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Social health and Dementia: A European consensus on the operationalization of the concept and directions for research and practice

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Abstract

Background: Because the pattern of illnesses changes in an aging population and many people manage to live well with chronic diseases, a group of health care professionals recently proposed reformulating the static WHO definition of health towards a dynamic one based on the ability to physically, mentally and socially adapt and self-manage. This paper is the result of a collaborative action of the INTERDEM Social Health Taskforce to operationalize this new health concept for people with dementia, more specifically the social domain, and to formulate directions for research and practice to promote social health in dementia.

Method: Based on the expertise of the Social Health Taskforce members (N D 54) three groups were formed that worked on operationalizing the three social health dimensions described by Huber et al.: (1) capacity to fulfil potential and obligations; (2) ability to manage life with some degree of independence; (3) participation in social activities. For each dimension also influencing factors, effective interventions and knowledge gaps were inventoried. After a consensus meeting, the operationalizations of the dimensions were reviewed by the European Working Group of People with Dementia (EWGPWD).

Results: The social health dimensions could be well operationalized for people with dementia and are assessed as very relevant according to the Social Health Taskforce and EWGPWD. Personal (e.g. sense of coherence, competencies), disease-related (e.g. severity of cognitive impairments, comorbidity), social (support from network, stigma) and environmental factors (e.g. enabling design, accessibility) that can influence the person with dementia's social health and many interventions promoting social health were identified.

Conclusion: A consensus-based operationalization of social health in dementia is proposed, and factors that can influence, and interventions that improve, social health in dementia identified. Recommendations are made for research and practice.

Key words

Social health, dementia, effective interventions, capacity, self-management, social participation.

Introduction

Dementia is described in the DSM-5 as a major neurocognitive disorder, caused by specific brain diseases (APA, 2013) such as Alzheimer's disease and vascular diseases, and which is characterized by significant cognitive decline in one or more cognitive domains (complex attention, executive function, learning and memory, language, perceptual-motor or social cognition). Besides the fact that the cognitive deficits interfere with independence in everyday activities, little attention is given in this diagnostic manual to how dementia influences the social functioning of people affected by it, even though it is evident that dementia can make it difficult to contribute to society and to maintain social relationships (Derksen, Vernooij-Dassen, Gillissen, Olde Rikkert, & Scheltens, 2006; Vernooij-Dassen & Jeon, 2016). The influence on social functioning is mentioned in the ICD-10 which states that the impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation (ICD-10; WHO, 2016).

For the most prevalent types of dementia, such as Alzheimer's disease, vascular dementia and Frontotemporal dementia no cure is currently available. During the last two decades new research and care practices have provided insight into how people adapt cognitively, emotionally and socially to the changes dementia entails, and how different types of interventions may support people with dementia and their carers, to maintain positive well-being (Clare, 2014; Droes, van der Roest, van Mierlo, Meiland, 2011; Nygård, 2004; Van't Leven et al., 2013). A large survey in the Netherlands among 230 community-dwelling people with dementia and 320 carers showed that one of the most frequently experienced unmet needs by people with dementia, besides having support for memory problems, is 'having company' (van der Roest et al, 2009a). As in the general population, social relationships have a high

impact on the quality of life and mortality of people with dementia (Gitlin et al., 2009; Gitlin, Hauck, Winter, Dennis, & Schulz, 2006; O'Rourke, Duggleby, Fraser, & Jerke, 2015). It is therefore important that the social consequences of dementia receive at least as much attention as the cognitive consequences, and also how to deal with these social consequences to optimize quality of life for people with dementia. In addition, there is growing evidence that psychosocial interventions that promote social relationships can enhance the well-being of people with dementia (Jang, Mortimer, Haley, & Graves, 2004; van Dijk, van Weert, & Droes, 2012).

Because of the growing size of the older population of whom a substantial number manage to live well with chronic diseases, Huber et al. (2011) recently proposed a reformulation of the WHO definition of Health, moving from the present static formulation ('a state of complete physical, mental and social wellbeing') towards a more dynamic one based on the ability to adapt and self-manage. Their first task was to define the three domains of Health: the physical, mental and social. *Physical health* was characterized as being capable of maintaining physiological homeostasis through changing circumstances. *Mental health* as a sense of coherence, which contributes to the capacity to successfully cope and recover from psychological stress. *Social health* was characterised by three dimensions: (1) having the capacity to fulfil ones potential and obligations; (2) the ability to manage life with some degree of independence, despite a medical condition; and (3) participation in social activities including work (Huber, et al., 2011).

According to Vernooij-Dassen & Jeon (2016), the added value of the concept of social health lies in several core features: it is an umbrella for an array of concepts reflecting human capacities to participate in social life, such as reciprocity and dignity (Vernooij-Dassen et al, 2011), and resilience (Gaugler, Kane, & Newcomer, 2007); it is a clear overarching concept

facilitating communication between the psychological, social and biomedical sciences; it does not focus on deficits but on remaining capacities and more importantly, it relates to normalcy. The new concept of social health proposed by Huber et al. is in line with the social model of disability (Hughes & Paterson, 1997), the importance of which has been recognized in social sciences for many years and also in the field of dementia care (Downs, 2000; Gilliard, Means, Beattie, & Daker-White, 2005; Marshall, 1994). In addition, this concept is also linked to “health” as viewed in the field of positive psychology (Seligman, 2008), because building on positive characteristics and capacities of individuals enables them to maintain well-being, and prevents and protects them from disabilities.

Until now, the concept of social health was not operationalized for dementia, although its three dimensions appear relevant for the social health of people with dementia in light of the difficulties they encounter in everyday life. Insight into the relevant themes within the three dimensions of social health, and the factors influencing the functioning of people within these dimensions, is a prerequisite for developing and providing effective support and care that promote their social health.

