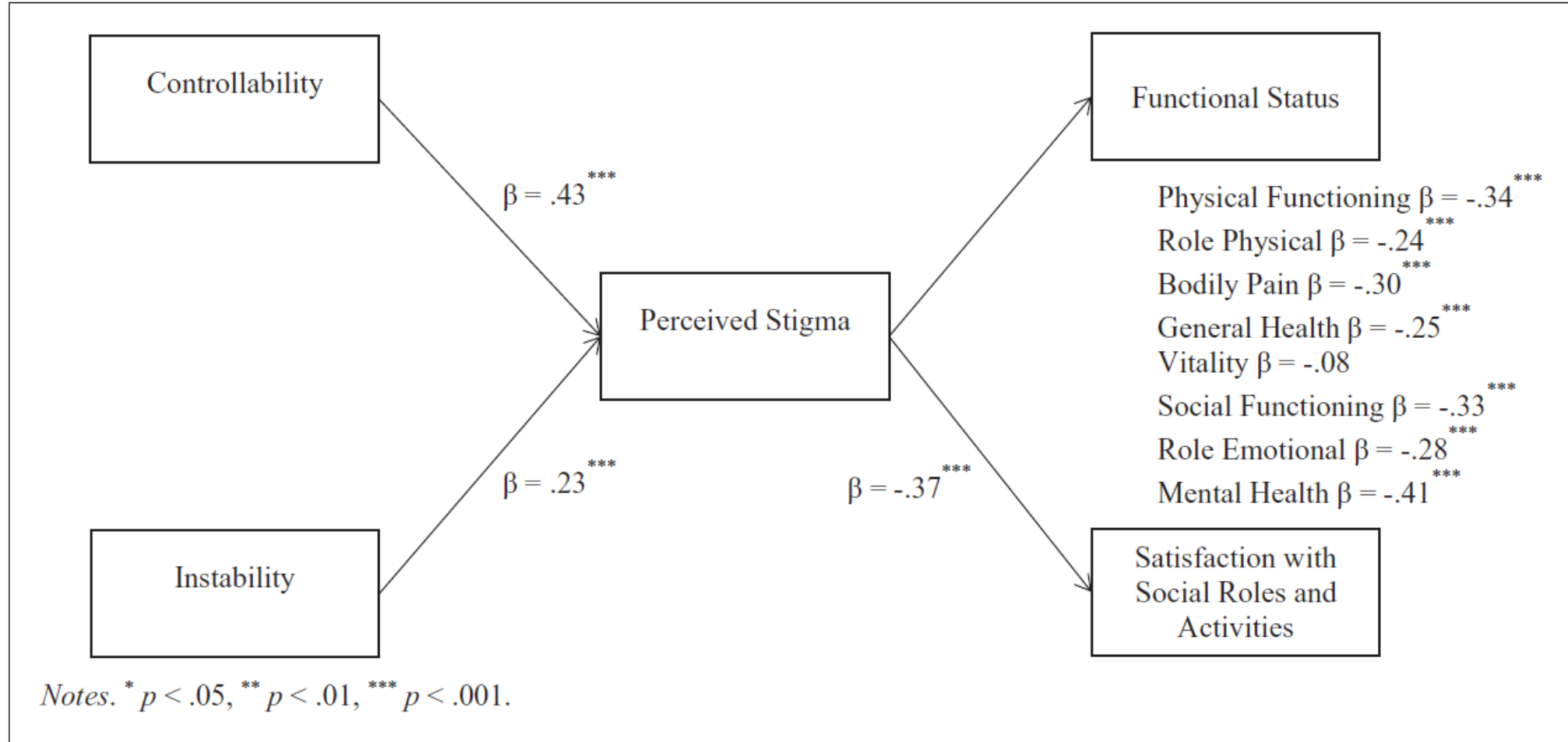
## Results Medical Care Situation

$N = 499$  (75% female, age:  $M = 47$  years,  $SD = 12$ ), fulfilled CCC

Barrier	Frequency	Percentage
No ME/CFS specialist in the geographic area	394	79.0%
Financial/insurance reasons	356	71.3%
Lack of knowledge of service availability (who treats my disease?)	331	66.3%
ME/CFS specialist is not covered by health insurance	287	57.5%
Travel distance and lack of transportation	278	55.7%
ME/CFS-associated impairment prevented access to service	270	54.1%
ME/CFS specialist has a full waiting list	191	38.3%

