



Gains and losses of caring for an older relative and the indication for geropsychological intervention

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Contact information on the last slide

Caring for an older relative - keywords

- What is care dependency?
- Needs and activities - the framing of care
- Care and the need for meaning
- Some first findings ...

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What is care dependency?

“care dependency” describes a situation where a person cannot satisfy (some of) his or her *basic needs* by own activities, but is dependent on support by one or more other persons to get his or her needs satisfied.”

Boll & Ferring, 2017

- Legal and academic framing of care
- Definitions differ with respect to which *needs* are included

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Needs and activities – framing of care

Which **needs** are covered?

- biological,
- psychological
- social

Which **activities** are included?

Help with ..

- Activities of daily living ADL
- Instrumental activities of daily living IADL
- Activities beyond ADL and IADL

Examples of further needs

- Cognitive functioning and stimulation
- Self-esteem
- Subjective well-being
- Spiritual needs
- Intimacy and love
- Sexual needs
- ...

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Who cares? - Phenomena

An adult daughter describing the apparent loss of personality of her mother and the inability to communicate in end-stage AD

“I don't have a mother anymore. My mother as I knew her has gone – I became aware of this when I looked into her eyes and got no form of any response. There is nobody in there anymore.”

Ferring, 2015

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Care and the need for meaning

Care demands

- Arranging and integrating care tasks into daily life
- Integrating **new** experiences
- Coping with Physical and emotional strain

Psychological tasks

- Construct meaning by integrating care experiences in one's view of the self and the world.
- Weighting „gains“ and „losses“

Ferring, 2017

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Sample and methods

Aspects of care (Boll & Haizmann, 2012)

- Instruction „Caring for ... means“ followed by
 - k=35 positive (e.g., a way to show my love and appreciation)
 - K=23 negative aspects of care (e.g., feeling emotionally strained)
- 6-point Likert scale: 1 „do not agree at all“ to „6 „totally agree“

Life satisfaction (Glaesmer et al., 2011)

- K=5 items (e.g., I am satisfied with my life);
- 6-point Likert scale: 1 „do not agree at all“ to „6 „totally agree“
- $\alpha=.88$ for composite score;

Subjective health rating

- 5-point Likert scale: 1 „very bad“ to „6 „very good“

Sample and methods

N=151 family carers;

- 111 women; M=57.89 yrs (SD=14)
- 117 married; 8 divorced; 9 widowed; 17 single
- Directly responsible for care: 105

Caring for

N=151

- M=80,9 yrs (SD=9,22)
- Duration of care: 4.8 yrs (SD=5.29); min=0 to max=40)
- Hours per week: M=23.7 (SD=26.5)
- Diagnoses: 55 dementia (incl. Alzheimer; vascular dementia); 79 other (e.g., arthrosis; stroke)

Results

Negative aspects rated as „true“

Do not agree at all 1	Do not agree 2	Do rather not agree 3	Do rather agree 4	Do agree 5	Do totally agree 6
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Caring for ... means ...

... see how dependent he or she is from me	4,86	1,11
... have to help with many daily activities	4,10	1,41
... have to look permanently after him or her	3,79	1,44
... that contacts with other people suffer	3,75	1,46
... that my life runs different than I wished	3,52	1,57

Positive self-related aspects rated as „true“

Caring for ...

... makes me see that I am important for him/her	4,74	1,04
... allows me to spend some nice hours with her him	4,58	1,10
... a way to show my love and appreciation	4,54	1,17
... allows me to show how grateful I feel for her /him	4,42	1,30
... learn new things and competences	4,38	1,24
... feel close to him/her	4,38	1,20
... helps me to accept my own mortality	4,25	1,23
... learn to appreciate my life more	4,21	1,11
... shows me my own strenghts	4,17	1,08

Do not agree at all	Do not agree	Do rather not agree	Do rather agree	Do agree	Do totally agree
1	2	3	4	5	6



Positive aspects rated as „true“ for the care receiver

Caring for ... means ...

.. he/she can life at home in a familiar environment	5,16	1,10
.. can lead a dignified life	5,01	,99
.. feels well	4,90	,87
.. basic help in daily life is guranteed	4,78	1,06
.. feels secure	4,74	1,06
.. allows him/her to do some things he/she likes	4,51	1,15
... health status stays stable	4,32	1,14

Do not agree at all	Do not agree	Do rather not agree	Do rather agree	Do agree	Do totally agree
1	2	3	4	5	6

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Factors of negative aspects

... feel emotionally exhausted	,857	→ Primary Burden
... physically tiring	,800	
... contacts with other suffer	,763	
... have to permanently look after him/ her	,733	
... my life runs different than I wished	,714	
... no breaks between my duties	,701	
... I am ashamed of his/her behaviour	,864	→ Secondary burden
... I feel embarrassed about his/her behavior	,824	
... don't feel at ease when friends visit	,697	
... angry about the way he she treats me	,675	→ Family strain
... puts a strain on my relations to other family members	,700	
... is not esteemed by my relatives	,670	
... angry about missing support from other family members	,593	