In the past few decades, research among people living with dementia has addressed several aspects of social health based on a variety of theories. This has resulted in a useful, but somewhat fragmented, knowledge base in this field. For example, more than 40 years ago Lawton and Nahemow (1973) described the *environmental docility hypothesis* which relates to the first dimension of social health, focusing on the capacity to fulfil ones potential within enabling or disabling environments. The concept of sense of control, as described in Rodin’s experiments on institutionalized elderly people (Rodin, 1986), highlights the remaining ability to manage life despite a medical condition. Based on such evidence, and building on remain-

ing cognitive skills, several interventions were developed in dementia care, such as the *home environmental skill building program* (Gitlin et al., 2003), *cognitive rehabilitation* (Clare, Woods, Moniz Cook, Orrell, & Spector, 2003), and *cognitive stimulation therapy* (Spector, Orrell, & Woods, 2010). Concepts such as adaptation and coping form the basis of support programmes, such as the *Meeting Centres Support Programme* for people with dementia and their carers, which aims to help people deal with the consequences of dementia (Dröes, Meiland, Schmitz, & van Tilburg, 2004; Dröes, et al., 2011). Finally, the concept of *Personhood* (being a person in relation to others), as introduced by Kitwood and Bredin (1992), emphasizes the importance of social participation for people with dementia. Interventions focusing on maintaining or improving social interactions with, and social relationships of, people living with dementia, e.g. person-centred care (Brooker & Latham, 2016; Kolanowski, Van Haitsma, Penrod, Hill, & Yevchak, 2015) and reminiscence (Subramaniam & Woods, 2012), appear to not only have beneficial effects on social interactions, but also improve mood and cognitive function (Woods, Aguirre, Spector, & Orrell, 2012), the use of antipsychotics (Brooker et al., 2015), and enhance the quality of life of institutionalised people with dementia (Charras, Eynard, Viatour, & Frémontier, 2011; Charras & Frémontier, 2010; Charras & Gzil, 2013; van Dijk, et al., 2012).

The social health concept as described by Huber et al. (2011) may be helpful to integrate the existing knowledge in the field of dementia care research, and also for tracing gaps in scientific, clinical and practical fields. Operationalizing ‘social health’ for dementia may also reveal under-acknowledged areas of concern regarding the condition of dementia, as well as opportunities for care and support which need further investigation. It may thus instigate optimization and innovation of dementia care. For this reason the INTERDEM network on research into early and timely psychosocial interventions in dementia decided to undertake a collaborative action by means of a Social Health Taskforce to (1) clarify and operationalize

Huber et al.'s (2011) concept of social health and its three dimensions for people with dementia; (2) identify factors influencing social health in dementia as well as interventions promoting social health on the basis of present scientific knowledge; and (3) indicate gaps of scientific knowledge on social health related to dementia that need further investigation and formulate recommendations based on this to promote research and innovative practice into social health in dementia.

This position paper is the result of this collaborative action of the INTERDEM Social Health Taskforce. After describing the method used by the taskforce, operationalisations of the three social health dimensions, factors influencing these dimensions, and interventions promoting social health are presented. Although the paper intends to operationalise the concept of social health from a scientific state-of-the-art perspective, members of the taskforce agreed, from the very first meeting, that it would be valuable to consult people with dementia on the results. A separate subsection reports on the views of people with dementia regarding the operationalizations of the three social health dimensions, suggested by the task force. After discussing the results, conclusions are drawn on the applicability and usefulness of the concept of social health in dementia. Based on identified gaps of knowledge within the three social health dimensions recommendations are made for further research and practice.

Methods

In autumn 2014, the European Interdem network set up a taskforce on Social Health in dementia. In June 2015 first a survey was conducted among the taskforce members (n=54) to get insight in their expertise on the three dimensions of social health as described by Huber et al. (Huber, et al., 2011), the research they had conducted in these areas, and on their willingness to participate in the preparation of a position paper on the subject. Forty four researchers (81%), with different educational backgrounds (clinical, social and environmental psycholo-

gists, old age psychiatrists, nurse practitioners, medical sociologists, elderly care physicians, occupational therapists and a human movement scientist) responded to this survey. Forty one of them (93%) had expertise in one or more of the social health dimensions and described specific topics within these dimensions on which they had conducted research. Thirty seven of the respondents were willing to participate in the preparation of the position paper. All research topics identified by respondents, for each dimension of social health, were listed and presented during a taskforce meeting in September 2015. Subsequently, based on their expertise, experience and interest, taskforce members were divided into three theme groups (resp. n=12, n=10, n=10) that further developed the operationalization of the three social health dimensions. Each theme groups was led by two of their members. Five taskforce members accepted the role as internal reviewers of (parts of) the paper.

Subsequently, a second survey was conducted in which all members were asked to indicate if they agreed with the categorisation of the listed topics within the three dimensions of social health or wished to (re)move or add relevant topics. Additionally, each theme group inventoried relevant research regarding one of the dimensions of social health, including effective interventions, which also enabled the collection of information on the most significant gaps in knowledge. Based on the results, the leaders of each theme group composed (1) a list of relevant topics for the dimension of social health they were responsible for and on which the majority of the theme group agreed, (2) a list of topics on which the majority of the theme group members disagreed and, (3) a list with new proposed topics. The results of this first topic analysis to frame the dimensions of social health were discussed during a consensus meeting of the theme groups (28 members present) in October 2015: the inventoried topics for each dimension were categorised by the theme groups based on consensus as (a) core elements of the dimension of social health, (b) influencing factors, and (c) interventions. Furthermore, knowledge gaps were inventoried. The main aim of this meeting was to reach con-

sensus on the operationalization of the three dimensions of social health for people with dementia.

