

Determinants of the care burden of spouses and children

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Structure of presentation

- Introduction
- Research questions
- Data & methods
- Results
- Conclusions



Introduction:

Why study care burden?

- More people to be confronted with relative in need of care
- Informal caregiving may have negative impact on quality of life
- Caregiver burden refers to caregiver's perceptions of impact caregiving has on their lives
- Predictor of care-related outcomes e.g. (desire for) institutionalization of care-recipient and general well-being of the caregiver
- Bulk of research on burden of informal care, however:
 - Studies often based on non-representative local samples
 - Studies often confined to caregivers of memory-impaired elderly
 - Results on determinants of caregiver burden often inconclusive



Research questions

- (1) What are the determinants of care burden?

Impact of:

- Contextual variables
- Intensity of caregiving
- Other roles
- Resources (internal and external)
(elements of stress-appraisal model Yates et al, 1999
and role theory)

- (2) What is impact of (quality of) professional help?



Data and methods

- “Informal care in Flanders”
 - Postal survey of informal carers, aged 25-79 (2003)
 - Representative sample of carers registered by Flemish care insurance
 - Care recipients severely impaired, no specific health problems
 - Net response: 68%
 - Relationship to care recipient: 1324 children, 617 spouses, 272 parents, 256 other family member, 146 friend/acquaintance/ neighbour
 - Here: only children and spouses
- Descriptive analyses
- Multivariate analyses: hierarchical linear regressions



Descriptive results: care burden

- Measurement care burden:
 - Impact of caregiving on different domains
 - 8 items, Cronbachs alpha = 0,88
 - Higher score, higher burden (1: entirely disagreeing -5: entirely agreeing)

	<i>% mainly / entirely agreeing</i>	Mean
I find it emotionally taxing	61	3,52
I find it physically taxing	54	3,32
My social life is suffering as a result	40	2,90
I have too little time for myself as a result	39	2,92
My family life is suffering as a result	29	2,62
I find it financially taxing	26	2,41
My health is suffering as a result	26	2,45
I am exhausted as a result	19	2,26
Scale care burden (1-5)		2,82



Descriptive results: determinants (1)

	All	Children	Spouses
Contextual variables			
- Gender (% women)	63	67	54
- Age (mean)	57	52	66
- Relation to care recipient (%):			
- Spouse	31		
- Child co-resident	18		
- Child extra-resident	50		
Intensity of caregiving			
- Hours of caregiving week (mean)	48	30	89
- Duration of caregiving, years (mean)	7	6	9
- Providing allround care (% yes)	56	45	80
Other roles			
- Children in household (% yes)	39	47	22
- Providing informal care to other person (% yes)	20	25	10
- Involvement in paid work (%):			
- No paid work	66	56	89
- Part-time	13	17	4
- Full-time	21	27	7



Descriptive results: determinants (2)

	All	Children	Spouses
Internal resources			
- Higher education (% yes)	17	21	8
- Relationship quality care recipient:			
- Main motivation for caring (%):			
- Love / friendship	63	58	75
- Moral duty	30	35	19
- Other feeling	7	7	7
- Reciprocity (% yes)	86	87	85
External resources (1)			
- Help other informal carers (% yes)	47	55	30
- Help professionals (% yes)	74	80	61
- Help volunteers (% yes)	12	14	10



Descriptive results: determinants (3)

