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Joining forces to improve psychosocial care for people with cognitive deficits across diagnoses: social health as a common framework

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ABSTRACT

Cognitive deficits such as memory problems have a major impact on independence in daily life and participation in society in several populations, such as people with dementia, brain injury (i.e. stroke) or a severe mental illness such as schizophrenia. Similarities in the impact on participation and well-being have resulted in the development of comparable psychosocial interventions across populations, aiming to support people to adapt to cognitive deficits or by adapting the environment. These interventions are developed separately, without using the expertise in other fields. We argue that each of the fields and the field of psychosocial care in general would benefit from closer collaboration on development and evaluation of innovative psychosocial interventions. Collaboration has been complicated by the use of different care models and theoretical frameworks, each with their own terminology. The concept of social health - the ability to participate in work or other meaningful activities and to feel healthy despite a condition - translates to the leading care models within the fields of dementia, brain injury and severe mental illness. The concept of social health provides a common language and framework. In this paper, we elaborate on strategies for collaboration using examples of interventions to improve social health.

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Introduction

Cognitive deficits such as memory problems are core to neurodegenerative diseases such as dementia (American Psychiatric Association, 2013), but enduring cognitive deficits are also common in people with acquired brain injury (ABI) such as stroke or traumatic brain injury (Rabinowitz & Levin, 2014; Cumming, Marshall, & Lazar, 2013), and in people with a severe mental illness (SMI) such as schizophrenia (Millan et al., 2012; American Psychiatric Association, 2013). In these populations, impaired cognitive functions are in large part responsible for dependence in daily life and restrictions in societal participation (Malloy et al., 2010; Sashika, Takada, & Kikuchi, 2017; Cumming et al., 2013; Reichenberg & Harvey, 2007). Evident differences such as the time course of the condition (stable vs. deteriorating) and the life phase (e.g. studying/working vs. retirement age) in which people are confronted with these problems are likely to cause variation in functioning and care needs of people with cognitive deficits. However, regardless of the underlying cause, people with cognitive deficits (and their informal caregivers) usually need to adapt in life domains that define the quality of life of any person: social and intimate relationships, having a place of your own, fulfilling occupational and/or recreational daytime activities, physical health, financial independence and being accepted as a person (Projectgroep PvA ernstige psychische aandoeningen, 2014; Theunissen et al., 2014; Farkas & Anthony, 2010; Vincent et al., 2007).

The need to adapt in response to life changes caused by the disease is central to the newly proposed definition of health, 'the ability to adapt and self-manage in the face of physical, social and mental changes'. This definition speaks to a person's opportunities and capabilities when it comes to coping with the physical, social and emotional consequences a condition may have and recognizes a state of positive well-being despite having a chronic condition. The dimensions of physical health (the ability to physiologically cope with or adapt to (potential) physiologically harmful circumstances), mental health (the capacity to cope with and recover from strong psychological stress) and social health (the ability of people to work or to participate in social activities and to feel healthy despite limitations) together determine a person's health (Huber et al., 2011). The dimension of social health best captures the life domains described above. The presence of cognitive deficits *requires* adaptation to achieve (social) health, as it puts a challenge on social participation and well-being, but at the same time cognitive deficits *hamper* the ability to adapt, since adaptability relies heavily on cognitive functions such as mental flexibility, problem solving, planning and self-awareness (Lorig & Holman, 2003). In other words, people with a chronic condition that includes cognitive deficits need to adapt to and self-manage the condition that hinders their adaptability and self-management. Thus, in order to maintain or improve their social health, people with cognitive deficits are

likely to be in need of support for adapting and self-managing their condition, taking into account the extra challenges caused by cognitive deficits.