After this meeting, all members of the *European Working Group of People with Dementia* (EWGPWD)¹, were consulted with a request for their feedback on the pertinence of the descriptions of the social health dimensions according to their experience of living with dementia. The EWGPWD meets 3–4 times per year. Members of the working group need to receive well in advance information about all the topics that will be discussed during their meeting. Due to the researchers tight timeline for the consultation with the EWGPWD and as the agenda for the next scheduled meeting of the group was already set, the researchers decided to consult the group via e-mail. The researchers worked with Alzheimer Europe (AE) staff members to find the best way to present the operationalization of the concept of social health and the questions in printed form for feedback to the working group. Only the text on the operationalization of the social health dimensions was sent (the information on state-of-the-art of knowledge of influencing factors, interventions and knowledge gaps was not shared with the group because it was thought to be too much information and too scientifically oriented). The group was invited to provide a short definition of what the dimension meant to them, and to provide feedback on the by the taskforce identified capacities/abilities within each dimension (i.e. to what extent each was meaningful to them and whether they felt there were any missing relevant capacities/abilities).

Based on the two surveys, the consensus meeting, and additional global literature searches on the main topics mentioned in the operationalizations of the three dimensions of social health in dementia, (for the period 2010-2015, using the electronic databases Pubmed and Google scholar), the theme group leaders prepared a text on each dimension of social health. This text included a short explanation/operationalization of the content of the dimension and existing knowledge on influencing factors and effective interventions relevant to the

dimension of social health. A separate text was written on knowledge gaps in the field. The draft texts were submitted for review to the members of the theme groups and adapted based on their comments. Subsequently, the draft texts were integrated into a position paper by the taskforce leaders. The feedback from the EWGPWD was included in a separate section.

Based on the

inventoried gaps, recommendations were formulated and integrated in the discussion section of the paper, which was then peer-reviewed by three INTERDEM members who had not been part of the theme groups. A revised version of the paper based on all comments was submitted for final approval to the theme groups, EWGPWD and the INTERDEM peer-reviewers.

Results

The results are summarised in Table 1.

Social Health dimension 1: Capacity to fulfil one's potential and obligations

Operationalization

The first dimension of social health is operationalized as the ability of a person living with dementia to function in society according to his or her competencies and talents ('potentials') in the best possible way, and to meet social demands ('obligations') on a micro- and macro- societal level. This means that the focus is not on deficits but on remaining capacities and more importantly, it relates to normalcy.

Analysis of the data from the group survey and consensus meeting among experts in dementia care and research, identified the following capacities as a precondition, essential to the capacity to fulfil one's potential and obligations on a micro level: the capacity to exercise choice and autonomy, the capacity to maintain own identity (personhood), the capacity to participate and contribute to communities, the capacity to give and receive support (reciproc-

ty), the capacity to collaborate with professionals and informal carers, and the capacity to participate in shared decision-making. Related to a macro level, the capacity to participate and contribute to communities was identified. When these capacities are in place the person with dementia will be able to fulfil their potential and it will also allow the person to fulfil their obligations by reciprocating and participating in personal and community life (Innes & Director, 2013; Sabat, 2001; Smebye & Kirkevold, 2013).

Influencing factors

Factors influencing this dimension of social health can be grouped into four categories. The first category concerns *personal factors* including mental well-being and a sense of coherence is identified by Antonovsky (1987; Caddell & Clare, 2011; Clare et al., 2012; Kaufmann & Engel, 2016; Kitwood & Bredin, 1992; Stoner, Orrell, & Spector, 2015; Thygesen, Saevareid, Lindstrom, Nygaard, & Engedal, 2009), self-efficacy, mastery, resilience (Clare, Kinsella, Logsdon, Whitlatch, & Zarit, 2011; Elliott, Scott, Stirling, Martin, & Robinson, 2012; Windle, 2012), and the ability to withstand stigmatization (Gove, Downs, Vernooij-Dassen, & Small, 2016; Milne & Peet, 2008; Sabat, 2001; Scodellaro & Pin, 2011).

The second category concerns *disease-related factors*, in this case factors caused by dementia and possible comorbidity, such as the severity of cognitive disabilities, the change in learning potential across the disease trajectory and disabilities in carrying out activities of daily living (Dröes, 2007; Dröes, et al., 2011; Giebel, Challis, & Montaldi, 2015a; Miranda-Castillo, Woods, & Orrell, 2010).

The third category relates to the *social factors*: presence or absence of support from the social network (Clare, Evans, Parkinson, Woods, & Linden, 2011; Dröes, Breebaart, Ettema, van Tilburg, & Mellenbergh, 2000; Dröes, Breebaart, Meiland, Van Tilburg, & Mellenbergh, 2004; Graff et al., 2007; Mazurek et al., 2015; Spruytte, Audenhove,

Lammertyn, & Storms, 2002; Toms, Quinn, Anderson, & Clare, 2015; Van Mierlo, Meiland, Van de Ven, Van Hout, & Dröes, 2015); stigma and/or discrimination, because these creates a lens through which others only see the deficit, resulting in capacities/capabilities and talents being ignored (Alzheimer's-Australia, 2016; Sabat, 2001; Urbańska, Szcześniak, & Rymaszewska, 2015); the extent to which there is a cooperative relationship with professionals and informal caregivers (Quinn, Clare, McGuinness, & Woods, 2013; Spruytte, et al., 2002); and, finally, the availability of enriching opportunities and professional education (Graff, Vernooij-Dassen, Thijssen, et al., 2006; Hattink et al., 2015).

The fourth category of influencing factors concerns the *material and environmental factors* in terms of design, living arrangement (homelike or not), the enabling aspect of the environment, and the availability and accessibility of assistive technology (Span, Hettinga, Vernooij-Dassen, Eefsting, & Smits, 2013).

