

# The existential life situation of spouses and adult children to persons with dementia



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# Background

- The number of people diagnosed with dementia will almost triple before 2050.
- Family caregiver often described as a homogenous group
- Spouses and adult children continue their commitment and engagement in the life of the person with dementia, even after the relocation to a nursing home
- Spouses and adult children's life situations are strongly influenced by the dementia disease in terms of physical, psychological, and financial aspects.



# The existential lifesituation

Is about peoples desire to:

- create and maintaining meaning in life
- Making choice
- Creating meaningful relationship
- Sustaining purpose and hope

Mostly kept at distance but actualized in situation that involve suffering, struggling, guilt and death

Ferrell BR, editor. The quality of lives: 1,525 voices of cancer. Oncol Nurs Forum; 1996.

Chochinov HM. Dying, Dignity, and New Horizons in Palliative End-of-Life Care<sup>1</sup>. CA Cancer J Clin. 2006;56(2):84-103.

Yalom ID. Existential psychotherapy. New york: Macmillian; 1980.

Jaspers, K. (1970). Philosophy (E. B. Ashton, Trans.). Chicago, IL, USA: The University of Chichago Press.

# Method

11 Spouses (age between 57-81 years)

11 adult children (age between 48-65 years)

to a person with dementia  
living at nursing home

In-depth interviews

Analysed with interpretive content analysis

Presented in two articles:

Hogsnes, L., Melin-Johansson, C., Norbergh, K. G., & Danielson, E. (2013). The existential life situations of spouses of persons with dementia before and after relocating to a nursing home. *Aging and Mental Health*

Hogsnes, L., Melin-Johansson, C., Norbergh, K. G., & Danielson, E. (2014). The existential life situations of adult children of parents with dementia before and after relocating to a nursing home. (Submitted)

# The existential life situation before relocation

**Spouses**

**Isolated**

**Psychological threats and  
physical violence**

**Own needs last**

**Shame and guilt**

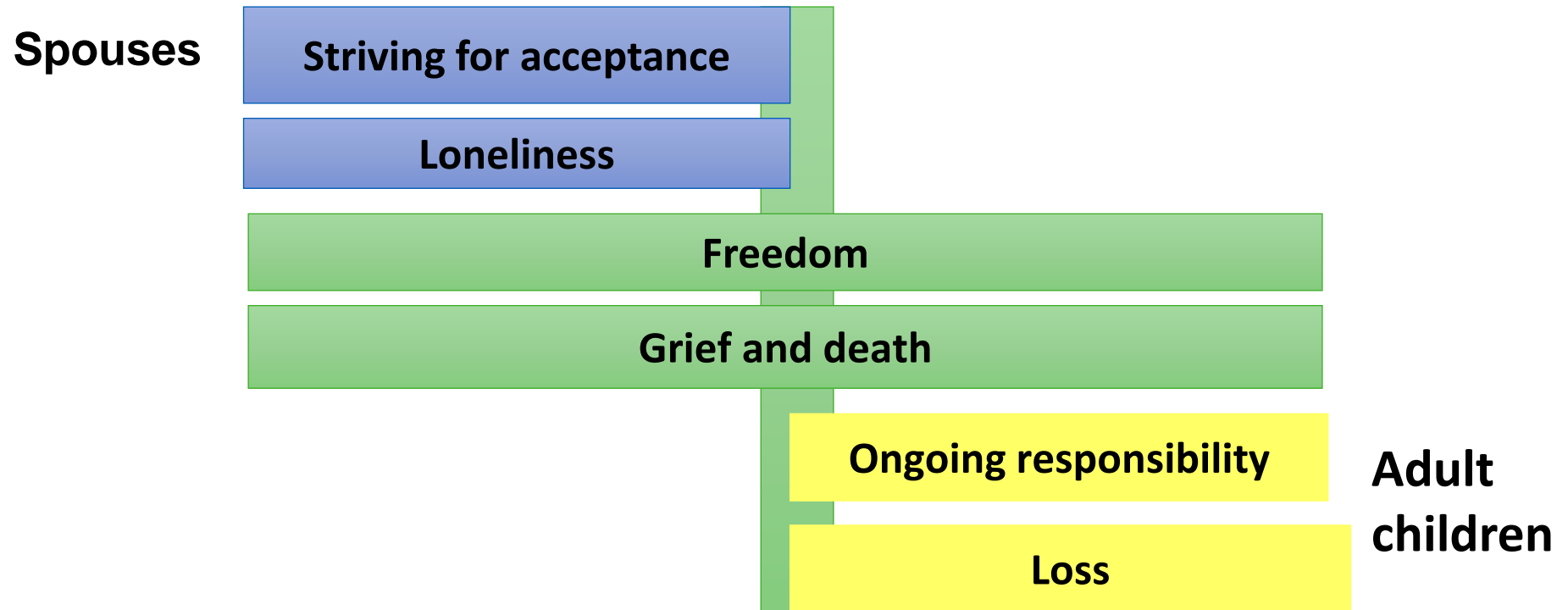
**Loneliness in responsibility**

**Powerless**

**Loss**

**Adult  
children**

# The existential Life situation after relocation



# Conclusion

Some of the existential issues that spouses and adult children are experiencing are the same; guilt and shame, grief and death and also feelings of freedom. But spouses also experiencing isolation, psychological threat, violence and placing their own need last. While adult children feel responsibility, powerlessness and loss.