Occupational therapy and the added value of volunteering

The Dutch perspective and the importance of enabling/empowering family caregivers.

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We are…

- 2 Dutch students from the regular 4 years OT
- 2 qualified OT’s from Germany and England attending BSG (Bachelor StudieGang) → 1.5 years
- Enothe within OTIS group (Occupational Therapy internationalisation students)
- Pilot: Cooperation between regular students and BSG OT’s, with different nationalities
- From Hogeschool Zuyd, Heerlen, in the south of the Netherlands
In the Netherlands voluntary family-caregivers and caregivers of acquaintances are called “Mantelzorgers”
Some numbers about “mantelzorgers” in the Netherlands (2008)

- 3.5 million people (age > 18) take care of a sick family member or acquaintance (Mantelzorg uit de doeken, Sociaal en Cultureel Planbureau, 2010)
- In more than 2.3 million cases, the care given by family members or acquaintances takes longer than 3 months (SCP, 2010)
- 18% of all family caregivers (470,000) take care for their partner (SCP 2010)
- Over 450,000 mantelzorgers feel burdened (mentally, physically and socially) (SCP, 2010)

[4 pillars of OT: context based (Hartingsveldt 2010)]
Our main point of interest:

Can OT have an added value in empowering family caregivers?

AND

Is the occupational balance of the mantelzorger influenced by taking care of his or her partner? And if so, how?
Why focus on occupational balance?

**Theoretical background**

Occupational Balance:

- "balance in lifestyle and balance between leisure, work and selfcare" (Westhorp 2003, page 437)
- “There is an underlying assumption that an individual needs a balance between different areas of engagement” (Hagedorn 2000, page 163)

[4 pillars of OT: client centred, evidence based (Hartingsweldt 2010); scientific reasoning, conditional reasoning (Feiler 2003)]
Influencing factors

- Social, Cultural, Physical Environment
  - Performance Skills
    - Motor Skills
    - Process Skills
    - Communication Skills

- Performance in Occupation
  - Activities of Daily Living
  - Education
  - Work
  - Play
  - Leisure

- Performance Patterns
  - Habits
  - Routines
  - Roles

Performance Context

Activity Demands

Client Factors

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Method

- Literature research
- A visit to “steunpunt mantelzorg” (a national organisation of caregivers and their supporters)
- Speaking with mantelzorgers and taking interviews
- Regular meetings with professionals i.e. teachers with ongoing relations to mantelzorgers and steunpunt mantelzorg

[4 pillars of OT: evidence based (Hartingsveldt 2010); scientific reasoning (Feiler 2003)]
Literature findings

- Care giving can be a burden (Andersson, 1993)
- Care giving affects Occupational balance (Brodaty & Green, 2001)
- Even daily activities can be difficult and stressful for the caregiver (McColl, 1998)
- Family care giving might cause psychological distress (Brodaty & Green, 2001)
- Caregivers have to handle the needs of their disabled relatives and they have to cope with their own fears/anxieties (Holicky, 1996)
- Family caregivers could get sick due to occupational imbalance (Matuska & Christiansen, 2009)

[interaktive reasoning, scientific resoning, conditional reasoning (Feiler, 2003)]
Outcomes of interviews (5)

- “The day begins with stress”
- “I am afraid to leave my partner, I am constantly occupied with the caretaking. I don’t have any moment to relax or think about something else”
- “I feel depressed and lonely, I have lost my friend and partner”
- “I feel mentally exhausted”
Concerns with family caregivers

- Most family members have no previous experience of rehabilitation (Tamm 1999)
- Family Caregivers have constant, stressful tension between taking over an activity and trying to involve the relative (Josephsson 2000)
- To provide support and to have a real influence, caregiver interventions need to acknowledge the ways in which relatives create an understanding of the disease and its occupational consequences (Tamm 1999)
- Family caregivers noted that they felt the need to address their own physical and emotional health or their effectiveness in the caregiver role (Gitlin 2001)
Enabling (verb) and enablement (noun), focused on occupation, is the core competency of occupational therapy, drawing on an interwoven spectrum of key and related enablement skills which are value-based, collaborative, attentive to power inequities and diversity, and charged with visions of possibility for individual and/or social change. (Townsend 2007)
Empowerment means the employee has greater access to support, resources, information and opportunities to learn and develop. (Engström 2010)

Definition psychological empowerment as four cognitions:

1. **Meaning** - the value of a work goal or purpose, judged in relation to an individual’s own ideals or standards

2. **Competence** - competence, or self efficacy, is an individual's beliefs in his or her capability to perform activities with skill

3. **Self-determination** - an individual’s sense of having choice in initiating and regulating actions, the caregivers autonomy over work methods and processes

4. **Impact** - the degree to which an individual can
Definition Occupational Balance

A balance of engagement in occupation that leads to well-being. For example, the balance may be among physical, mental, and social occupations; between chosen and obligatory occupations; between strenuous and restful occupations; or between doing and being. (Wilock 2006)
How can OT enable/empower and support occupational balance?

- In OT-programs promoting **learning** are essential to support this dynamic relationship.
- OT can help to develop **strategies** to help establish a balance of care giving with their other life roles.
- Supporting caregivers as they identified and worked to **meet their own needs** and expanded their network of helpers.
- **Enhances the abilities** of individuals to engage in all life roles, including that of caregiver.
How can OT enable/empower and support occupational balance?

- OT can **address the issue** of the caregivers' burden, his fatigue or frustration.
- OT's can provide a solid basis of **information** that enhances the environment and minimalize the negative effects of caregiving.
- OT’s use their acquired clinical reasoning to communicate acceptance, trust and hope to construct a shared language with the ultimate goal to engage the client.


[interactive reasoning, narrative reasoning (Feiler 2003)]
Conclusion

- Provide information
- Support to sustain the caregivers' occupational balance
- Understand and support the issues surrounding the role change
- Allow room for the caregiver to address their own concerns
OT Interventions

- Being a coach (help to schedule daily activities)
- Being advisor (assistive devices, ergonomic advice)
- Giving mental and physical support (helping to re-establish occupational balance,..)
- Providing information (about the condition of the partner, how and where to find assistive devices, financial support and so on)
- Being a confident for the family-caregiver
- Being a spokesperson

Townsend 2007, Taylor 2008
Can OT have an added value in empowering family caregivers?
Discussion

What ways of enabling family caregivers have you personally found effective?
Do you have any questions???
**Literature**


