

The dualism of being trapped and alone but also precious and invaluable. The voice of spouses of a partner with dementia.

Background and aim

Spouse carers experience more negative effects from providing care than other informal carers, report low quality of life, and perceive their responsibilities too overwhelming. The professional support offered in Sweden are not specialized or individualized to meet the unique needs of *spouse* caregivers. The aim of the study is thereby to explore spouse carers' unique experiences and needs when living with and caring for a partner with dementia.

Methods

Data include individual interviews with 24 spouses of persons with dementia, living in middle of Sweden. The interviews were analyzed with latent content analysis.

“ *The support they offer is not what works for us, and that make me feel abandoned...* ”

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Conclusions

Spouses has unique needs and the professional support offered needs to be specialized based on that. Enable a holistic care, this knowledge is crucial for registered nurses and other staff supporting couples affected with dementia.

Results

The analysis resulted in one overarching theme: *Being trapped, alone but invaluable* which were build up by three subthemes: Being alone in the relation; Being abandoned; Being precious and unique. The results describe the dualism of being the one with best solutions for his/her loved one and wanting to give care and feeling deeply meaningful for that, but at the same time being unable to go on and enjoy one's own life nor take care of own needs and health. The spouses also described feelings of being lonely in the care role and abandoned by society, but also lonely in their marriage as they described slowly losing their partner, and the intimacy which made them feel as no longer being married.



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