

Social Health Taskforce

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25th Alzheimer Europe Conference, Interdem meeting, Ljubljana, 2015

02/09/2015

Critics from the 2009 Dutch expert consensus on W.H.O. definition of Health (Huber et al. 2011)

- "complete well-being":
 - "is neither operational nor measurable"
 - "leaves most of us unhealthy most of the time"
- "Physical": Emphasis on physical health detrimentally to mental & social well-being
- Changes in demography and nature of diseases
 - Improvements in nutrition, hygiene, sanitation and medical care, more chronic diseases

"Health is a state of <u>complete physical</u>, mental and social well-being and not merely the <u>absence</u> of disease or infirmity." W.H.O., 1946



Critics from the 2009 Dutch expert consensus on W.H.O. definition of Health (Huber et al. 2011)

- Aging with chronic diseases has become the norm.
- WHO definition contributes to stigmatise people with diseases and disabilities as definitely ill.
- Minimises human capacity to cope autonomously with life's physical, emotional and social challenges.
 - How about psychological challenges?

Is gain in survival more important than gain in quality of societal participation and increase in coping capacity?



A new definition of Health (Huber et al., 2011)

- Despite illness and disabled conditions:
 - "resilience or capacity to cope and maintain and restore one's integrity, equilibrium, and sense of well-being."
 - Physical Health: allostasis
 - Mental Health: sense of coherence
 - Social health: manage one's life

Ability to adapt and self manage



Social Health (Huber et al., 2011)

- Dimensions of Social Health:
 - capacity to fulfil potential and obligations,
 - ability to manage life with some degree of independence despite a medical condition,
 - participation in social activities.
- Determinants of social health?

Determinants of social health

Dimensions of social health:
Fulfil obligations
Manage life
Social activities

Social Health: Adaptation & Self

Adaptation & Self management





Overlapping definitions & concepts

- Social determinants of health: "conditions in which people are born, grow, work, live, and age".
- Mental health (WHO):
 - self-efficacy, autonomy, competence
 - cope with the normal stresses of life,... make a contribution to his or her community
- Quality of Life and well-being :
 - A multidimensional concept encompassing social,
 psychological and physical domains (Birren, Lubben & Rowe,
 1991)
 - For people with dementia in care homes, mainly related to social variables: family, friends, mariage, do things for fun, life as a whole (Hoe, Hancock, Livingston & Orrell, 2006)
 - Integrates, among others: daily activities, social interaction, interaction capacity (Brod, Stewart, Sands & Walton, 1999)

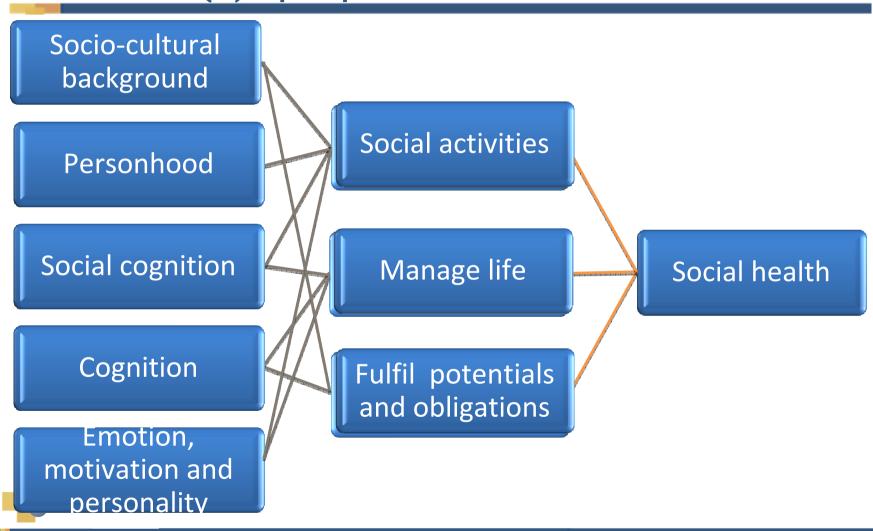


Determinants and dimensions of Social Health (1): according to scientific literature