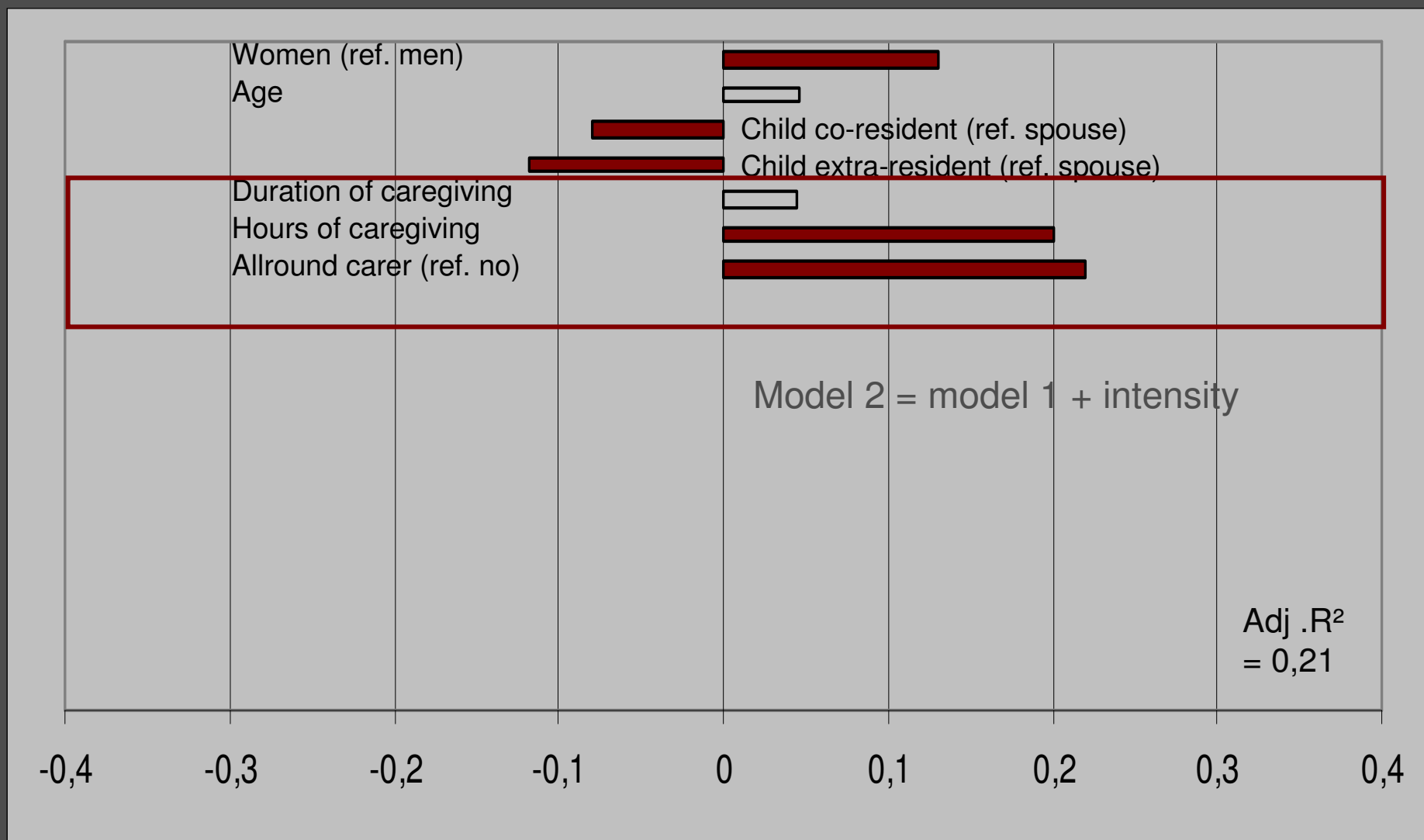
	All	Children	Spouses
External resources (2)			
- Contact with professionals (%):			
- Very difficult	1	1	1
- Rather difficult	2	2	2
- Not difficult or easy	5	4	5
- Rather easy	30	30	30
- Very easy	56	55	61
- No contact	6	8	1
- Quality of professional help (% <i>mainly / entirely agreeing</i>)			
*Professional carers and informal carers are well matched	71	72	69
*Professional carers have less respect for the person in need of care than informal carers	18	17	20
*Professional carers are not considerate enough of the informal carer	18	16	21



Multivariate results: determinants scale care burden* (1)



