



## Background

- In Switzerland
  - 90% between the age of 80 and 89 years and 55% over 90 years old live at home
- Ability to live in the community is influenced
  - by biological age, disability, and illness
  - capacities to master everyday life if necessary with the support of others

Meyer, 2009, Baker, 2005, Höpflinger & Hugentobler, 2005, Lilly, 2005, Mack, Salmoni, Viverais-Dressler, Porter, & Garg, 1997

3

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## Background II

- In contemporary society, families are expected to care for their elder family members
  - From transitional to long-term care at home.
- Caregiving
  - adds new responsibilities
  - requires balancing multiple roles and duties
  - affects both the family as a system and the caregiver as an individual.

United Nations, 2007, Schumacher, Beck, & Marren, 2006, Schumacher, Stewart, & Archbold, 2007

4

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## Truth about age

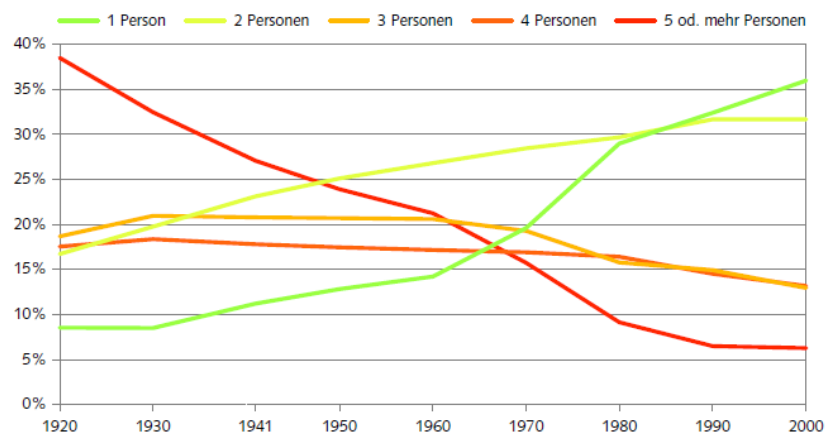
- Never before such high life expectancy
- 20-25 years after retirement - more time than childhood and adolescents
- heterogeneous health status in the elderly
- More generations live together over longer periods of time

**➔ New challenges for all generations**

5

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## Number of person per household



Quelle: Eidgenössische Volkszählungen

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(BFS, 2009)

6

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## Aging in Place

- Most wanted
  - ambulatory vs. institutionalized health care
- Combination of barrier free accommodations, local services close to home, informal and voluntary support and ambulatory professional nursing services allow «aging in place».

➔ requires investment in social support networks (home health care, voluntary work, **family members**)