- Capacity to fulfil potential and obligations
 - Environmental pressure (Lawton & Nahemow, 1973);
 - Social support (Gitlin, 2011); combined support (Dröes et al, 2000);
 - Awareness (Clare,; Keady, et al., 2007);
- Ability to manage life with some degree of independence despite a medical condition
 - Sense of control (Rodin, 1986);
 - Adaptation and Coping (Dröes et al., 1991, 1996, 2011)
 - Resilience and successful aging (Harris, 2006);
 - Life events (Orrell & Bebbington, 1995-1998);
- Participation in social activities
 - Personhood (Kitwood & Bredin, 1992);
 - Self (Kelly, 2007); Selfhood (Sabbat, 2001);
 - Stigma (Vernooij-Dassen et al., 2005); socially integrated activities
 Dröes et al, 2000, 2004)
 - Sharing meals and night shifts (Charras et al, 2010)...



Determinants and dimensions of Social Health (2): proposition for debate





Determinants and **dimensions** of Social Health(3): proposition for debate

- Socio-cultural, educational and economic background
 Societal contextual factors impacting one's social relationships
- Personhood
 - "the first personal state is a sense of personal worth, the "deepest" level of self-esteem" (Kitwood and Bredin, 1992)
- Social cognition (social psychology)
 Sociological, social and psychological processes that relate to one's ability to live in and relate with the community
- Cognition
 Involved cognitive processes to complete a task or adapt to a situation
- Emotion, motivation and personality
 Emotional, motivational and personality factors that influence social processes and health



Aims and goals of the taskforce

- Promote research and clinical practice on the concept of social health of people with dementia
 - State of the Art / position paper
 - European research grants: JPND, H2020, ...
 - And maybe:
 - Develop interventions to promote Social Health
 - Evaluate Social Health in different care settings
 - Promoting through a Blog on the Interdem Website



State of the art/Position paper

- Who? Interdem members from social health taskforce.
- What? Social health: dimensions and determinants?
- How? Internal peer reviewing, systematic review
- Which journal? Int. Psychogeriatrics, A&MH, Dementia, J. of Geront Social Work, AJADOD, ...
- When? 1st January 2016?



Inventory of expertise and interest among members of Taskforce Social Health

July 2015

Task Force Social Health in Dementia	Organisation, country	Capacity of Pwd to fulfill his/her potential and obligations Community/ Institutional care (please fill in an X if you have expertise in research in this area and indicate in key words the specific topics you studied/study and in what setting (Home and/or Istitutional)	Ability to manage their life despite the dementia Community/ Institutional care (please fill in an X if you have expertise in research in this area and indicate in key words the specific topics you studied/study and in what setting (Home and/or Istitutional)	Participation in social activities Community/ Institutional care (please fill in an X if you have expertise in research in this area and indicate in key words the specific topics you studied/study and in what setting (Home and/or Istitutional)	Interest in Theme 1,2, and/or 3' Other (sub)themes? Interest in a) co-writing state of the art/position paper? b) collaborate in preparation of new research proposal(s) for JPND, Horizon2020 etc. (Write below the Theme number(s) of interest, or your suggested theme, and add the preferred option a or b (so e.g. Theme1 and option a, or Theme 1,2 and option b)
Lead					
Charras, Kevin	Eondation Mederic Alzheimer, F	X/inst Rights of people with dementia in ethical perspective of environmental design.	X/inst Activities of Daily Living, environmental design of facilities, and professional training	X/C+inst Night time care, leisure activities, mealtimes, garden, visits in museums, circus	Theme 2,3; option a (mainly) and b
Dröes, Rose. Marie	VUmc, NL	X / C+Inst Assistive technology	X / C+Inst Several interventions based on Adaptation-coping model (e.g. meeting centers)	X / C+Inst Theatre in nursing homes Nature activities Interactive tours in Museums	Theme 2,3; Option a and b
Vernooij- Dassen, Myrra	RadboudUMC, NL	X / C+Inst	х	X	Theme 1,2,3 Option a