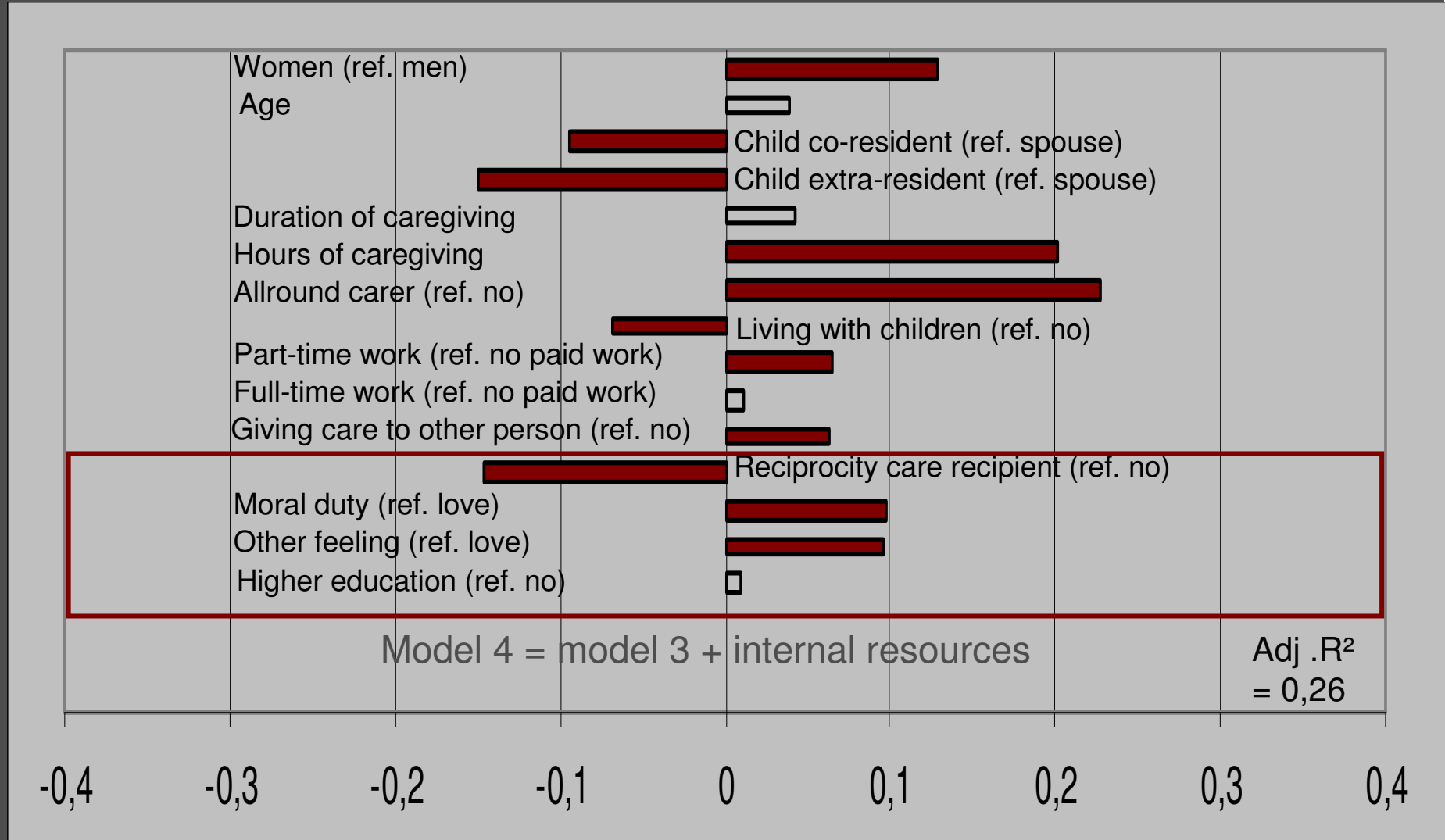
Multivariate results: determinants scale care burden* (2)