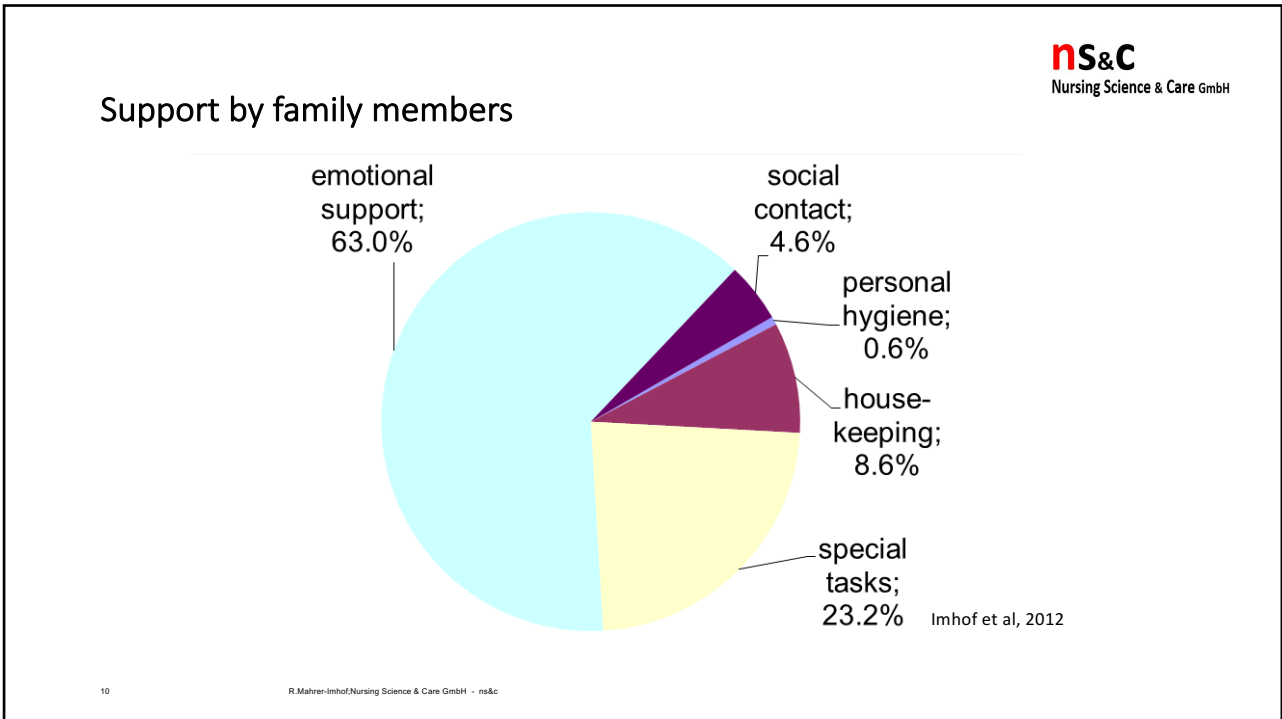
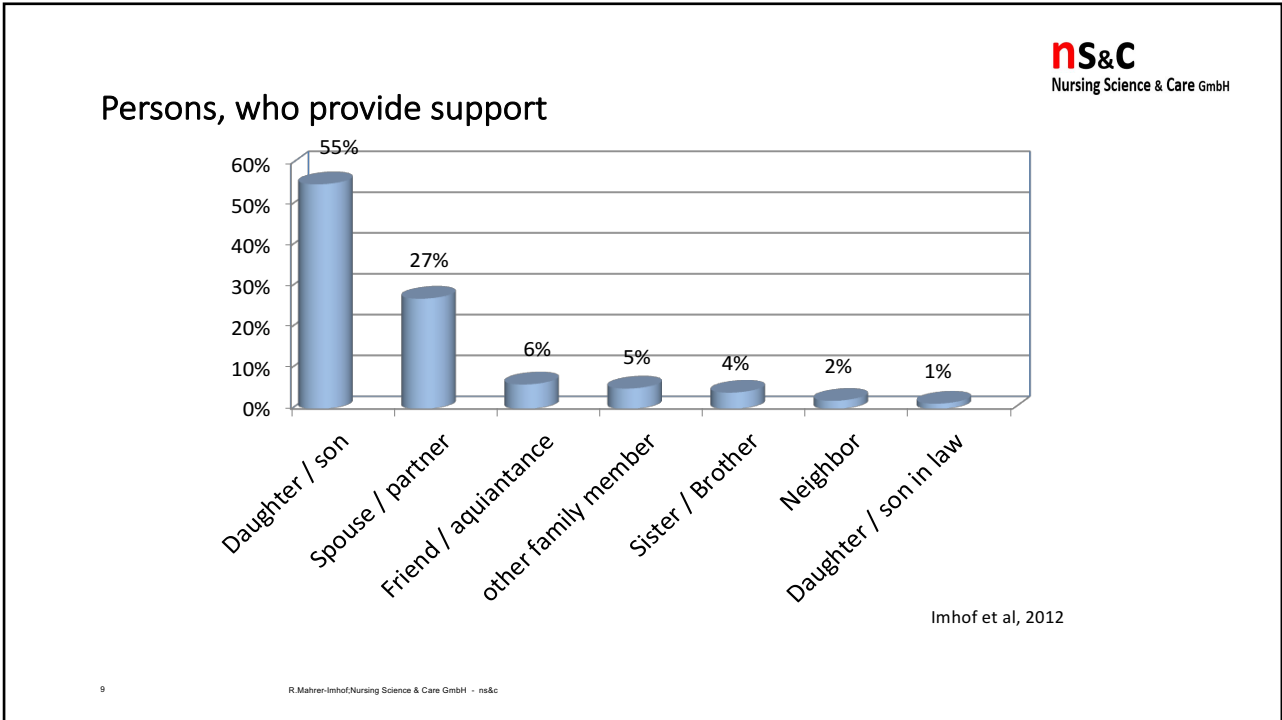
7

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## Family in late life....



