

# Participation in everyday life and life satisfaction in the stroke-caregiver dyad

6th International Carers Conference Gothenburg 4-6 September 2015

Aileen Bergström, Occupational Therapist reg., MSc, PhD
Post doctoral researcher, Swedish National Family Care Competence Centre
and Lecturer, Karolinska Institutet, Stockholm













# A dyadic perspective regarding participation in everyday life



#### **Participation**

 "Participation necessarily occurs at the intersection of what the person can do, wants to do, has the opportunity to do, and is not prevented from doing."

MALLINSON, T. & HAMMEL, J. 2010 Measurement of participation: intersecting person, task, and environment *Arch Phys Med Rehabil*, 91, S29-33.

### **STROKE**



### Life Satisfaction



carer

person with stroke



carer

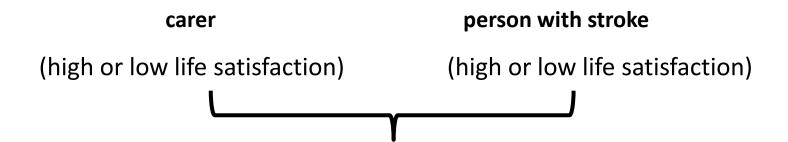
(high or low life satisfaction)

person with stroke

(high or low life satisfaction)

November 29, 2012 Aileen Bergström 7





Combined high, low, or discordant life satisfaction

November 29, 2012 Aileen Bergström 8



### Rationale

- Dyadic perspective
- Participation in everyday life
- Life satisfaction



#### Aim

 To describe persons with stroke and their carers' perceived participation in everyday life 3 to 6 months post stroke and to depict this in relation to their life satisfaction and with the dyads combined life satisfaction.



#### Methods /Instruments

- Life Satisfaction Checklist (LiSat-11) (Fugl-Meyer et al, 1991)
  - Global life satisfaction
    - Combined High
    - Combined Low
    - Discordant
- Occupational Gaps Questionnaire (OGQ)



#### Occupational Gaps

- Subjective measure of participation in everyday life
- The discrepancy between what an individual wants to do and what he or she actually does



### Example of an item in the OGQ

#### **Participating in outdoor activities**

(e.g. walking, hiking, hunting, fishing, camping)

1. Do you perform the activity?

- Yes No

#### Perceptions of occupational gaps

Question 1: yesQuestion 2: noQuestion 2: yes



#### Study participants n = 210 (105 dyads)

Persons with stroke

- Age 70 (46-90)

– Male/female 73% / 27%

Carer

- Age 68 (18-88)

– Male/female 24% / 76%



#### Results of the Occupational Gaps Questionnaire

Activities	Persons with stroke	Carers	
Travelling for pleasure	(1) 61%	(1) 48%	
Performing heavy duty maintainence	(2) 54%	15%	
Participating in Hobbies	(3) 51%	16%	
Participating in cultural activities	(4) 50%	(2) 31%	
Participating in sports	38%	(3) 30%	
Visiting restaurants and bars	35%	(3) 30%	



### **Not-want-to-do-gaps** for the carers

	Total % of gaps	Negative gaps
Cleaning	25%	22%
Cooking	17%	14%
Performing light maintenance	17%	11%
Doing the laundry	11%	8%
Grocery shopping	10%	7%
Managing personal finances	10%	6%



Combined Life Satisfaction	Dyads %
High/high	24%
Low/low	38%
Discordant	38%



### Combined Life Satisfaction in relation to occupational gaps

Combined Life Satisfaction	Dyads %	OG's for the persons with stroke (median,QR, range)		OG's for the carers (median,QR, range)	
High/high	24%	5/6/0-17	p = 0.003	5/3/0-11	p = 0.007
Low/low	38%	8.5/4.5/2-18		5/5/0-19	



Life satisfaction

Participation in everyday life (Occupational Gap)

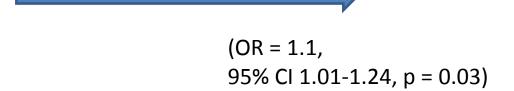
Person with stroke



Life satisfaction

Participation in everyday life (Occupational Gap)

Person with stroke

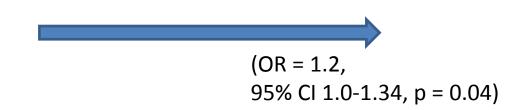




Life satisfaction

Participation in everyday life (Occupational Gap)

Person with stroke

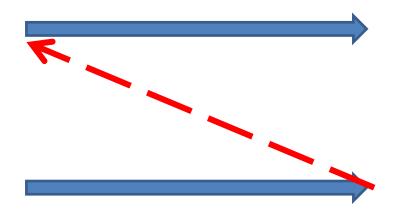




Life satisfaction

Participation in everyday life (Occupational Gap)

Person with stroke

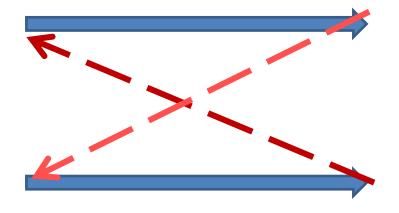




Life satisfaction

Participation in everyday life (Occupational Gap)

Person with stroke





#### **Conclusions**

 Carers have restrictions in participation in everyday life after their partners stroke



#### **Conclusions**

- Carers have restrictions in participation in everyday life after their partners stroke
- The carers life satisfaction accounts for their participation in everyday life



#### **Conclusions**

- Carers have restrictions in participation in everyday life after their partners stroke
- The carers life satisfaction accounts for their participation in everyday life
- Those dyads where they both had a low level of life satisfaction had a significantly greater level of participation restrictions



### Clinical implications



J Rehabil Med 2015; 47: 508-515

PARTICIPATION IN EVERYDAY LIFE AND LIFE SATISFACTION IN PERSONS WITH STROKE AND THEIR CAREGIVERS 3–6 MONTHS AFTER ONSET ORIGINAL REPORT

Alleen L. Bergström, OT, PhD12, Lena von Koch, PT, PhD13, Magnus Andersson, MD, PhD3, Kerstin Tham, OT, PhD¹ and Gunilla Eriksson, OT, PhD¹24

From the \*Department of Neurobiology, Care Sciences and Society, Division of Occupational Therapy, Karolinska Institutet, Huddinge, "Department of Neuroscience, Rehabilitation Medicine, Uppsala University, Uppsala, \*Department of Neurology, Karolinska University Hospital, Stockholm and \*Department of Neuroscience, Research in Disability and Habilitation, Uppsala University, Uppsala, Sweden

Objective: To explore and describe persons with stroke and their caregivers' restrictions in participation in everyday occupations, i.e. occupational gaps, 3-6 months post-stroke, in often receive assistance from an informal caregiver (2). We have modified the definition of informal caregiver (shortened to "caregiver" in this paper) from Pearlin et al. (3), referring

Bergstrom AL, von Koch L, Andersson M, Tham K, Eriksson G. Participation in everyday life and life satisfaction in persons with stroke and their caregivers 3-6 months after onset. Journal of Rehabilitation Medicine 2015. Epub 2015/04/18.



# Thank you for your attention!

aileen.bergstrom@lnu.se

www.lnu.se