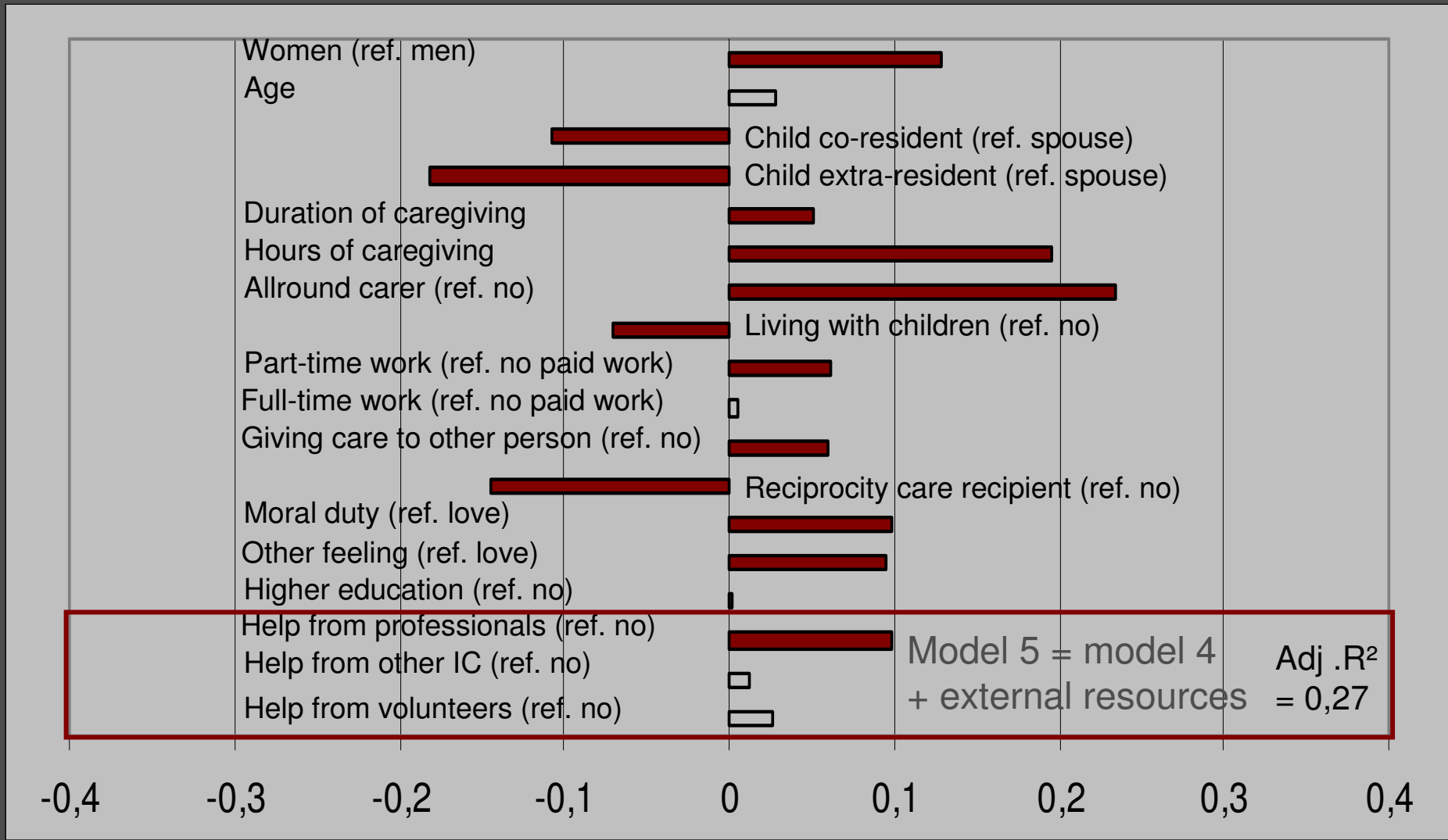
Multivariate results: determinants scale care burden* (3)