Although some before mentioned group differences between dementia, ABI and SMI may require population-specific interventions, the similarities in the impact of cognitive deficits on areas of daily functioning as well as the ability to adapt across diagnoses is reflected by the development of very similar psychosocial interventions across populations with cognitive deficits, such as psycho-education, self-management programs or cognitive rehabilitation strategies. Many interventions are centered around supporting people to make use of existing capabilities and gaining skills when possible, or by adapting the environment when necessary (Dröes, van der Roest, van Mierlo, & Meiland, 2011; Nehen & Hermann, 2015; Winstein et al., 2016), and therefore target social health. This may refer to modifications in the physical environment, such as the use of environmental supports, but can also involve adaptations by the social environment. For example, family members such as spouses or children may need to adapt their behavior to the changes in their loved one, to optimize their loved ones' functioning and well-being. Especially those who take on the role of informal caregivers, providing supervision, care and support with daily life activities, are at risk for physical and psychological problems themselves (Martin-Carrasco, Ballesteros-Rodríguez, Domínguez-Panchón, Muñoz-Hermoso, & González-Fraile, 2014; Camak, 2015; Saunders, 2003; De Vugt & Verhey, 2013), causing a need for support for the caregiver as well.

Despite the parallels in impact on daily life and intervention strategies, interventions for people with cognitive deficits are traditionally developed within separate fields linked to a certain diagnosis and published and presented in specific scientific and practice communities. The use of different care models and theoretical frameworks with their own terminology complicates the identification of similar issues to tackle. Because of this, time and financial resources in each of the fields are being invested in designing and evaluating the same interventions.

In the field of psychiatry the transdiagnostic approach has received increased interest, looking beyond diagnostic classifications at, for example, treatments that can be applied to a broader range of individuals based on symptoms, behaviors, coping styles and other factors (Clark, 2009; Sauer-zavala et al., 2017). In this paper, we argue that the concept of social health within the new definition of health offers a framework to link research on

psychosocial interventions for people with cognitive deficits caused by several etiologies. The concept of social health provides an opportunity to more easily make use of the expertise and existing psychosocial interventions in the other fields and take advantage of the other's successes and knowledge on facilitators, barriers and pitfalls. Without aiming to be exhaustive in describing populations in which cognitive deficits are common, we discuss how the framework of social health could connect psychosocial interventions for dementia, ABI and SMI, including directions for collaboration.

Social health: a common framework

Social health is characterized by three dimensions that refer to the ability to function in accordance to competencies and talents, autonomy in daily life, and engagement in social activities. These dimensions have been operationalized recently for dementia to stimulate optimization and innovations of care (De Vugt & Dröes, 2017; Dröes et al., 2017; Vernooij-Dassen & Jeon, 2016) (Table 1). Cognitive deficits are not only core to dementia, but are also considered as a major factor influencing these aspects of social health in ABI and SMI. Perhaps it is therefore not surprising that the guiding principles in the psychosocial care for people with ABI and SMI show considerable overlap with the operationalization of social health for dementia.

In line with the concept of social health, social participation (being active in social roles) is considered the ultimate goal of rehabilitation for people with ABI (Vincent et al., 2007). The leading framework used in ABI-rehabilitation is the WHO International Classification of Functioning, Disability and Health (ICF; WHO, 2001, 2000). The ICF-model looks beyond body function and structure (such as motor function, but also cognitive functioning) and takes into account the individuals' activities (such as activities of daily living, mobility and problem solving) and participation (including employment, recreational and leisure activities and interpersonal activities), as well as the influence of these concepts on each other and the influence of environmental (e.g. support from family or technology) and personal factors (such as coping strategy) (Langhorne, Bernhardt, & Kwakkel, 2011; WHO 2001). In ABI-rehabilitation, optimizing activity and participation by adapting to persisting impaired body functions (including cognitive deficits) is central to the aftercare in the chronic phase (>6 months) (Winstein et al., 2016). The ICF classification

Table 1. The operationalization of social health for people with dementia^a.

Dimensions of social health	Operationalization for dementia
1. <i>Having the capacity to fulfil one's potential and obligations</i>	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.
2. <i>The ability to manage life with some degree of independence despite a medical condition</i>	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.
3. <i>Participation in social activities including work</i>	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.

^aThe dimensions of social health was proposed by Huber and colleagues¹² and the operationalization for dementia by Dröes and colleagues.²⁷

framework is being used as a tool in clinical practice to visualize and discuss the need for psychosocial support on an individual level. The concepts of the ICF-model in large part encompass the concepts described in the model of social health.

