



## **Informal Caregivers of Patients with Disorders of Consciousness:**

**A Qualitative Study of Communication Experiences and Information Needs with Physicians**

**Effective  
Communication  
and Information  
of  
neurodiagnostic  
results**

Boegle K, Bassi M, Comanducci A, Kuehlmeier K, Oehl P, Raiser T, Rosenfelder M, Sitt JD, Valota C, Willacker L, Bender A, Grill E

Neuroethics 2022

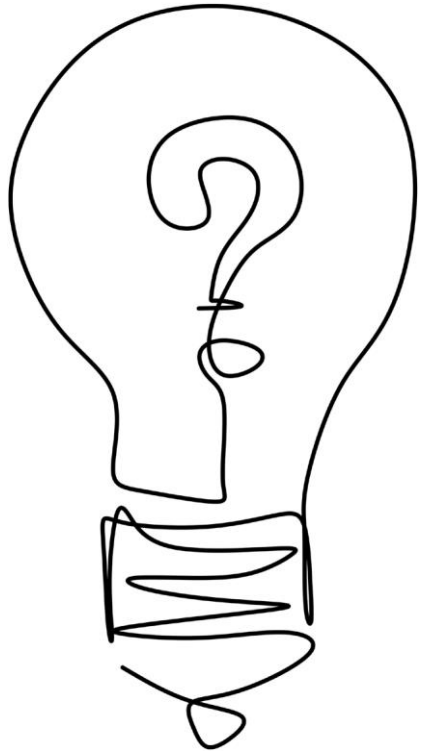
<https://doi.org/10.1007/s12152-022-09503-0>

# Who should read the paper?



- **Neuro-rehabilitation Experts and health professionals working in neuro-rehabilitation settings**
- **Science and Medical Studies Scholars**
- **Public Health Ethicists**
- **Healthcare Professionals**
- **Everyone interested in communication in neurological rehabilitation**
- **Everyone interested in medical surrogate decision making**

# What's it about?



*“How do informal caregivers perceive and experience communication with medical staff regarding diagnostic results, namely of prognostic tests, and prognosis of the DoC\* patient? What are their specific informational needs?”*

**Empirically exploring information needs among a group of caregivers of DoC\* patients, how they manage the obtained information, and their perceptions of and experiences with caregiver-physician communication.**

# Study design

What did the researchers do?

**Methodology:** Qualitative study design with a critical realist approach

**Data acquisition:** Semi-structured interviews

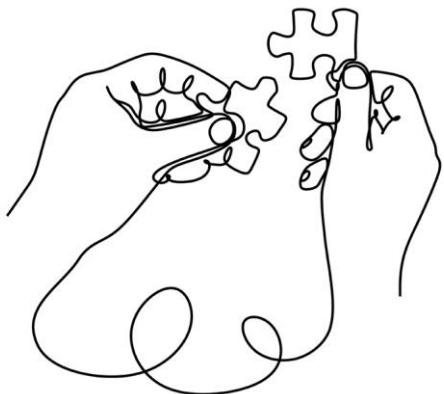
**Setting:** Neurological rehabilitation facilities in Germany and Italy in 2021

**Participants:** Formal and informal caregivers of patients with DoC

**Data analysis:** Reflexive Thematic Analysis (Braun & Clarke)



# What did the researchers find out?



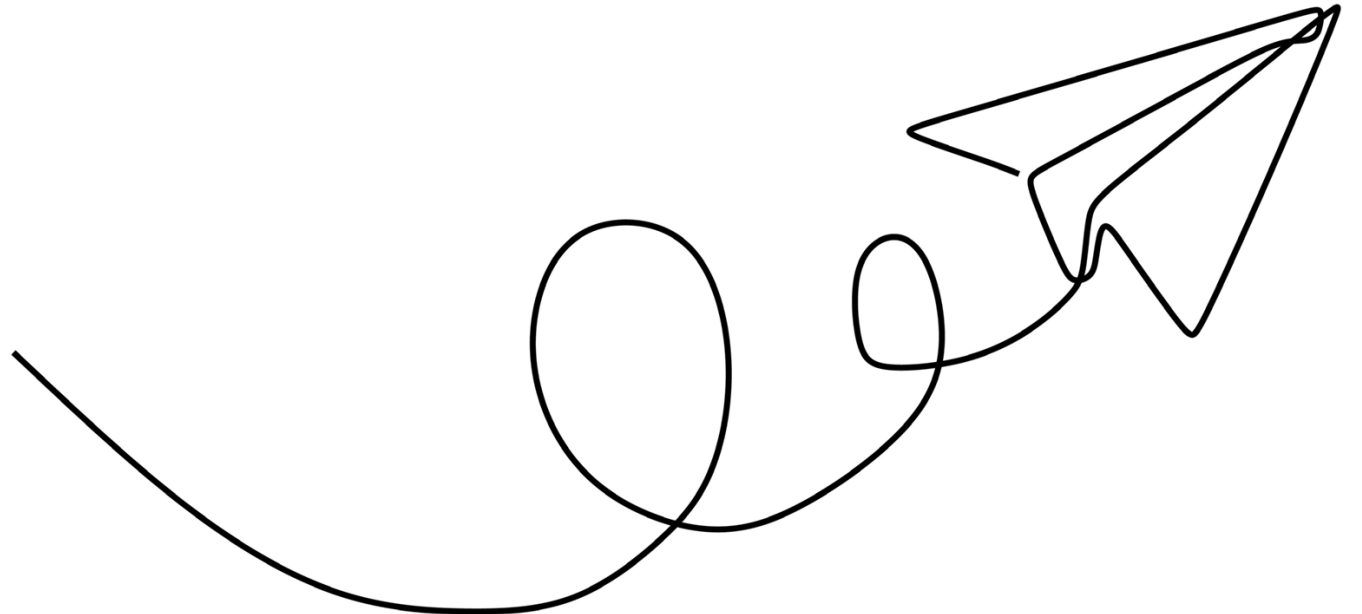
## Results of the study

- Doctor-caregiver conversations entail an emotional exposure with potential burdens and benefits.
- Caregivers cope with the obtained information by keeping their expectations low, mistrusting, and looking for secondary opinion, creating an illusory image or by confronting themselves with reality.
- Informational needs are grounded in the coping process with the loss of a loved one despite their ongoing need for care and support, namely the need for good news, information on progress, coherent and detailed information, and information regarding therapeutic and nursing instructions.
- The regularity of conversations and information, invitations for conversation initiated by physicians, having a direct link to the treatment team, the use of illustrative and text material as well as positive atmosphere and empathy are contextual needs stated by the participants.

# How can the results be used?

- They show that a sensitive doctor-surrogate information and conversation is key to building trust in the care facility and the therapeutic process.
- They show the need for awareness and communication training for health professionals.
- They may serve as a basis for the development and evaluation of further interventions for effective communication.
- They may foster the development of precise and accessible educational material for laypeople such as brochures.

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