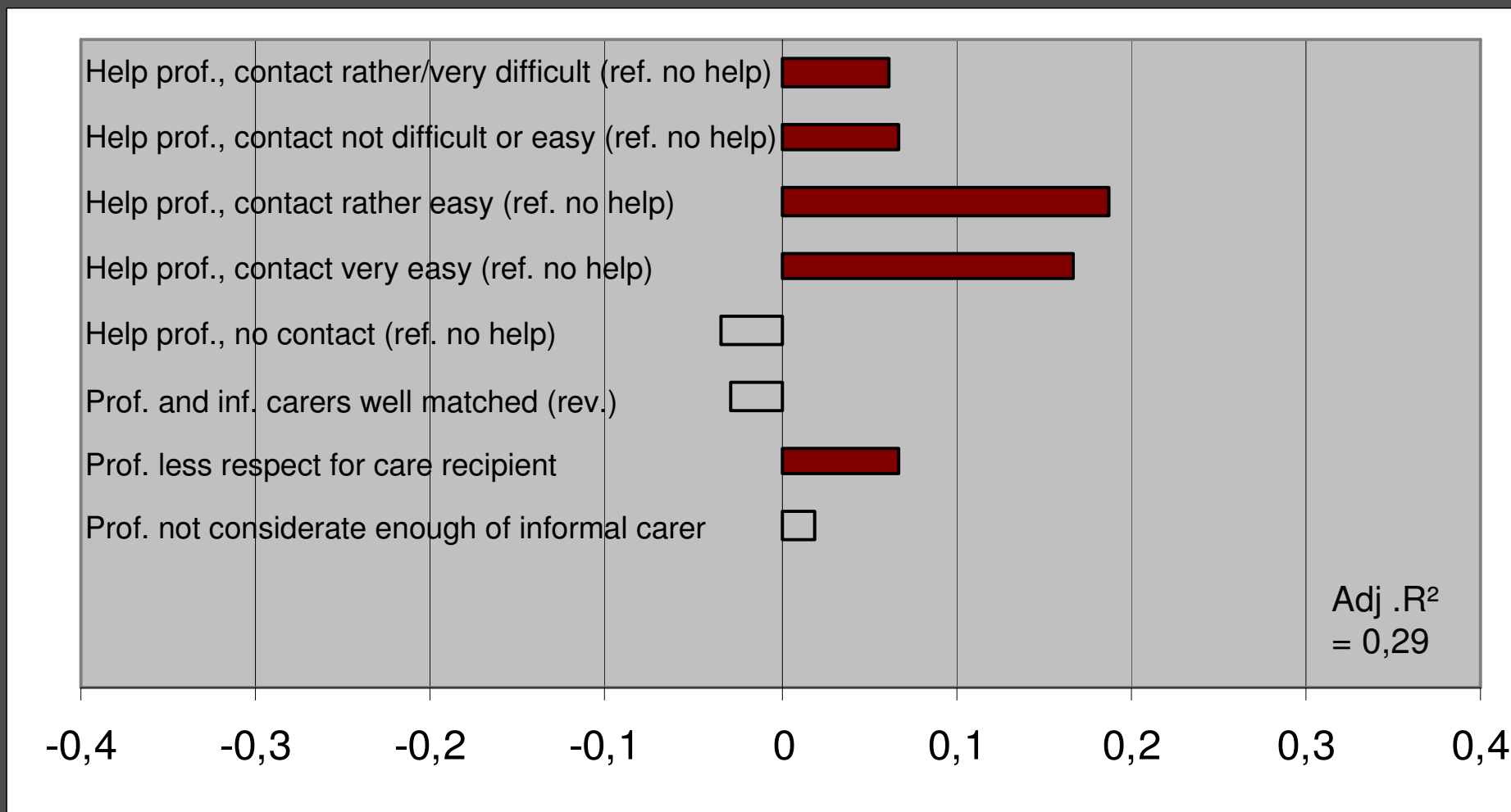
Multivariate results: determinants scale care burden* (4)



Multivariate results: determinants scale care burden* (5)



Multivariate results: determinants scale care burden*: impact quality professional help



Conclusions

- Determinants of care burden: greatest impact of contextual variables, intensity of care, quality of relationship with care recipient
- Women and spouse-carers especially at risk
- Amount, type and duration of care play role
- Reciprocity and love/friendship lower burden
- Other roles informal carers: mixed results
- Professional help and burden: selection effect?
- Quality of professional help: respect for care recipient
- What's next? Studying impact of determinants within groups, impact on positive aspects of caregiving, qualitative study on meaning / experience of formal care among spouses and children



Questions?

Thank you!

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