Results: Expertise (20/36 members)

Community

1) Capacity to fullfill potential (n=11)

Needs, methods to access the experiences of PwD, stigmatization, legal, mental & decision-making capacity, rights, assistive and every day technology, enabling environments, approaches promoting well being, ADL

2) Ability to manage life despite dementia (n=9)

Interventions supporting adaptation/coping, problem solving in daily life, social support & care, pathways to support, dementia friendly/inclusive communities, assistive technology, personal relationships, quality of life, carer support

3) Participation in social activities (n=11)

Enriched opportunities and Meetingdem programme, participation in teaching, nature activities, museum visits, technology for social contact, lifespace assessment, empowerment, discrimination

Institutional

1) Capacity to fullfill potential (n=11)

Ethical rights/issues (restriction of freedom), environmental design, assistive technology, enriched opportunities, enabling environments, legal, mental & decision-making capacity, approaches promoting well being, home like living arrangements

2) Ability to manage life despite dementia (n=8)

ADL, environmental design, Interventions supporting adaptation/coping, increasing autonomy in daily life, meaningful activities, training professionals, green care farms, assessment tools

3) Participation in social activities (n=8)

Theatre, clowns, nature activities, involvement in meaningful activities, social engagement by physical exercise, small-scale homelike care settings



Results: Interest (20/36 members)

Interested in

Theme 1 - Fulfill potential
n=9

Theme 2 - Manage life n=15

●Theme 3 - Social participation n=15

Prefered type of collaboration

■Co-writing position paper (n=17): Charras, Dröes, Vernooij-Dassen, Chattat, Evans, Franco, Goncalves-Pereira, Gzil, Innes, Johannessen, Kristensen, Meiland, Moniz-Cook, Rymaszewska, Verbeek, Wolf-Osterman, Zuidema

Collaborate in new research proposals (n=17): Charras, Dröes, Alzheimer Europe, Brooker, Chattat, Evans, Franco, Goncalves-Pereira, Gzil, Van Hout, Innes, Kristensen, Moniz-Cook, Rymaszewska, Verbeek, Wolf-Osterman Zuidema



Proposed task division position paper based on interest & expertise

Theme 1 Fulfill potential	Theme 2 Manage life	Theme 3 Social participation
 Vernooij-Dassen (1,2,3) Chattat (1) Evans (1) Goncalves-Pereira (1,2,3) Gzil (1,2) Rymaszewska (1,2,3) 	 Dröes (2,3) Franco (2,3) Kristensen (2,3) Meiland (2,3) Moniz-Cook (2) 	 Charras (2,3) Johannessen (2,3) Verbeek (3,2) Wolf-Osterman (2,3) Zuidema (3) Innes (1,2,3),



Collaboration in new research proposals H2020

Relevant calls

- Personalised medicine: Treating and managing diseases
- Personalised Medicine: Methods and data



Call for Research Proposals 2016: H2020

- Personalised medicine: Treating and managing diseases
 - PM 8 2016 Patient-centred therapies for chronic diseases: Proposals should focus on clinical trial(s) supporting proof of concept in humans to assess the clinical safety and efficacy of novel therapies (pharmacological as well as nonpharmacological) and/or the optimisation of available therapies (e.g. repurposing) for chronic diseases.
 - PM 18 2017- Research activities in Personalised coaching for well-being of older persons: Proposals should develop a proof of concept of a "virtual" personalised "3600 coach", building upon highly intelligent environments, new forms of accessible interaction based on tangible user interaction concepts, open platforms and emotional computing. Solutions should be capable of autonomous learning and adaptation to the personalised needs, emotional and behaviour patterns, conditions and preferences as well as the users' living environment and their social connections.



Call for Research Proposals 2016: H2020

- Personalised Medicine: Methods and data
 - PM 24 2016- Implementation research for scaling-up of evidence based innovations and good practice: Proposals should seek to scale up an innovative and evidence based health systems & health services intervention. The selected intervention to be scaled up should be one that makes health systems and services more responsive, safe and efficient.