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Factors of positive aspects

... helped me to accept the disease	,798	→ Gains-Self
... made me more self-reliant	,730	
... made me more patient and comprehensive	,725	
... made me more empathic	,719	
... feel needed and useful	,698	
... showed me what really counts in life	,686	
... how to master difficult situations	,674	
... gives meaning to my life	,659	→ Gains-other
... that he/she feels secure	,782	
... encourages him/her	,695	
.. leads a dignified life	,693	
... guarantees basic needs	,660	
... feels well	,640	
... Allows me to spend nice hours with him/her	,638	
... health status stays stable	,616	

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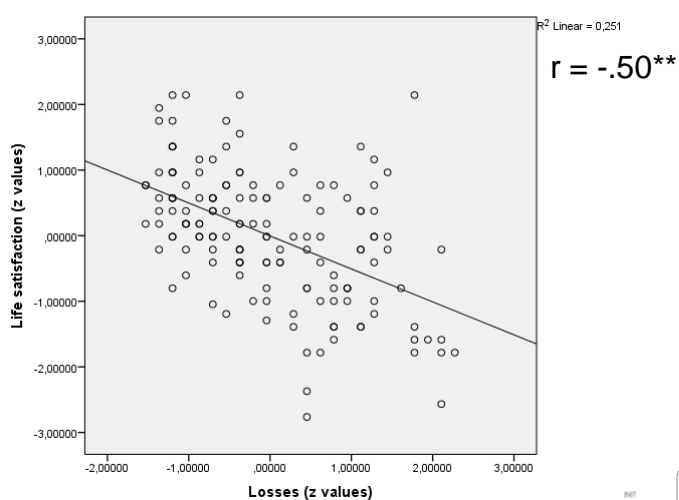


What makes the difference? Gains or losses

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Losses and life satisfaction

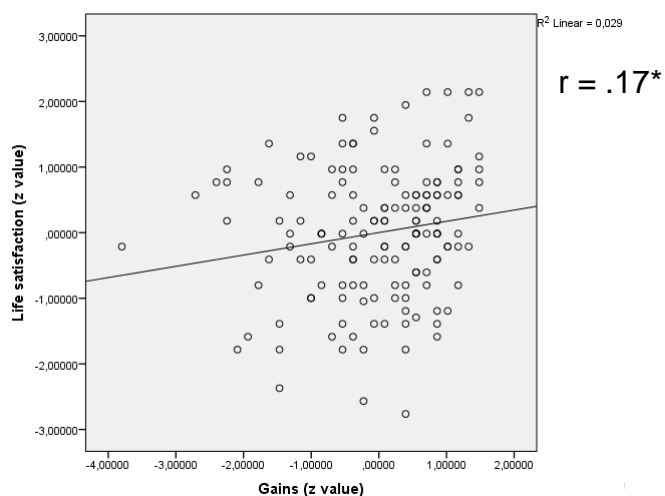


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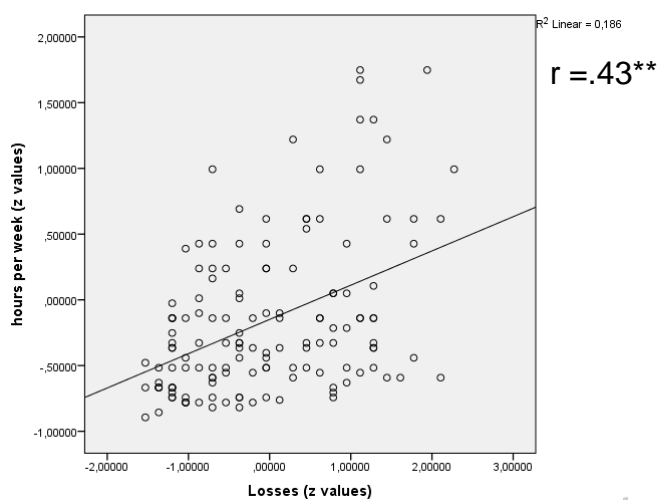
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Gains and life satisfaction



Losses and hours of care by week*

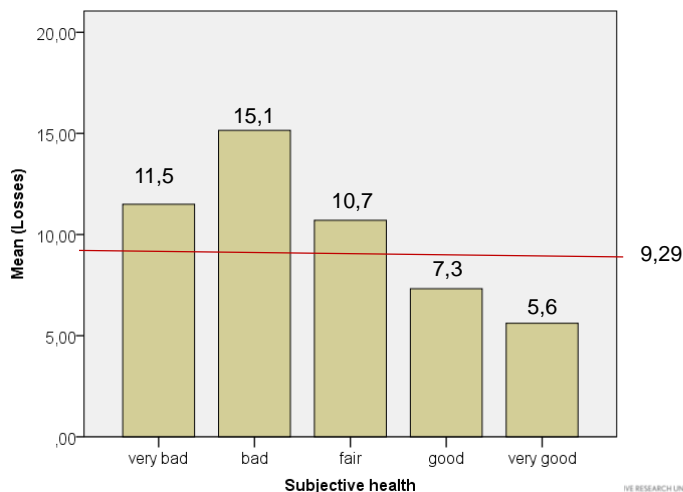


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* Corrected for extreme values showing for hours of care

Losses and subjective health



$F(4/145) = 8.46, p < .00; \eta^2 = .18$

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Short conclusion

- Hours per week make the difference = objective strain
- Losses seem to count more than gains
 - (-> possible limitation: social desirability)
- Interventions:
 - At the individual level: Broaden the view and promote the evaluation of gains
 - At the public level: Changing care policy

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