Interventions

There are a number of interventions that intend to optimize and promote the capacity of people with dementia to fulfil their potential and obligations. On a micro level these include: building capacities, use of talents, use of assistive technologies related to social inclusion, and advance care planning. On a macro level actions are undertaken regarding legal and normative aspects of care, dementia friendly communities and community engagement. Some interventions are aimed at the capacity itself, others at facilitating factors:

Interventions that can be seen as *building capacity to fulfil potential* on a micro level are approaches focussing on enhancement of resilience, (Clare, Kinsella, et al., 2011; Harris, 2008; Resnick, Gwyther, & Roberto, 2010; Windle, 2012) aiming to promote adaptation, utilising personal and social assets, and overcoming the consequences of the disease for personal wellbeing. New interventions such as DemenTalent, in which people with dementia work as

volunteers, allow people to use their talents and contribute to social domains such as professional education and care of the public green spaces (<http://www.dementalent.nl/en/home>).

Interventions on a macro level that can have an effect on the capacity to fulfil one's potential are those related to social inclusion, dementia friendly communities and community engagement (Cantley & Bowes, 2004; Dröes, Meiland, et al., 2004). They aim to support the person with dementia and to remove factors that are barriers for the fulfilment of their potential.

Focusing on facilitating factors, on a micro level, there are many approaches that are successfully used to enable people with dementia to fulfil their potential and promote their wellbeing and quality of life (Logsdon, McCurry, & Teri, 2007), such as goal-oriented cognitive rehabilitation (Clare, et al., 2014; Graff, et al., 2007; Logsdon, McCurry, & Teri, 2007; O'Shea et al., 2014; Potter, Ellard, Rees, & Thorogood, 2011; Szczepanska-Gieracha, Kowalska, Pawik, & Rymaszewska, 2014; van Dijk, et al., 2012; Woods, Thorgrimsen, Spector, Royan, & Orrell, 2006; Woods, et al., 2012). In addition the use of assistive technologies to compensate for functional disabilities regarding, e.g. memory, orientation, action, can play a role in enabling the person with dementia to function according to their competencies and talents (Boots, Vugt, Knippenberg, Kempen, & Verhey, 2014; Lauriks et al., 2007; Meiland et al., 2014; Span, et al., 2013). Interventions for advance care planning enable and stimulate people to decide on the care they wish to receive (Ampe et al., 2015; Mariani, Engels, Koopmans, Chattat, & Vernooij-Dassen, in press).

On a macro level, there is a set of interventions regarding the legal and normative aspects of care to protect and promote the possibility for the person with dementia to be part of the process of decision-making and regarding mental competency – the ability to make decisions for oneself - (Bahar-Fuchs, Clare, & Woods, 2013; Caddell & Clare, 2011; Galeotti et

al., 2012; Johnson & Karlawish, 2015; Mariani et al., in press; Sabat, 2005; Span et al., 2014; Woods, et al., 2012) social inclusion (Innes, Archibald, & Murphy, 2004), and issues related to human rights and ethics (Johnson & Karlawish, 2015).

Social health dimension 2: Manage life despite the disease

Operationalization

The ability to manage life with some degree of independence can be operationalized for dementia as the ability to preserve autonomy and to solve problems in daily life, as well as to adapt to and cope with the practical and emotional consequences of dementia (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002; Martin, Turner, Wallace, Choudhry, & Bradbury, 2013; Townsend & Polatajko, 2007, 2013). Being autonomous, self-reliant and able to adapt and cope with daily difficulties by using problem solving and compensational strategies and by adapting the environment, are central aspects of effective management of life in dementia (CAOT, 2015; Dröes, Meiland, et al., 2004; Dröes, et al., 2011; Graff, 2014; Graff et al., 2008; Graff, Vernooij-Dassen, Zajec, et al., 2006; Olazarán et al., 2010; Townsend & Polatajko, 2013; Van't Leven, et al., 2013).

Influencing factors

Many personal, disease related, social and material factors can influence the ability of people with dementia to manage life. *Personal factors* involve the person's (pre-morbid) personality, competencies and skills, life history and important life values, including spiritual values, but also the person's engagement in activities and relationships, his or her sense of usefulness, the awareness of having dementia and the recognition and acceptance of care needs (Apte, Kielhofner, Paul-Ward, & Braveman, 2005; Ennals & Fossey, 2007; Kielhofner, 2008; Townsend & Polatajko, 2013). *Disease-related factors* involve dementia-related disabilities in the subsequent stages of the disease, other existing cognitive and physical disabilities, and co-morbidity (Giebel & Challis, 2015; Giebel, Challis, & Montaldi, 2015b; Muo et al., 2005).

Social factors also play an influential role, especially in engaging in meaningful activities and personal relationships. Examples are the capacities within the social environment, such as carer competence, caregiving relationship(s), reciprocity in relationship(s), social support and the formal care a person receives and support received by the informal carer, and cultural aspects (Dröes, Breebaart, et al., 2004; Dröes, Meiland, et al., 2004; van der Roest, Meiland, Comijs, Derksen, Jansen, van Hout, Jonker, & Droes, 2009; Vernooij-Dassen, Leatherman, & Rikkert, 2011; Zunzunegui, Alvarado, Del Ser, & Otero, 2003). Low ratings of relationship quality, as assessed by carers, are associated with greater carer stress, whereas low ratings made by people with dementia are associated with depression and lower quality of life (Clare, Kinsella, et al., 2011). Other social factors that can influence the person's ability to manage life are the living situation (e.g. living alone or cohabiting with a carer), living in a dementia friendly/inclusive community, accessibility/pathways to support, and the degree to which the provided support is need-based (de Rooij et al., 2012; Miranda-Castillo, et al., 2010; Miranda-Castillo, Woods, & Orrell, 2013; Orrell et al., 2008; van der Roest, Meiland, et al., 2009a; Van Mierlo, Van der Roest, Meiland, & Dröes, 2010).