For SMI, the recovery model of mental health underpins health care policy (Meehan, King, Beavis, & Robinson, 2008; Pincus et al., 2016). Not to be confused with restoration of (body) functions or structures, recovery in this model rather describes an individual process of learning to adapt to the illness and its consequences in order to live a satisfying life over which one has control; 'learning to live better in the face of mental illness' (Anthony, 1993; Dröes & Plooy, 2010; Whitley & Drake, 2010). The recovery model also distinguishes several aspects of this process, which roughly translate to the dimensions of social health. For example, functional recovery involves the ability to participate effectively and successfully in aspects of everyday life and in society (such as employment, housing, and education)¹⁵ and recovery of daily functioning refers to the preferred daily routines and caring for oneself and others.¹⁶ Social recovery involves establishing and maintaining rewarding relations with family, friends, peers, and significant others and engaging in rewarding social activity (for example, sports), actual and felt community integration, and active citizenship¹⁵. Furthermore, the capacity to maintain identity or personhood as part of social health and the influence of factors such as life values, sense of coherence, self-efficacy and resilience (Dröes et al., 2017), reflects the aspect of personal recovery, referring to such factors as psychological processes with an emphasis on regaining hope, courage and self-esteem and control over one's own life (Leamy, Bird, Boutillier, Williams, & Slade, 2011).

What these care models have in common is that the underlying diagnosis or pathology is subordinate in determining the care and support provided: it is about peoples' needs, wishes and goals and how to overcome the consequences of a condition in order to meet them. In all of the fields, focus shifted from a biomedical paradigm of reducing symptoms to a biopsychosocial paradigm including emphasis on adapting to the consequences of a condition. Accordingly, not the illness but the person is central and capabilities are emphasized rather than disabilities. The concept of social health translates to these different care models and therefore provides a common language, which facilitates collaboration across fields.

Combining our efforts for common goals

Overcoming common barriers

With a common language, the framework of social health facilitates joint efforts in optimization and innovation of psychosocial interventions for people with cognitive deficits. One strategy could be collaborating on overcoming barriers that are experienced in each of the fields for a certain intervention, and using each other's knowledge on barriers and facilitators for the efficacy or implementation of interventions. For example, the literature on psycho-education reports patients' and family members' dissatisfaction with the information provided, difficulties with implementation, and the lack of effective strategies for the engagement and retention for dementia as well as for ABI and

SMI (Lyman et al., 2014; Sterk, Winter van Rossum, Muis, & de Haan, 2012; Hare, Rogers, Lester, McManus, & Mant, 2006; Murray, Young, & Forster, 2007; Wang et al., 2015). Psycho-education may not seem the obvious choice when thinking about collaborating across fields, but in addition to information provision about a certain condition, common key elements are education, which refers to providing insight in for example the impact of executive dysfunction to the individuals' daily life tasks as well as teaching coping strategies, and support, referring to facilitation of the emotional adjustment of the patient and their family (Lafosse, 2016; Zhao, Sampson, Xia, & Jayaram, 2015; Bunn et al., 2012). Common directions are internet-based psycho-educational programs (Jackson, Roberts, Wu, Ford, & Doyle, 2016; Andersson, Cuijpers, Carlbring, Riper, & Hedman, 2014). Very similar programs have been developed for caregivers of dementia and ABI separately (Boots, de Vugt, Kempen, & Verhey, 2016; Cox, 2016), while a program consisting of modules that can be adjusted to population-specific information if necessary would be less costly. In relation to social health, understanding one's condition and especially the consequences and impact on daily life tasks is essential to be able to adapt and self-manage, which stresses the importance to collaboratively overcome current barriers.

