

# CMS-16 Perceived benefits from peer-support among family caregivers of people with amyotrophic lateral sclerosis and cognitive impairments in a palliative rehabilitation blended online learning program

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## Results

Three themes reflected the various ways family caregivers of people with ALS and cognitive and/or behavioral impairments (PALS/CIs) interacted in online group meetings and how the interactions evolved around practical, emotional, and forbidden thoughts: 'Relating my situation to others', 'Making room for forbidden thoughts' and 'Longing for normalcy' (Figure 1).

Sharing personal and sorrowful concerns and frustrations engendered feelings of trust and a sense of belonging. This empowered the participants to address their genuine wishes and their longing for normalcy with all its trivialities of which they had been robbed by their relative's disease.

## Aim

To understand how family caregivers of PALS/CIs interact with and perceive virtual face-to-face peer-support in a palliative rehabilitation program designed to promote targeted palliative rehabilitation initiatives for caregivers of PALS/CIs (Figure 2).

## Methods

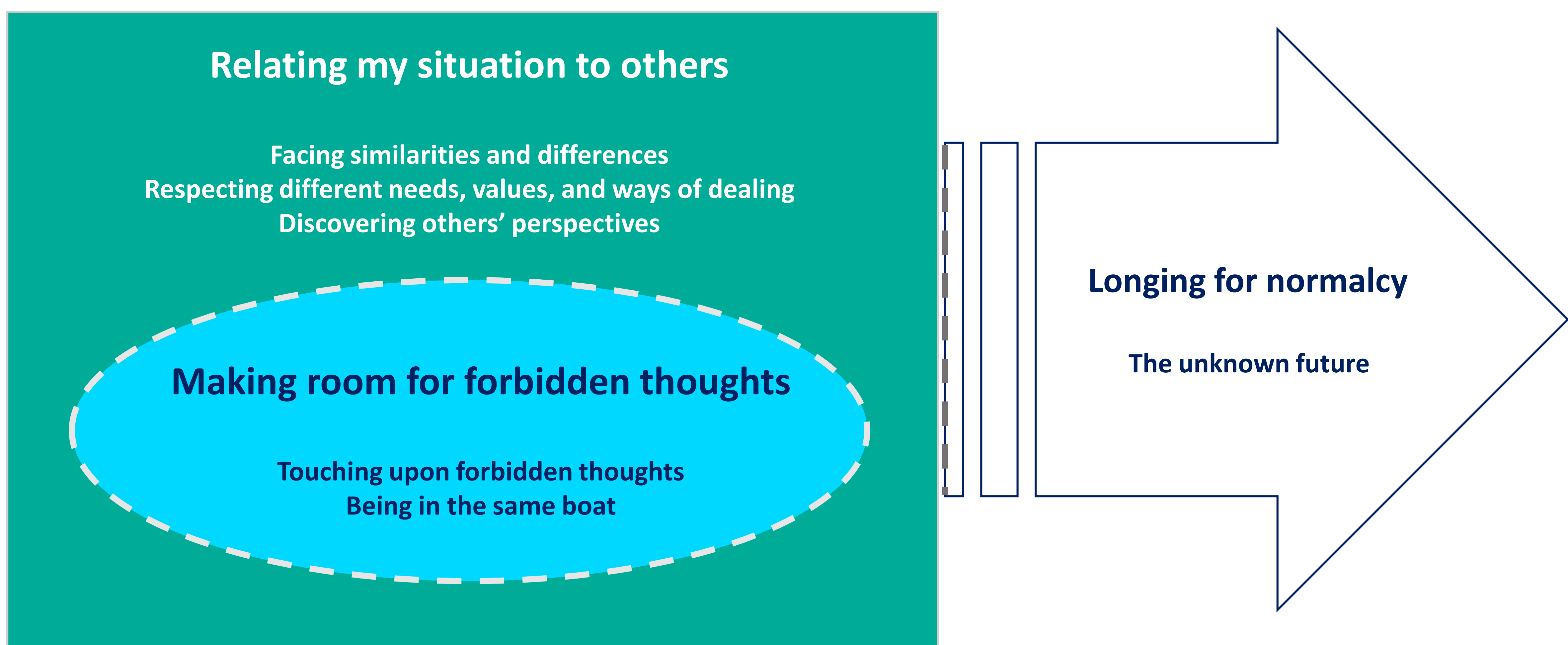
A qualitative design using participant observations of 17 recorded virtual group-facilitated meetings from two rounds of a four-month intervention. The Medical Research Council framework, the inductive Interpretive Description methodology, and the theoretical framework Sense of Coherence guided the study. Nineteen participants, divided into four groups, were included (Table 1).

