Social participation and dementia

a qualitative study

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Background social participation

• “a person’s involvement in activities that provide interactions with others in society or the community” (p.2146) Levasseur et al., 2010

• Associated with physical & mental health & well-being, positive social behaviour Fratiglioni et al., 2000; Glei et al., 2005; Minagawa & Saito, 2014; Penninx et al., 1999; Piskur et al., 2014

• Domain of social health Huber et al., 2011

• WHO advocates improvement Gordon & Bickenbach, 2013; WHO, 2002

• Central theme for good quality of psychosocial dementia care Vasse et al., 2012
  • Few studies on effectiveness Cohen-Mansfield & Perach, 2015; Pitkala et al., 2010
  • Research theme in dementia care Moniz-Cook et al., 2011
  • How is social participation perceived? Keating & Gaudet, 2012
Research questions

• How do people with cognitive problems and their caregivers perceive social participation?

• What factors are of influence on their social participation?
Methods

- Qualitative, explorative study
- Semi-structured, in-depth interviews (n=13 dyads), Thematic analysis
- Embedded in research related to user-oriented development of new Social Fitness intervention Programme.

Population of dyads:
- community-dwelling elderly people with cognitive problems (memory problems or dementia diagnosis);
- caregiver providing assistance > 1x/week;
- wish to maintain or increase their social participation
Social Fitness: coaching and training to enable people to participate in social activities (again)
Results - perception

- Dyads experienced a reduction in activities and roles
  - All people with cognitive problems
  - Most caregivers, especially when married
- Satisfaction?
  - 11/13 people with cognitive problems; 10/13 caregivers

C: “I think the contacts I currently have are pleasant, I oversee them. I do not want all my days to be full anymore.” (i1)

- 8 caregivers dissatisfied with social participation of significant other
Results – influencing factors (1)

1) Behavioural
   (not) Accepting less activity - (No) Initiative – (Not) Managing cognitive decline
   
   C: “The fact I do not initiate actions, there is no one to blame but myself of course.” (i7)

2) Physical
   Mobility related - physical problems (e.g. hearing)

3) Social environmental
   Others’ lack of initiating - No understanding - Losing others
   
   C: “They treated me as if I was a small child there <day care centre>.” (i5)
Results – influencing factors (2)

4) Physical environmental
   Weather - Transportation

5) Activity related
   Experience – Preconditions - Evaluation
   C: “... I do not want to play games, because I dislike playing games. ” (i11)
   Cg: “…that <organised physical group activity> is something she likes. Highlight of her week. ” (i6)
Discussion

• Social participation has objective and subjective dimensions
  • Satisfaction with reduced social participation
  • Acceptance
  C: “I think it is normal to become less active when you are getting older...” (i7)
  • Lowered expectations
  C: “... I do not have a lot of contacts ... but I am not bored. It is alright” (i3)

• (When) to intervene?
Questions?

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