Finally, *material and environmental factors* involve the availability of financial resources, assistive technologies, a supportive environmental design in public spaces, such as dementia friendly environments that have the capacity to support people with dementia, in an empowering, inclusive, and non-stigmatising manner, in different places and community services such as post-offices, shops, libraries, hospitals, public transport or places where social or leisure activities are offered, and a supportive (adapted) physical environment in the home of the person with dementia to support them in managing meaningful daily activities (Malinowsky, Almkvist, Nygard, & Kottorp, 2012; Mountain, 2004; Nygard & Starkhammar, 2007; Topo, 2009).

Interventions

Interventions aimed at supporting people with dementia to manage life can be divided into interventions intended for the person with dementia, for the caregiver or both.

Effective interventions *for the person with dementia* are, for example, those supporting the person to adapt to, and cope with, their changing abilities and limitations, including cognitive rehabilitation therapies, such as goal oriented tailored cognitive rehabilitation therapy, group cognitive stimulation group therapy, cognitive training, and exercise and psychomotor therapy (Bahar-Fuchs, et al., 2013; Dröes, et al., 2011); case management based on the model of empowerment (MacNeil Vroomen et al., 2015) and other interventions aimed to enhance a person's strengths and capabilities (from care for basic needs to support to participate in a community, taking stock of one's life through reminiscence, and providing opportunities for gaining new skills); staff awareness training, which aims to enable professional caregivers to better identify signs of awareness in people with dementia to improve their quality of life and that of their caregivers; (Clare et al., 2013); and support groups (Toms, Clare, Nixon, & Quinn, 2015). Other beneficial interventions are those aimed at recognising care needs (Miranda-Castillo, et al., 2013) and at providing meaningful activities creating stimulat-

ing, positive experiences, like green care farms (de Boer et al., 2015; Verbeek, 2015) and horticultural activities (Gonzalez & Kirkevold, 2015), and when dementia is more advanced, methods like doll therapy and snoezelen and Namaste (Shin, 2015; Stacpoole, Hockley, Thompsell, Simard, & Volicer, 2015; van Weert, van Dulmen, Spreuwenberg, Ribbe, & Bensing, 2005).

Examples of effective interventions intended *for the informal and formal caregivers* are: psychoeducational programmes, including online skills training (Hattink, et al., 2015); staff awareness training (Clare, et al., 2013) and cooperative communication interventions between staff and family caregivers as partners in caregiving (Robinson et al., 2007); brief, individually tailored behavioural interventions designed for caregivers to reduce reluctance of people with dementia to attend day care services (Nogales-González, Losada-Baltar, Márquez-González, & Zarit, 2014); and a web-based tool supporting carers to find services they need (Van Mierlo, et al., 2015).

Effective combined interventions *intended for both the person with dementia and the carer* are self-management group interventions (Toms, Quinn, et al., 2015); support programmes offered in community based meeting centres (Dröes, et al., 2000; Dröes, Meiland, et al., 2004; Dröes, et al., 2011), home community occupational therapy (Gitlin, Hauck, Dennis, & Winter, 2005; Gitlin, et al., 2006; Gitlin, et al., 2003; Graff, et al., 2008; Graff, Vernooij-Dassen, Zajec, et al., 2006), and advance care planning interventions (Ampe, et al., 2015; Cohen-Mansfield, Dakheel-Ali, & Marx, 2009).

Social Health Dimension 3: Participation in social activities

Operationalization

Participation in social activities can be operationalized in dementia as the act of being occupied or involved with meaningful activities and social interactions (Cohen-Mansfield, et al., 2009) and having social ties and relationships, which are meaningful to the person living with dementia (O'Rourke et al, 2015).

The Interdem Social Health Taskforce considers the *emotional* aspect in the operationalization of participation in social activities essential for experiencing social health. Frequency and quantity of participation in social activities, such as the number of activities in which one is involved or the size of the social network, should not be considered as sole indicators of social health in itself. As indicated by Kuiper et al. (2015), when evaluating influence of social relationships on dementia onset, the quality of participation in social activities, i.e. that they are being experienced as meaningful by people with dementia themselves, should also be taken into consideration. From this perspective, participation in social activities can be considered indicative of social health, i.e. how a person with dementia stays connected with the social environment and experiences this as meaningful.

Influencing factors

There are many factors that can influence the participation of people with dementia in social activities. First, *personal and disease-related factors*: participation in social activities not only requires cognitive ability to attend social activities, but also physical ability to actively partake (Kolanowski et al., 2006). People with dementia may feel insecure participating in social activities due to communication difficulties, while caregivers may experience difficulties in communicating adequately with people with dementia in different stages of the disease, when and if cognitive impairments alter communication abilities (Murphy & Oliver, 2013).

Second, *social factors*, such as care support networks of (in)formal caregivers can significantly influence the participation of people with dementia in everyday life activities, both

at home and in institutional settings (Gräske, Meyer, Worch, & Wolf-Ostermann, 2015; Johannessen, Hallberg, & Möller, 2013; McDonough & Davitt, 2011). Strong social networks appear to positively impact physical, mental and social health (Heaney & Israel, 2008). They increase the capacity and capability of communities to involve people with dementia (Wiersma & Denton, 2016) and support them emotionally, instrumentally by providing constructive feedback and affirmation that is helpful for a positive self-evaluation (Heaney & Israel, 2008). In addition, social factors turn out to also protect against further cognitive decline (Kuiper et al., 2015), while stigmatization and discrimination negatively impact social participation (see Social Health dimension1, influencing factors).