Adopting interventions

Another way of combining our efforts is by using the expertise on interventions that have been developed in a certain field, for example by adjusting key elements of interventions that have shown to be effective in a one population for use in other populations. A successful example is provided by Twamley and colleagues, who developed a training that involves teaching compensational strategies and habit learning for SMI which they subsequently adapted for use in TBI, showing positive results for both populations (Twamley, Vella, Burton, Heaton, & Jeste, 2012, 2014). In a similar vein, interventions for caregivers of people with dementia could be adjusted to fulfil the unmet needs for support in caregivers of people with ABI or SMI (Wynaden & Orb, 2005; Kuipers, 2010; Camak, 2015; Visser-Meily et al., 2008; Yesufu-Udechuku et al., 2015; Saunders, 2003). It seems safe to assume that if multicomponent, individualized interventions are most successful in decreasing burden and improving mood and quality of life in dementia caregivers (Laver et al., 2016; Olazaran et al., 2010), these elements are also important for caregivers in other populations. Going beyond the aim of psycho-education to help people cope with their condition, self-management programs aim to support people to participate as partners with health care providers by increasing their feelings of self-efficacy (Holman & Lorig, 2004; Taylor et al., 2014). Randomized controlled trials of self-management programs in dementia are scarce (Taylor et al., 2014; Martin et al., 2015; Quinn et al., 2016) and ABI and SMI could provide expertise (Fryer et al., 2015; Siantz & Aranda, 2014; Warner et al., 2015; Zou et al., 2013; Taylor et al., 2014), such as including the involvement of peers in the program, enabling participants to witness their capability of empowering themselves (Sterling et al., 2010; Lorig et al., 2014; Siantz & Aranda, 2014; Cook et al., 2012), the

involvement of informal caregivers, as feeling emotionally and socially supported increases self-efficacy (Warner et al., 2015; Murray et al., 2003; Reed et al., 2012; Nordén et al., 2012), and the integration of physical and mental health in the program (Lorig et al., 2014; Druss et al., 2010).

Developing interventions

Working together on new interventions could potentially benefit social health in people with cognitive deficits. An example here could be acceptance and commitment therapy (ACT), a relatively new form of psychotherapy which is transdiagnostic by design (Hayes et al., 1999). The example of ACT also shows the interplay between the different dimensions of health: learning to accept negative thoughts and feelings (Graham et al., 2016; Kangas & McDonald, 2011) is most closely related to psychological health, while the focus on learning to re-engage in behaviors that facilitate living a valued and purposeful life (Graham et al., 2016; Kangas & McDonald, 2011) relates more to social health. With an emphasis on pursuing goals that are valuable to a person without necessarily changing negative thoughts and feelings, ACT, in line with the concept of social health, relates more to health than to illness (Hayes et al., 1999). As cognitive behavioral therapy (CBT) attempts to change certain negative or unhelpful thoughts or beliefs, which in long-term conditions may actually be realistic at certain times, focusing on reducing the impact of such thoughts on behavior and functioning could be more appropriate for people with long-term conditions (Graham et al., 2016; Kangas & McDonald, 2011). Although a certain level of cognitive awareness and flexibility is required for ACT, ACT may be less cognitive demanding than CBT, which places an additional demand on meta-cognitive processes for challenging and changing unhelpful thought content (Kinney 2001; Kangas & McDonald 2011). On the other hand, ACT requires understanding of more abstract concepts compared to CBT (Losada et al., 2015). Randomized controlled trials for people with cognitive deficits are lacking to date, despite several recent meta-analyses reporting an exponential increase in studies showing positive results for a number of mental and medical health conditions (Öst 2014; A-Tjak et al., 2015; Powers et al., 2009; Ruiz Jiménez 2012). Studies in people with psychosis have shown positive results, although it participants' cognitive impairments were not described (Gaudio & Herbert, 2006; Bach & Hayes, 2002; White et al., 2015). Modifications of ACT for cognitively impaired people with ABI as well for older people have been suggested in the literature (Kangas & McDonald, 2011; Petkus & Wetherell, 2013; Soo et al., 2011) and can potentially be used to create an adaptation of ACT for the application in dementia, ABI and SMI and their caregivers.

Evaluation of interventions

An issue that may warrant joint research as well is the evaluation of interventions aiming to improve social health. Traditional measures are often phrased in such a way that items emphasize impairment rather than health, and therefore do not correspond well with current perspectives and intervention goals. Furthermore, since symptom reduction

is not the primary aim of such interventions, symptom assessment should only be included as secondary measurements. The individualized nature of interventions and the focus on goals that have personal value, make it difficult to capture social health in global measures of functioning or participation. That is, two people functioning optimally according to their capabilities could be functioning on completely different levels, and certain activities or relationships which are meaningful to one person could be of less value to another. Recently a paper was published which identified several potential outcome scales for dementia relating to positive psychology using the constructs of resilience, hope, optimism, autonomy and spirituality, in the literature of traumatic brain injury and chronic illness (Stoner et al., 2015). This study could serve as an example to further explore appropriate constructs and instruments for measuring the efficacy of interventions aimed to maintain or improve social health.