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## 1. Study: What influences preparedness to care in caregivers?

- Cross-sectional design
- Major city in German speaking Switzerland
- Convenient Sample
- Inclusion:
  - dyads of community-dwelling elderly in the age of  $\geq 80$  years and adult children who provided care to their elder parent
- Exclusion:
  - elderly at the end of life
  - with a major psychiatric diagnosis
  - severe cognitive impairment.

## Measures

- Caregiving Burden Scale (CBS# ) German Version
- Family Care Inventory (FCI\*) German Version
  - Preparedness to care
  - Mutuality within family

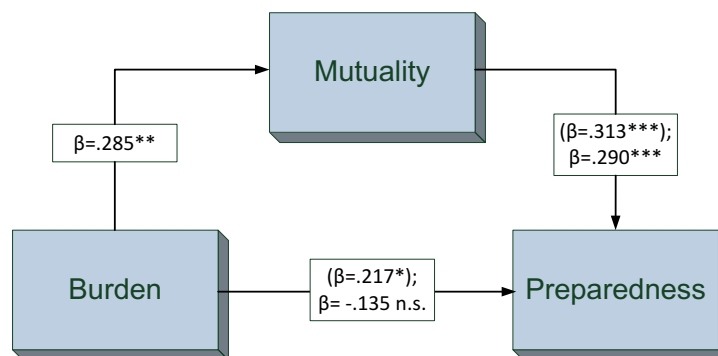
# Carey, Oberst, McCubbin, & Hughes, 1991; Oberst, Thomas, Gass, & Ward, 1989; \*Archbold, Stewart, Greenlick, & Harvath, 1990; Imhof, Naef, Wallhagen, & Mahrer, 2012

### Results: Demographics and social characteristics

	Caregiver	Person 80+
	n (%)	n (%)
Gender, n=142		
women	100 (70.4)	118 (83.1)
men	42 (29.6)	24 (16.9)
	mean ± SD (range)	mean ± SD (range)
Age, (year) n=142	56.8 ± 5.9 (41 - 78)	85.9 ± 4.0 (80-98)
CBS Burden <sup>1</sup>	1.5 ± 0.62 (1 - 4.13)	
FCI Preparedness <sup>2</sup>	2.6 ± 0.7 (0.88 - 4)	
FCI Mutuality <sup>3</sup>	2.9 ± 0.77 (0.6 - 4)	

Source: RCT on Advanced Practice Nurses In-Home Health Consultation Program, ZHAW, 2012  
<sup>1</sup>Caregiver Burden Scale Difficulty of care 1=not - 5=very difficult; <sup>2</sup> Family Care Inventory Preparedness 0=low - 4= high preparedness; <sup>3</sup>Family Care Inventory Mutuality 0=poor -5=good relationship

### Mediator Model



## Conclusions

- Quality of relationship is main predictor for preparedness

➔ Interventions to improve relationship amongst family members have to

- ameliorate stress
- reduce conflicts
- facilitate communication
- be tailored to particular family situation

15

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## Goal: Support families in diverse life situations



16

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## Methods: CBPR to develop a nurse-led service

- Family caregivers and local health service providers participated to develop a service in a city of 250'000 inhabitants.
- individual family sessions recommended
- Topics:
  - reflecting on the family situation
  - exploring caregiving challenges
  - enhancing practical skills of caregivers
  - supporting self-efficacy of the family system



## Intervention

- Telephone or email contact by the family member
  - Website and ads in newspapers
  - Public events
- Face-to-face therapeutic conversations
- Probes of questions
  - Opening question: would you like to tell me what did bring you to the counselling session?
  - What is your concern about which you want to talk?
  - Can you describe what your family member would say if he/she would be here?

