Occupational therapy and the added value of volunteering

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

Enothe Congress 2011. Ghent, Belgium

Hs. Zuyd, Heerlen, the Netherlands. University of applied sciences & health, faculty of health and care, department of OT.

Kelly Ackroyd, Miriam Bruning, Franziska Lohmeyer, Hélène Weusten Z



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 U of the Netherlands

In the Netherlands voluntary family-caregivers and caregivers of acquaintances are called

"Mantelzorgers"

ZU YD

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)]

ZU YD

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?



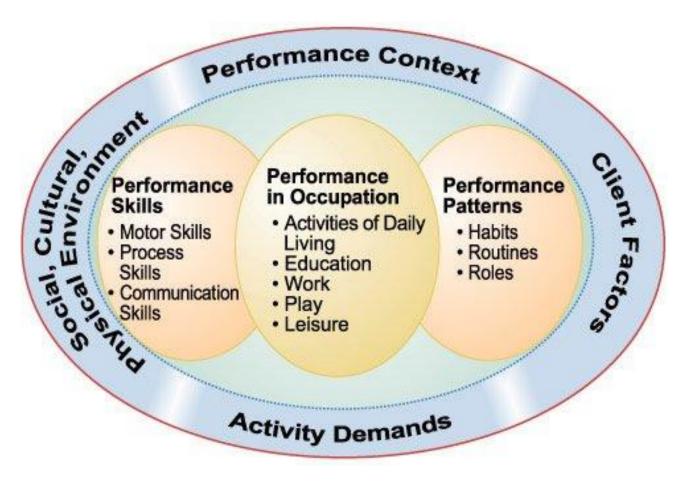
Theoretical background

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 (Hartingsveldt 2010); scientifier D reasoning, conditional reasoning (Feiler 2003)]

Influencing factors



ZU YD

Method



Rode Kruis Zuidelijk Zuid-Limburg

- 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)] November 11

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)

ZU

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"



ZU

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)
 November 11

Definition Enablement

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) ΖU



Definition Empowerment

- 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 individuals own ideals or standards
- (2) competence competence, or self efficacy, is an individuals beliefs in his or her capability to perform activities with skill
- (3) self-determination an individuals 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

ΖU

Enhances the abilities of individuals to engage in all life roles, including that of 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 negativ effects of caregiving

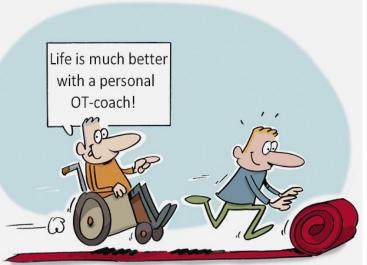
OT's use their aquired clinical reasoning to communicate acceptance, trust and hope to construct a shared language with the ultimate goal to engage the client

Josephsson 2000, Corcoran 2002, Clark 1993, Crepeau 1991, Lyons & Crepeau 2001, Mattingly & ZU Fleming 1994

[interactive reasoning, narrative reasoning (Feiler 2003)]

Conclusion

- Provide information
- Support to sustain the caregivers occupational balance
- Understand and support surrounding the role cl
- Allow room for the caregiver to address the own concerns



ZU

OT Interventions

- Being a coach (help to schedule daily activities)
- Being advisor (assistive devices, ergonomic advice)
- Giving mental and physical support (helping to reestablish 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

- Andersson, L. (1993). Elderly in Sweden and Europe. In: Ädelutvärderingen 93:4, 35pp., Socialstyrelsen The National Board of Health and Welfare
- Clark, F. (1993). Occupation embedded in a real life: Interweaving occupational science and occupational therapy- 1993 Eleanor Clarke Slagle lecture. American Journal of Occupational Therapy, 47, 1067-1078.
- CORCORAN, A.GITLIN, L. LEVY, L. ECKHARDT, S. VAUSE EARLAND, T. SHAW, G. KEARNEY, P. (2002). An Occupational Therapy Home-Based Intervention to Address Dementia-Related Problems Identified by Family Caregivers. In: Alzheimer's Care Quarterly 3(1): 82– 90
- Brodaty, H. Green A. (2001) Family caregivers for people with dementia. In: O'Brien J, Ames D, Burns A, eds. Dementia, 2nd edn. London: Chapman & Hall
- Engström, M., Wadensten, B., Häggstrom, E., (2010) Caregivers' job satisfaction and empowerment before andafter an intervention focused on caregiver empowerment. In: Journal of Nursing Management 18,14–23
- Feiler, M. (2003). Klinisches Reasoning in der Ergotherapie Überlegungen und Strategien im therapeutischen Handeln. Heidelberg: Springer Verlag
- Gitlin LN. Corcoran MA. Winter L. Boyce A. Hauck WW. (2001). A randomized controlled trial of home environmental intervention to enhance self-efficacy and reduce upset in family caregivers of persons with dementia. In: Gerontologist. 41(1):4–14.
- Hagedorn, R. (2000). Tools for practice in occupational therapy: A structured approach to core skills and processes. Edingurgh: Churchill Livingstone.
- banian, A. (2010). *Beroepsprofiel ergotherapeut*. Utrecht: Ergotherapie Nederland.
- Holicky R. (1996). Caring for the caregivers: the hidden victims of illness and disability. In: Rehabilitation Nursing; 5: 247–252.

Literature

- Josephsson, S. Bäckman, L. & Nygard, L. Borell, L. (2000). Non-professional Caregivers' Experience of Occupational Performance on the Part of Relatives with Dementia: Implications for Caregiver Program in Occupational Therapy. In: SCANDINAVIAN JOURNAL OF OCCUPATIONAL THERAPY 2000;7:61–6
- Lyons, K. D., & Crepeau, E. B. (2001). The clinical reasoning of an occupational therapy assistant. American Journal of Occupational Therapy, 55, 577-581.
- Mattingly, C. & Fleming, M. H. (1994). Clinical reasoning: Forms of inquiry in a therapeutic practice (pp. 178-196). Philadelphia: FA Davis.
- Matuska, K, & Christiansen C.(2009). Life Balance Mulitdisciplinary theroies and research. Basel: AOTA Press
- McColl MA. (1998). What do we need to know to practice occupational therapy in the community? In: Am J Occup., 52: 11–18.
- Occupational Balance (picture) <u>http://www.facebook.com/photo.php?fbid=211304652216694&set=a.211304648883361.65046.211303488883477&type=1&theater</u> [Zugriff 15. September '11)
- Tamm, M. (1999). Relatives as a Help or a Hindrance—A Grounded Theory Study Seen from the Perspective of the Occupational Therapist. In: SCANDINAVIAN JOURNAL OF OCCUPATIONAL THERAPY 6:36–45
- Taylor, R. R. (2008). The intentional relationship: Occupational therapy and use of self. Philadelphia: F.A. Davis Co.
- Townsend, E. A., & Polatajko, H. J. (2007). *Enabling occupation II: Advancing an occupational therapy vision for health, well-being & justice through occupation*. Ottawa: Canadian Association of Occupational Therapists.
- Wilcock, A. A. (2006). An occupational perspective of health. Thorofare, N.J: SLACK.