Third, *material and physical environmental factors* influence participation of people living with dementia in social activities and the range of places in which they engage in activities (Cohen-Mansfield et al., 2011; Day, Carreon, & Stump, 2000). The relative accessibility of the environment, both at home and in long-term institutional care, including transport to places where activities are organised, can be perceived as a facilitator or barrier to social participation (Charras, et al., 2011; Johannessen, 2012; Verbeek, van Rossum, Zwakhalen, Kempen, & Hamers, 2009).

Interventions

A key element of interventions promoting participation in social activities appears that they serve as a communication channel for people with dementia to engage, interact and talk with others, also referred to as collective engagement (Jones, Sung, & Moyle, 2015): Besides connecting people to others, participation in social activities can provide empowerment, pleasure and contribute to a reduction of cognitive deterioration (Kuiper et al. 2015). These key elements distinguish interventions aimed at promoting participation in social activities from activity based *therapies*, as the latter often focus on the individual and are generally

aimed at self-engagement. Social activity interventions must be tailored to specific individual needs and, instead of being problem-oriented, enhance positive experiences, such as maintaining positive or meaningful social relationships (de Vugt & Verhey, 2013).

Examples of effective interventions to engage people with dementia in social activities include programmes aimed at the *social and physical environment*, such as community-based meeting centres for people with dementia and their carers (Dröes, Meiland, et al., 2004), the Enriched Opportunities Programme (Brooker, Argyle, Scally, & Clancy, 2011), support groups (Parkes & Ward, 2015), intergenerational programmes involving, for example, young adults in social activities for people with dementia, or people with dementia acting as volunteers in e.g. educational activities for young people (Park, 2014), small scale homelike care environments (Charras, 2011; Verbeek et al., 2014), and green care farms (de Bruin et al., 2009). Other effective interventions concern *specific and meaningful activities* –such as activities using pets, dolls, singing in chorus, listening or making music, dance theatre, many different types of creative art work and museum visit programmes, or clowns (Kontos et al., 2016)– or are *multi-component*, focusing on improving social support or mobilising the social network (Dam, de Vugt, Klinkenberg, Verhey, & van Boxtel, 2016). Furthermore, design guidelines have been developed to increase ‘dementia-friendliness’ of environments at home (Gitlin, et al., 2009; Gitlin, et al., 2006), local neighbourhoods (Mitchell & Burton, 2006) and long-term care institutions (Fleming & Purandare, 2010). It is recommended that environmental design supports autonomy, privacy, personal identity, socialization, familiarity, legibility (e.g. signposting), comfort, and safety (Calkins, 2009; Charras, Eynard, & Viatour, In Press; Fleming & Purandare, 2010).

Feedback from the European working group of people with dementia

Due to the abstractness of the topic and the way the consultation was carried out (via email) only half of the members of the working group provided feedback and the feedback provided was limited as people with dementia and their carers found it difficult to grasp some of the concepts and questions. In total, five people with dementia and two carers provided feedback, two of whom (one person with dementia and one carer) mostly gave general comments. The participants emphasized the need to involve people with dementia in the taskforce from the beginning. Overall, people from the group welcomed the concept of Social Health and felt this could be a good approach for dementia care and research. One of the group members illustrated this by stating that this approach (i.e. social health) ‘implies an important step forward as we, people with dementia, are recognized as individuals with unique capacities, responses and requirements, both medically and physically, rather than a large number of people with just one common “disability”.’

Four participants gave feedback on the specific dimensions of social health. A recurring topic was the importance of time and how the idea of change over time should be given more attention: ‘Our “condition” is dynamic, it varies over time.’, ‘People with dementia have a constantly changing target as far as potential and obligations are concerned, and their capacity is also constantly changing.’ In addition to the fact that competencies or abilities while living with dementia are considered as a ‘moving target’, one person addressed the timeframe of activities themselves: ‘I want to participate in activities. However, this may slow down a study or community service (or whatever), because I need more time to prepare to fulfil obligations, compared to the past.’

Regarding dimension 1 (‘Capacity to fulfil potential and obligations’), several members of the group felt that this capacity is often also influenced by their relationships with others and by the suitability of the environment to support them, to be dementia-friendly and non-stigmatizing: ‘Some of my abilities to fulfil my obligations are not dependent on my own

capacity but on external – social and environmental – factors, e.g. how someone interacts and reacts to me.’; ‘Our capacity is somewhat beyond our control in terms of the measures they talk about, we either have it or we don’t and it is related to each specific point in time.’ Here again the idea of temporality was raised and two participants linked the concept of capacity to the uncertainty about the future and their fluctuating capacities. It was felt that when looking at capacities it may not be clear whether the assessment should be based on the person or on the challenges that he faces with regard to capacity: ‘I keep getting tripped up by the term – it’s difficult to grasp. Do they want my assessment as it relates to me or to dementia in general?’ As an overall recommendation some participants suggested using the concept of ‘capacity’ cautiously and one person even suggested that a different approach might be more appropriate: ‘should we be moving away from this word (“capacity”) altogether?’

Regarding dimension 2 (‘Ability to manage life with some degree of independence, despite the disease’, as formulated by Huber et al, 2011), one person felt that the wording of this dimension mainly highlighted deficiencies, which was perceived as devaluating and disempowering: ‘(...) the statement “the ability to manage life despite the disease”. It’s very disempowering. It’s worded as if because I have dementia there is an expectation that I shouldn’t be autonomous and it’s surprising if I am e.g. “despite my disease”.’