## 2. Qualitative Study :Family members' concerns

- Qualitative design
- Tape-recorded counseling sessions of face-to face encounters
- Content analysis according to Mayring (2015)
  - Whole read
  - Paraphrasing of paragraphs/ topics
  - Comparison among interviews
  - Categorization of contents
- Atlas.ti as data management tool

## Results

People seeking consultation	
Gender n(%) n =63	
female	45 (71.4)
male	18 (28.6)
Age M±SD (range)	59.1 ±13.9 (24- 89)
Relationship n (%)	
children	30 (52.7)
partners	24 ( 33.3)
children in law	4 (7)
others	4. (7)

## Results

- Outlining and including current developments into the family story
- Addressing loss and strains due to disease and deterioration in health of the elderly
- Focussing on former strategies and conflicts with the elderly managing the illness
- Highlighting excessive demand to own resources and its consequences to own physical/mental health
- Coming up with new coping strategies/plans

## Outlining current developments

- Explaining a crisis situation
- Seeing events in line with one's life



## Addressing loss and strains

- Mourning about the elder's frailty
- Questioning one's role
- New responsibilities



## Former strategies and conflicts

- Trying to parent their elderly family member
- Dealing with resistance
- Lack of understanding



## High demands on own resources and own health

- Expectations and reality
- Remorse
- Being burdened
- Asking for release



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25

## Coming up with new coping strategies/plans

- Considering own resources
- Asking for information
- Organizing services
- Rehearsing new communication strategies
- Planning new distribution of tasks



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26

### 3. Quasi-experimental Design: Effects of a nurse-led counselling service for family members of the elderly

- Measures:
- Family caregiver preparedness to care (Family Care Inventory)
  - 0= not prepared at all to 4 = fully prepared
- Family caregiver burden
  - VAS scale 0= no burden to 100= highest burden

Archbold et al, 2001, Archbold, Stewart, Greenlick, & Harvath, 1990; Bakas, 2004; Carey, Oberst, McCubbin, & Hughes, 1991; Oberst, Thomas, Gass, & Ward, 1989

## Results

**Table 1 Socio-demographic characteristics of caregivers and care receivers**

	<b>All caregivers n = 121</b>	<b>Main caregivers n = 74</b>	<b>All care receivers n = 90</b>
<b>Sex, n (%)</b>			
Women	98 (81)	66 (89.2)	53 (58.9)
Men	23 (19)	8 (10.8)	37 (41.1)
<b>Age, M ± SD (range)</b>	59.8 ± 12.1 (33 – 89) n = 106	67 ± 62.2 (35 -87) n = 67	81.1 ± 8.4 (61 – 97) n = 90
<b>Marital status, n (%)</b>			
Married/ Partnership	76 (70.4)	49 (73.1)	45 (52.9)
Widowed	3 (2.8)	3 (4.5)	30 (35.3)
Single	14 (13)	9 (13.4)	4 (4.7)
Divorced	15 (13.9)	6 (9)	6 (7.1)

<b>Type of relationship, n (%)</b>		
Spouse/partner	31 (25.8)	28 (37.8)
Daughter/son	76 (63.6)	38 (51.4)
Other family members	6 (5)	5 (6.7)
Other persons	5 (4.1)	3 (4.1)
<b>Living in the same household with the care receiver, n (%)</b>		
Yes	38 (31.7)	36 (48.6)
No	82 (68.3)	38 (51.4)
<b>Main caregiver, n (%)</b>		
Yes	74 (62.7)	
No	35 (29.7)	
I don't know	9 (7.6)	
<b>Time of care by caregiver</b>		
Hours a week, <i>M ± SD</i> (range)	42.8 ± 64.1 (0.1 – 168) <i>n</i> = 71	63.3 ± 71 (0.1 – 168) <i>n</i> = 46
Duration of care in years, <i>M ± SD</i> (range)	6.1 ± 6.9 (0.1 – 30) <i>n</i> = 77	5.9 ± 6.1 (0.1 – 30) <i>n</i> = 55
<b>Number of children of the care receiver</b>		2.1 ± 1.3 (0 – 6) <i>n</i> = 87
<b>Does the care receiver live alone? n (%)</b>		
Yes		27 (31.8)
No		58 (68.2)



*n* = number, *M* = mean, *SD* = standard deviation

## Results II

n = 121	pre-consultation	post-consultation	p-value
<b>Caregiver burden</b>			
burden * MD±SD	68.6 ±21	59.5 ± 23.4	.016
<b>Preparedness to care</b>			
preparedness # M ± SD	2.1 ±0.53	2.4 ±0.56	<.001

\*Wilcoxon-Test, Z-value=-1.108; scale: 0=no burden to 100=high  
# Wilcoxon-Test, Z-value: -2.59; scale 0= not prepared to 4= very good prepared

## Discussion

- The findings show that family members benefit from the nurse-led counselling program.
- Preparedness 
- Burden 

31

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## Questions?



32

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