## Conclusion

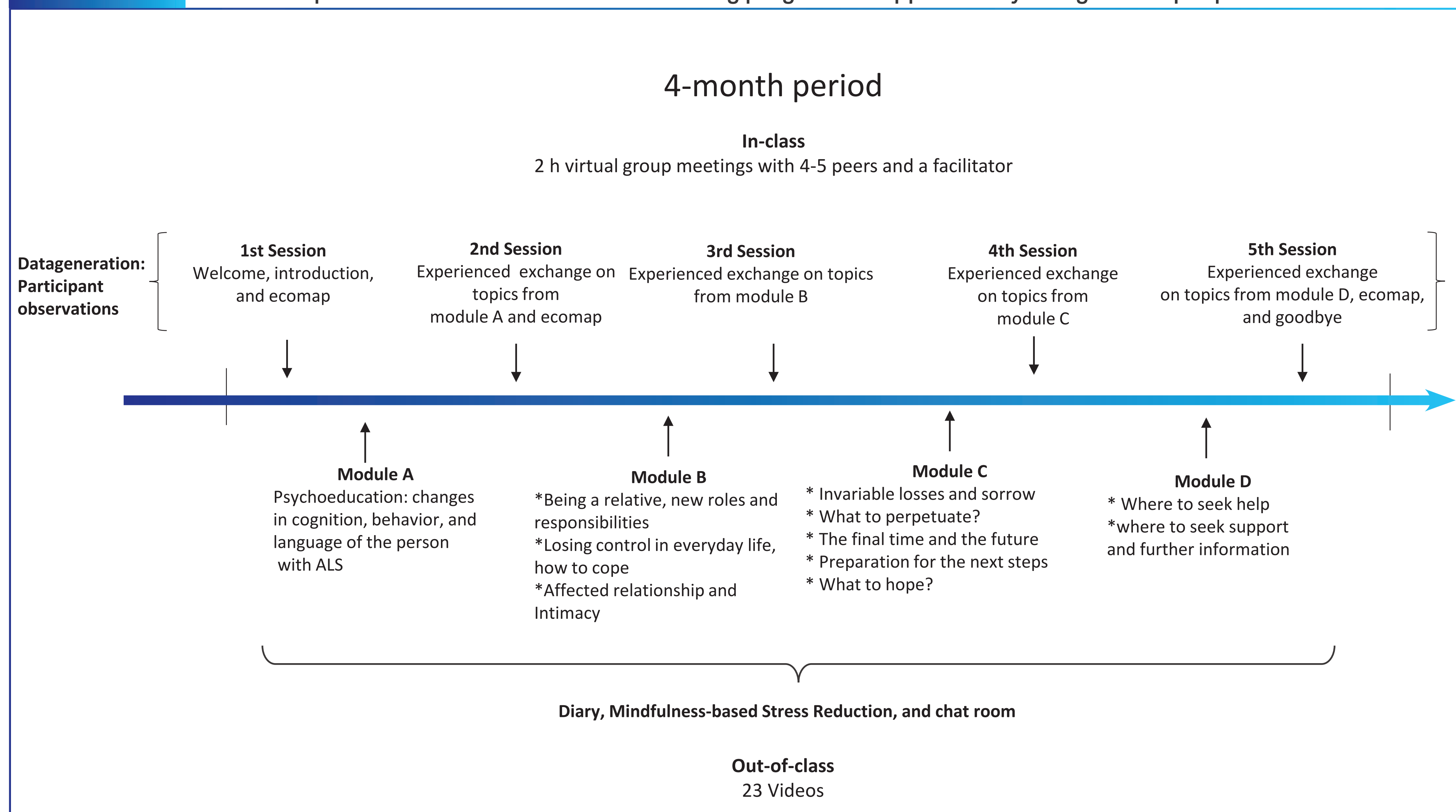
Virtual face-to-face peer-support can enable caregivers of PALS/CIs to share experiences of everyday life challenges that cannot always be shared elsewhere. Being able to relate to and learn from peer experiences alleviated feelings of loneliness, frustration, and concerns and enhanced comprehensibility, manageability, and meaningfulness.

Online palliative rehabilitation interventions should provide an opportunity for caregivers of PALS/CIs to meet regularly in interactive groups. Familiarization takes time online and is necessary to improve a sense of feeling safe to share their deepest thoughts. Such group interventions, facilitated by trained healthcare professionals, offer a means to support dynamic group interactions and discussion of sensitive topics.

**Figure 1** Exploration of how family caregivers of people with ALS and cognitive/behavioral impairments interact with and perceive virtual face-to-face peer-support in a palliative rehabilitation program



**Figure 2** The EMBRACE intervention. A 4-month palliative rehabilitation blended learning program to support family caregivers of people with ALS/CIs



**Table 1** Participant demographics

		(n=19)
Gender	Male	5
	Female	14
Age	39-50	3
	51-55	5
	56-67	7
	68-74	4
Marital status	Married	19
Occupational status	Working	9
	Early retirement	10
Trajectory of ALS (years)	0-2	10
	3-4	3
	5-8	4
	9-14	2
	15-20	0
ALS-FTD-Q score	22-30	6
	31-35	5
	36-40	4
	41-46	2
	47-55	1
	56-74	1