With regard to dimension 3 (‘Participation in social activities’), communication was mentioned as being an important factor to support people with dementia participate in society, and feel useful at different levels of social and societal participation: ‘as long as I am able to make a positive contribution on a local level, I feel great pleasure.’ This person further described the relevance of his current contribution to the community in terms of reciprocity as he realized that at some point, as his dementia progresses, he will need help and support from the community: ‘it may justify my future condition when I will not be able to offer any help, but just need whatever services are available. Of course no such justification is required but it

adds to my peace of mind.’ Another suggestion referred to the necessity of including people with dementia in society and politics: ‘social inclusion in all Community/ State Projects for people with dementia’, ‘representation of people with dementia on a political level.’

Discussion

The aim of this position paper was threefold: to operationalize the concept of social health as suggested by Huber et al. (Huber, et al., 2011) for people living with dementia; to identify factors influencing social health and interventions promoting social health on the basis of present scientific knowledge; and to identify knowledge gaps in this field to formulate recommendations for research and practice to promote social health in dementia.

The results show that the concept of social health as proposed by Huber et al., more specifically ‘the capacity to fulfil one’s potential and obligations’, ‘the ability to manage life with some degree of independence’ and ‘participation in social activities’, can be operationalized for people with dementia. Each of the three dimensions is thought to be relevant for their social health, both by members of the Social health task force of INTERDEM and the EWGPWD. Several personal, disease-related, social and material factors were mentioned that can influence the individual’s capacities on these three dimensions. Moreover, for each dimension examples were provided of interventions that have beneficial effects on the person with dementia or their caregiver, and can be recommended for care innovation to promote social health. Sometimes there seems to be some overlap of influencing factors and interventions between the different dimensions of social health, as some themes are discussed in more than one dimension. However, this appeared relevant as these themes are considered from different perspectives within the three dimensions, with dimension 1 focusing on the ability to contribute to society as a person, dimension 2 focusing on the ability to manage one’s own

life, and dimension 3 on the ability to socially engage and live a meaningful life. The EWGPWD agreed on the importance of fully considering social health in dementia care and research, and that it should be related to the course (the ‘time frame’) of the disease - because abilities change as the disease progresses, but also to the capacity of the environment to support people with dementia in a dementia-friendly, empowering, inclusive and non-stigmatizing manner. This is in line with the factors influencing social health mentioned by the members of the Social Health Taskforce.

Although a considerable amount of research has been done in this field in the last three decades, several gaps were identified, by the Social Health Taskforce, based on which recommendations for further research and practice were made. Regarding the first dimension ‘*the capacity to fulfil one’s potential and obligations*’ further research is recommended into the development and validation of new assessment tools for positive outcomes, reframing cognition as a major primary outcome, and the evaluation of new and promising interventions related to this social health dimension. Research is also needed into how to effectively implement interventions aimed at helping people with dementia to fulfil their potential and obligations, either in the community or in institutional care settings. Other areas that need further investigation are: how the capacity to fulfil potential and obligations, in different stages of the disease, may be influenced by factors such as awareness and insight of the person with dementia into his or her own condition, religiosity/spirituality and stigma experienced by the person with dementia and their carers. Since personhood is seen as an important part of the experience of the person with dementia, conceptual analysis and research is needed to understand how some of the factors described can influence the experience of personhood, and consequently the ability/capacity of people with dementia to function according to their wishes, talents and capacities during the course of the disease. This includes further research into shared decision-making. It should be investigated if successful interventions developed for

other target groups, such as Acceptance and Commitment Therapy (ACT; Ruiz, 2012), may provide tools for helping people with dementia and their families to find ways to live their lives, according to their wishes and values. Another aspect, related to this first dimension of social health, that needs investigation is the application of the UN convention on the rights of people with disabilities in the field of dementia.

Regarding the second dimension manage one's life with some degree of independence further methodologically sound research is recommended into effective solutions for frequently observed unmet needs, such as information on one's own condition, memory support, meaningful activities, company and safety; the effectiveness of promising interventions to help people manage their life, such as person-centred approaches like emotion-oriented care (Finnema, Dröes, Ribbe, & Van Tilburg, 2000), living well with dementia interventions (Clare et al., 2014; de Rooij et al., 2012), and Dementia Care Mapping (Brooker, 2005; Vermeulen et al., 2014); (psycho)educational programmes and self-management group interventions (Quinn, Toms, Anderson, & Clare, 2015); intergenerational interventions; assistive technologies (Fleming & Sum, 2014) and companion robots (Moyle et al., 2013); interventions that create dementia-friendly environments, and small-scale normalized living (de Rooij et al., 2012). Further research is also recommended to identify factors that reduce or promote the ability to manage life in dementia, such as communication skills of caregivers, and how to influence these factors. Finally, the development of appropriate assessment tools that can be used for people with dementia with a migration background and living in different countries and cultures is recommended.

Regarding the third dimension participation in social activities, research is recommended that will provide insight into the consequences of social support – when is it beneficial, when does it induce care dependency? – as well as relevant (outcome) indicators for social participation interventions. Research is also needed into factors that may interact with the

effect and suitability of social support interventions, such as personality, current needs, gender and culture of the individual (Van Mierlo et al., 2010). Better understanding is needed of social inclusion and participation in different social strata and how these are affected by social inequalities. In addition, knowledge on how to effectively take care of people with dementia and carers in different types of minority communities is needed, and how to enable them to engage and participate in meaningful activities. Other themes to be investigated include involving the informal care network in promoting social participation of people with dementia; the potential of social media to increase access to social support and interaction for people with dementia; and the impact of the physical, social and organizational environment on activity participation in residential care settings.

Several research recommendations apply to all dimensions of social health, for example: the development of new assessment tools and outcome measures for each dimension (which can build on previous work of INTERDEM; Moniz-Cook et al., 2008), and strategies to promote the personalized implementation of effective interventions; research into dementia friendly (social and architectural) environments, as well as into the influence of social cognition factors (e.g. social inclusion and effect of stigma), and conative factors (e.g. meaningfulness of activities, empowerment) on social health in dementia.

