The National Rehabilitation
Center for Neuromuscular Diseases

COG-02 Reflections of family caregivers and health professionals on the everyday challenges of caring for people with ALS and cognitive impairments: a qualitative study

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Results

Three interrelated themes: "Accepting that nothing else matters", "Adjusting to new roles while balancing", and "Realizing different values in relationships" revealed that family caregivers of people with ALS and cognitive impairments (PALS/CIs) were constantly struggling to understand the meaning and impact of their situation (figure 1).

The themes unfold the family caregivers' difficulties in comprehending and managing the challenges of living with a PALS/CIs which caused an overall sense of non-coherence in their lives.

The professionals acted as an outside interference in the families' everyday lives while also being a necessary source of help and support. This was represented in the themes: "Collaboration a balancing act", "Working in a home of sorrow", and "Coordinating threads to tie".

Aim

To explore experiences of family caregivers of deceased PALS/CIs and their health professionals to understand the challenges and needs related to their everyday lives and to develop a targeted palliative rehabilitation blended learning program.

Methods

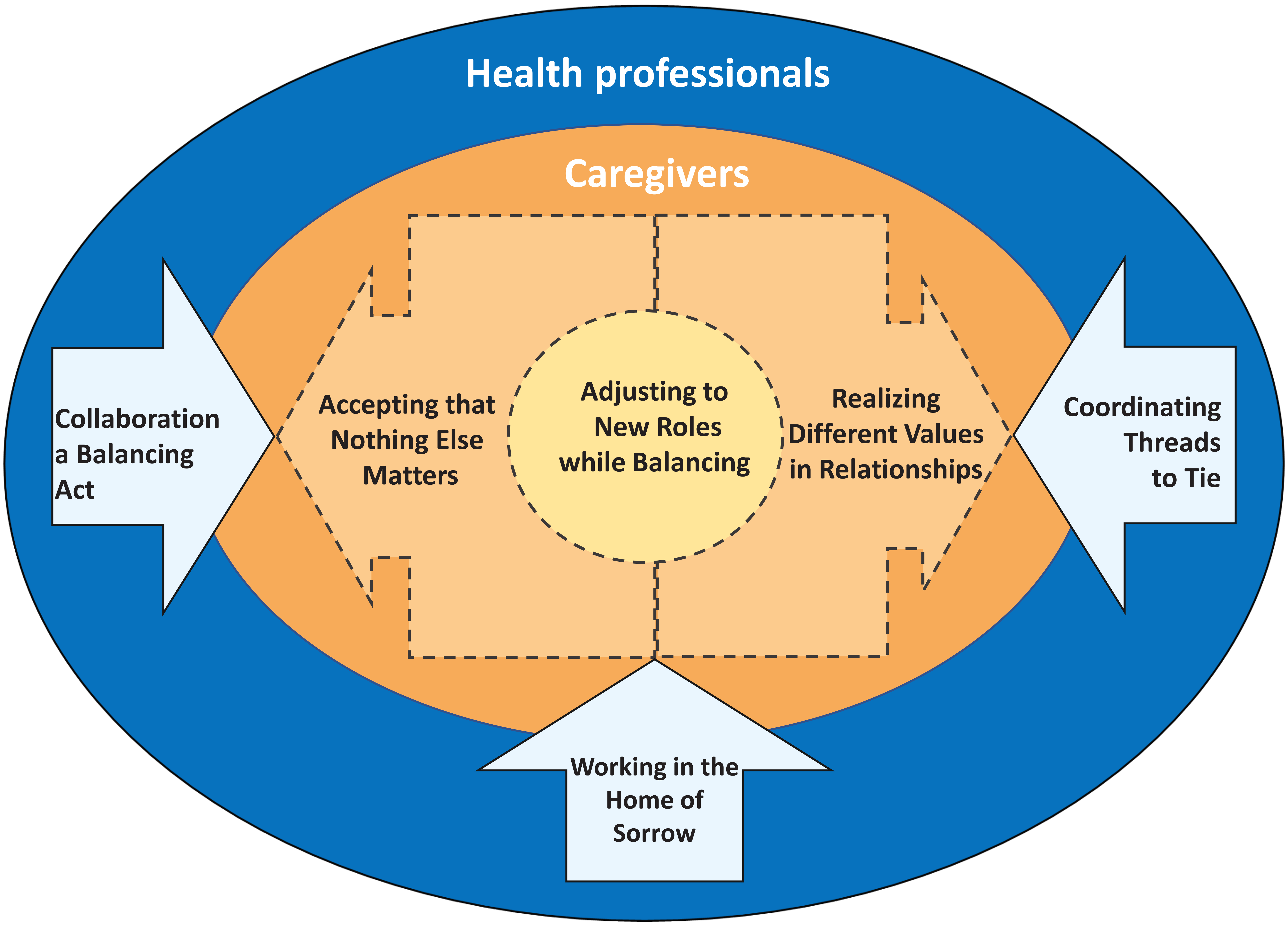
This design was a qualitative interview study guided by the Interpretive Description methodology and Aaron Antonovsky's theory of Sense of Coherence.

One focus group and 10 individual semi-structured interviews were conducted with nine health professionals and seven family caregivers after the death of their relative with ALS/CIs.

Conclusion

The study adds to an understanding of the challenges and needs of family caregivers and health professionals and the relationship between them.
Family caregivers found it challenging to cope with the complexity of the diseases. They had to constantly adjust their lives, dealing with new family roles, coping with inappropriate behavior, and navigating through the progression of their relative's diseases while collaborating with numerous health professionals. The severeness and complexity of the diseases made it difficult for the professionals to coordinate the care and to collaborate with the families and other colleagues.
Findings point to the importance of a good relationship between caregiver and professionals and a need to provide support to caregivers through an online palliative rehabilitation program that teaches coping strategies for living with a PALS/CIs.

Figure 1 Reflections on everyday challenges and needs of family caregivers and health professionals when coping with a person with amyotrophic lateral sclerosis and cognitive impairments. The figure represents the caregivers (illustrated in the inner circle) interactions with the health professionals, who they regarded as outside interferences in their lives.



Health professionals

Caregivers

Accepting that Nothing Else Matters

Adjusting to New Roles while Balancing

Realizing Different Values in Relationships

Collaboration a Balancing Act

Coordinating Threads to Tie

Working in the Home of Sorrow

Clinical and practice implications

- Family caregivers experience imbalances in their relationships due to the gradual loss of their relatives and are challenged by the caregiver role with which they have no previous experience.
- Health professionals struggle to support the families while maintaining a professional relationship and need specialized support and knowledge to meet this challenge.

- It is important that family caregivers and health professionals form strong professional relationships to better meet the challenges of caring for and supporting a person with ALS/CIs.
- Family caregivers and health professionals are challenged by the trajectory of ALS/CIs and would benefit from getting support and knowledge from other health professionals through a targeted online palliative rehabilitation intervention.

- Interventions in an online format offer high flexibility and accessibility for family caregivers which may bridge the gap between their need for support and lack of time.
- Elements to address when developing a targeted online palliative rehabilitation intervention for family caregivers are psycho-education, peer-support, and specialist knowledge on changes in roles, loss of control, intimacy, preparation for the future, coping with loss and sorrow, and taking care of oneself.

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