Concluding remarks and recommendations for researchers

This is not the first time a common framework is sought to overcome differences in terminology between fields, as almost twenty years ago the ICF-model provided a unified and standard language for the description of health across disciplines, specifically for incorporating psychosocial factors in decision-making in medical treatment (WHO, 2001). While the ICF-model is used in ABI rehabilitation, it has not been established as a dominant model in dementia care (even though the focus started to shift to psychosocial care around that time), and it could not compete with the upcoming recovery model for SMI which was proposed a decade before (Anthony, 1993). The ICF-model is a classification framework and can be used as a tool in clinical practice, but it does not necessarily inform the development of interventions. In contrast, the concept of social health describes the ultimate goals and guiding principles for psychosocial interventions and thereby provides a framework with not only a common language, but also a guiding vision. It is not our aim to replace the established models, but to promote social health as a concept that can be used as a common perspective and to communicate about psychosocial care to enable collaboration across fields.

The framework as presented here is limited to the broad concepts of participation, engagement, functioning and adaptation as provided by the dimensions of social health. Taking the operationalization for dementia as an example, a next step could be to further operationalize the influencing personal, disease-related, social and physical environment factors as well as targets for interventions, based on experts' and service users' consensus in other fields. We expect a large overlap in personal factors (e.g. self-efficacy, resilience, acceptance of care needs) and social factors (e.g. support from social network, stigma, relationship with professionals), but also in physical environment factors (e.g. assistive technology, financial resources, enabling aspect of the environment) and to some extent even factors that were labelled as disease-related (e.g. disabilities in carrying out activities of daily living, communication difficulties, cognitive ability to attend social activities); and therefore also overlap in the focus of interventions (e.g. promotion

of empowerment, social inclusion, shared decision-making). Comparison of overlap could lead to a rich common framework and comparison of the available and lacking interventions would further direct future (collaborative) research. Furthermore, such an approach would also point out aspects that uniquely contribute to the need for psychosocial support of a particular population, such as psychotic symptoms in schizophrenia, visual field problems after ABI and the deteriorating nature of cognition in dementia. Another issue to consider is that we limited our discussion to cognitive deficits. Cognitive deficits are an important target to adapt to because of their profound impact on daily functioning and are important to take into account when developing interventions because they challenge adaptability. However, a sole focus on cognition would not do justice to the challenges imposed on social health caused by other disease-related aspects, since other (common) aspects such as apathetic or disinhibited behavior, lack of insight into impairments and co-occurring somatic comorbidities influence social health as well.

To foster the use of the suggested strategies for collaboration, some recommendations can be made for researchers involved with the development and evaluation of psychosocial care. In the process of developing an intervention for a certain population, it is recommended that researchers expand their literature search to other populations. Looking for evaluation studies of similar interventions, published study protocols or trial registers, gaps in research or in care, barriers and facilitators, could result in a more elaborate base for the intervention to be developed. Options for collaboration could range from incorporating the insights of such studies or study designs based on the available publication on trial registration, to actively reaching out to other researchers for consultation or even to jointly develop or optimize an intervention. That being said, it is important to recognize the different fields are often separate worlds both in research (i.e. scientific journals, targeted conferences) as in clinical practice, with their own organization of care (i.e. different health systems and service deliveries as well as different health and social care practitioners' scope of practice). For example, for interventions that are developed to be carried out by case managers, it should be taken into account that community outreach is more common for dementia and SMI, but not for ABI (at least in the Netherlands). Furthermore, population specific needs may require complex interventions that sometimes cannot be easily adopted or transferred to another population. Nevertheless, it would be helpful if researchers include the terminology relating to social health in future publications, to facilitate the identification of opportunities for collaboration and for a better understanding of research in different fields.

In conclusion, the concept of social health can serve as a common language and framework, which translates to the leading models of psychosocial care for people with cognitive deficits. As such, it facilitates collaboration between different fields. Collaboration on common directions for new interventions, on overcoming common barriers or gaps for similar interventions, on adjusting key elements of interventions that were successful in other fields and using knowledge of barriers and facilitators for interventions that have been further developed in other

fields as well as joining forces to fill gaps for the evaluation of interventions could drive the care for people with cognitive forward.

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