Many of these recommendations, such as needs-based intervention programmes, insight into factors influencing the effect of interventions, insight into the impact of social support and participation interventions, are in line with recommendations in recent literature reviews regarding psychosocial difficulties and needs of people with neuropsychiatric disorders in general (such as dementia, depression, migraine, multiple sclerosis, Parkinson's disease, schizophrenia and stroke) (Coenen et al., 2016) and frail older people (Bindels et al., 2014), psychosocial interventions for people with dementia and their family caregivers (Van't Leven et al., 2013; Van Mierlo et al., 2010) and social support group interventions (Leung, Orrell, &

Orgeta, 2015). Other recommendations, such as insight into how religiosity/spirituality and stigma play a role in fulfilling one's potential and may affect the experience of personhood, the person's ability to function according to their wishes and talents over the course of the disease, as well as the potential role of social inequalities and social media in the social health of people with dementia, have not been mentioned previously in the literature as far as we know.

Limitations of the study

Although the scope of this paper was not a systematic review of the literature, the broad expertise of the INTERDEM Social health task force members, their different professional and cultural backgrounds, and the methodology followed to achieve the aims of this position paper, which also included a consultation of people with dementia through the EWGPWD, resulted in a broad and rich overview of the state of knowledge regarding social health in dementia. We are aware, though, that as the focus of the article was limited to the operationalization of the concept of social health as described by Huber et al. (2011), we did not discuss relevant new related models on health in Alzheimer's disease, such as the eco-psychosocial model (Whitehouse, 2014; Zeisel, Reisberg, Whitehouse, Woods, & Verheul, 2016). Some caution is indicated regarding generalization of the concept of social health. Because almost all task force members and all members of the EWGPWD were from Europe, it is not clear whether other cultures, in other parts of the world, would operationalize social health in dementia in the same manner. Also no differentiation was made between different types of dementia.

The method of consultation of the EWGPWD by email, due to time restrictions of the Taskforce, posed considerable challenges and some members of the group were therefore unable to respond. The working group felt that consultations should be carried out in face-to-

face meetings instead of via email, as the latter, in their view could lead to misinterpretation and misunderstandings.

The scientific value of this paper is that it provides a consensus-based operationalization of the concept of social health in dementia, as well as insight into the state of the art regarding (positively/negatively) influencing factors and effective interventions promoting social health in people with dementia. Additionally, the paper provides a comprehensive research agenda to overcome the present knowledge gaps. The recommended research will eventually contribute to an improved care practice and a more dementia-friendly society, which will better enable people with dementia to adapt to and manage the changes dementia brings in their lives. The paper has also emphasized the relevance of including people living with dementia in research and in task forces addressing issues that matter to them. The feedback from the group suggested that such involvement should be throughout the whole cycle of the research and in a way that they can contribute in a meaningful way.

The value of the paper for clinical practice is that it offers many tools to improve care by providing insight into the different aspects of social health, factors that may positively or negatively influence these aspects, and interventions that can help to maintain, or promote, social health in people living with dementia.

Conclusions

A consensus-based operationalization of the concept of social health in dementia is proposed. Additionally, an overview of factors influencing social health and interventions that can improve social health in people with dementia is provided. Based on the existing scientific knowledge and identified gaps, recommendations are made for research and practice with the aim to promote social health in people living with dementia, now and in the future.

Note

1. In 2012, Alzheimer Europe set up a Working Group of People with Dementia (EWGPWD). The EWGPWD is composed of 10 people with dementia from different countries and with different types of dementia. The EWGPWD works to ensure that the activities, projects and meetings of Alzheimer Europe duly reflect the priorities and views of people with dementia. The group operates independently, with its own Board and agenda of activities. The Chairperson of the EWGPWD also sits on the Board of Alzheimer Europe.

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Table 1. Operationalization of social health (Huber et al., 2011) in dementia, factors influencing social health and focus of interventions to promote social health. (The mentioned factors within the three dimensions do not exclude cross-over with other dimensions.)

Dimension of SH operationalization	Influencing factors	Focus of interventions to promote social health
1) Capacity to fulfil one's potential and obligations The ability of a person living with dementia to function in the society according to his or her competencies and talents ('potentials') in the best possible way and to meet social demands ('obligations') on a micro and macro societal level	Personal factors	<ul style="list-style-type: none"> • Promotion of adaptation, wellbeing and quality of life • building assets, focussing on potential, and overcoming the consequences of the disease on personal wellbeing advance care planning • social inclusion • dementia friendly communities • community engagement • rights and ethics • protecting and promoting the possibility for the person with dementia to be part of the process of decision-making • assistive technologies • supportive design • facility arrangement (homelike)
	Disease-related factors	
	Social factors	
	Physical environment	
2) Manage life despite the disease The ability to manage life with some degree of independence, can be operationalized as the ability to preserve autonomy and to solve problems in daily life, as well as to adapt to and cope with the practical and emotional consequences of dementia	Personal factors	<ul style="list-style-type: none"> • interventions supporting the person to adapt to, and cope with, their changing abilities and limitations • case management based on the model of empowerment • interventions aimed to strengthen people with dementia in their forces and capabilities • staff awareness training • support groups for both the person with dementia and the caregiver • recognizing care needs • meaningful activities creating stimulating, positive experiences
	Disease-related factors	
	Social factors	
	Physical environment	
3) Participation in social activities: The act of being occupied or involved with meaningful activities and social interactions and having social ties and relationships, which are meaningful to the person living with dementia themselves	Personal factors	<ul style="list-style-type: none"> • involvement in social activities • activity based therapies • tailored interventions to specific individual needs • enhance positive experiences, • maintain positive and meaningful social relationship
	Disease-related factors	
	Social factors	
	Physical environment	