- Only 33% visited specialist
- Satisfaction with medical care by GP low

## Results Stigmatization



Article

# Medical Care Situation of People with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome in Germany

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**Causal attributions and perceived stigma for myalgic encephalomyelitis/chronic fatigue syndrome**

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## Increasing Health Professionals' Knowledge about ME/CFS

# Live-Webinar

[Postvirale Erkrankungen: ME/CFS und Long COVID]

13. Oktober 2021 | 18.30 Uhr

Anmeldung | Infos:

[www.mecfs.de/webinar\\_anmeldung](http://www.mecfs.de/webinar_anmeldung) | [www.mecfs.de/webinar\\_informationen](http://www.mecfs.de/webinar_informationen)

Agenda:

<b>Prof. Dr. med. Carmen Scheibenbogen</b> [Charité Fatigue Centrum]	30 Min.
Überblick ME/CFS: Epidemiologie, Pathogenese, Diagnostik u. Therapieansätze	
<b>Prof. Dr. med. Uta Behrends</b> [Technische Universität München]	30 Min.
ME/CFS und Long COVID bei Kindern und Jugendlichen	
<b>Dr. med. Claudia Kedor</b> [Charité Fatigue Centrum]	15 Min.
Long COVID in der Forschung	
<b>Dr. med. Michael Stingl</b> [Neurologie, Wien]	30 Min.
ME/CFS und Long COVID in der niedergelassenen Praxis	
<b>Fragen der Teilnehmer:innen</b>	30 Min.

Akkreditiert durch:

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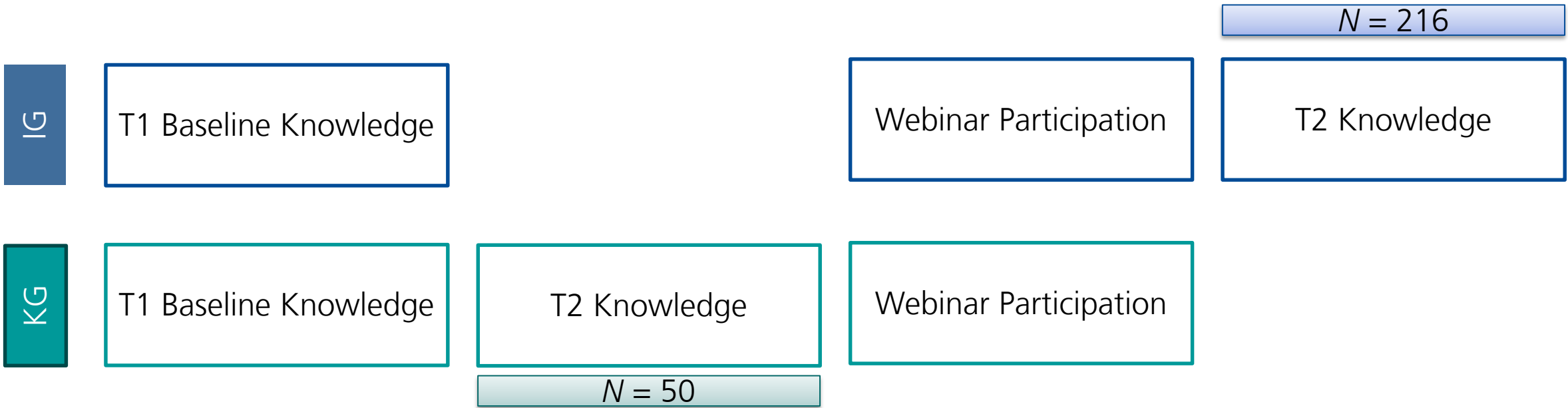
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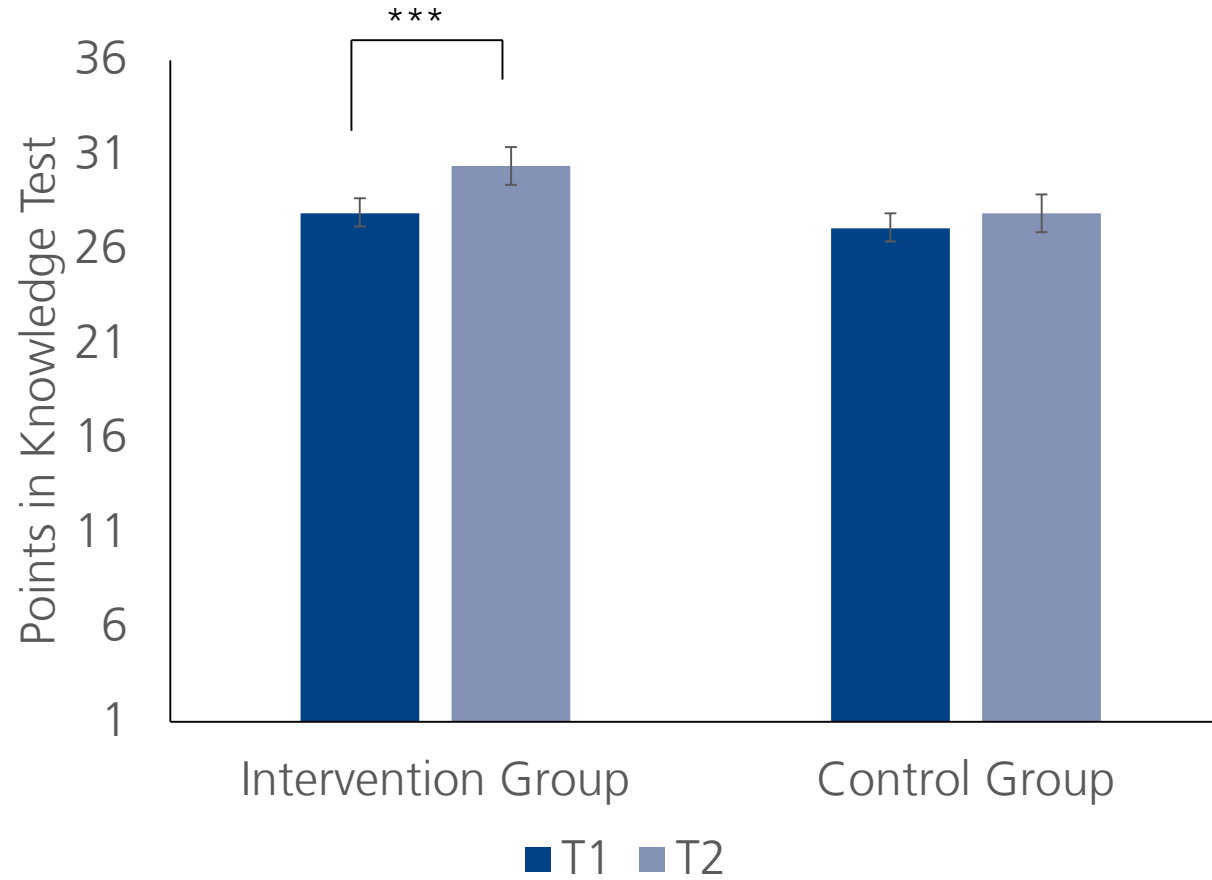




# Increasing Health Professionals' Knowledge about ME/CFS



## Results Webinar



## Discussion

- People with ME/CFS in Germany report
  - barriers to accessing medical care
  - Low satisfaction with medical care by GP
  - Stigmatization
- Webinars are a cost-effective means to provide continuing medical education to health professionals
  - Increase diagnostic ability
  - Reduce attribution of symptoms to psychological factors

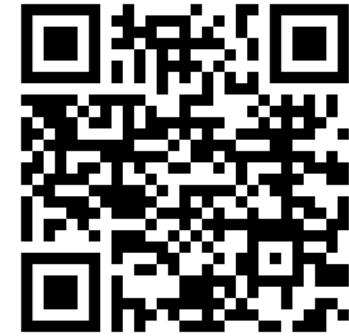


German version of  
DSQ SF/ PEM

## Questions or Comments? Thank you for your attention!

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German translation:  
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Daniel Hattesoht



Jasmin Niedrich



Carmen Scheibenbogen



Uta Behrends



Leonard Jason

