

#### **REVIEW ARTICLE**

# Promoting dementia-friendly communities to improve the well-being of individuals with and without dementia

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Received: 7 July 2019 Revised: 25 December 2019 Accepted: 9 January 2020 A community is the totality of human relationships, in which individuals live with and for others. This article discusses promoting dementia-friendly community from the perspective of human relationships within a community. Improving the social well-being of aging people is important; it is especially important for people with dementia, as dementia is a life-changing syndrome that affects all aspects of one's life, including human relationships, Dementiafriendly community requires support from the community in improving the social adaptation of people with dementia, as they experience greater difficulties in social interaction as a result of cognitive decline, especially deterioration of social cognition. They need to be empowered to stay motivated for the opportunity to maintain an active and meaningful life, despite dementia. Flexible provisions of such tailored support can be effective to improve the support network in the community to meet the individual's needs. As social and human resources are limited, it is also necessary to discuss how to share socioeconomic burdens to meet both social sustainability demands and the welfare of aging adults. More discussions that include people with dementia and their family members are required to achieve the purpose of dementia-friendly community. This is important to enhance the well-being of individuals with and without dementia, as well as the society as a whole, through dementia support and dementia prevention activities. Geriatr Gerontol Int 2020; 20: 511-519.

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#### Introduction

## Dementia is a life-changing condition that affects human relationships

Dementia, or major neurocognitive disorder, is characterized by substantial impairment in one or more cognitive domains, whereby the impairment interferes with independence in everyday activities. Dementia is a life-changing disease that affects independence in all aspects of one's life, including relationships with family and friends.<sup>2</sup>

#### Promotion of dementia-friendly community

Dementia is one of the major healthcare challenges of the 21st century<sup>3</sup> and promoting a dementia-friendly community (DFC) is a common issue in most aging societies. "Dementia awareness and friendliness" has been emphasized in the World Health Organization guide published in 2018.<sup>4</sup> Alzheimer's Disease International defines DFC as "a place or culture in which people with dementia and their caregivers are empowered, supported and included in society, understand their rights and recognize their full potential." This definition places emphasis not on institutional and physical environments, but on dignity and human relationships. Furthermore, the European Union's Joint Action emphasizes the following concepts: acceptance/ understanding/lack of stigma; inclusion/community-led responsibility; feeling safe and secure; and being respected.<sup>6</sup>

### For a more balanced view of social participation of dementia

The public's focus on the symptoms and disabilities brought about by dementia might have been influenced by efforts to search for causes of and cures for dementia.<sup>7–9</sup> In practice, more consideration has been given to the management of symptoms, rather than the social factors of dementia.<sup>7–9</sup> At present, there is a global movement to shift the focus from these symptoms and disabilities toward the capacity and potential of each person with dementia.4 For social and political promotion, it is important to emphasize a more positive view on living with dementia. However, for medical and psychosocial research and practice with aims to improve the well-being of people living with dementia and their surroundings, it is becoming increasingly important to adopt a balanced perspective. This requires recognition of positive aspects, including preserved functions, as well as negative aspects, such as cognitive deficits that can be progressive in nature. A biased perspective that emphasizes only the positive aspects will not help in solving any social difficulties faced by people with dementia. To innovate effective measures for DFC promotion, the approach should consider people's adaptation difficulties that accompany living with dementia.8 People with dementia both benefit and suffer from social interactions;9 social interaction can cause negative experiences for people living with dementia,8 who have described how interpersonal behavior in social settings can undermine their sense of self.9

Optimizing the social health of people with dementia requires more than providing opportunities for social interactions

As living with dementia is accompanied with a lack of independence and affects all aspects of one's life, those with dementia inevitably require support from others.<sup>2</sup> However, little attention has been given to how dementia influences the social functions of people living with dementia. It is nevertheless apparent that it can become difficult for them to contribute to society and to maintain social relationships.<sup>9</sup> To promote social participation, the impact of cognitive decline on social interaction, and the support required to participate and contribute to the communities should be analyzed.<sup>9</sup>

Need for interventions to support people with cognitive disabilities to maintain their social relationships

In the Identifying Best Practices for Care-dependent Older People by Benchmarking Costs and Outcomes of Community Care Project, researchers examined home care clients in Europe's capacity to complete everyday tasks, including social activities. It was observed that cognitive functions clearly influenced the ability to fulfill various obligations at home and in the community. Furthermore, people with mild-to-moderate cognitive impairment had limited social networks, and mostly interacted only with close relatives and friends. <sup>10</sup> The observation suggested the need for interventions to support people with cognitive disabilities to maintain and enhance their social network and relationships. <sup>7</sup>

The failure to differentiate between dementia and normal aging can cause people to overlook the needs of support for social participation. Without appropriate support, social interaction might cause further maladaptation. People with dementia can encounter various barriers when participating in social networks, and experience a mismatch between demand and supply of social support. Optimizing their social health requires more than simply providing opportunities for social interactions; it is desirable to provide support optimizing their potential and capabilities. This can be achieved through comprehensive assessment of personenvironment fit, person-directed goal setting and interdisciplinary team support to maintain a sense of autonomy and independence.

As seen above, there is an urgent need to create a more balanced view of dementia to enable people and their families to adapt to the changes associated with the disorder, and to continue to live well within their communities. In this article, we discuss DFC from the perspective of human relationships: first, the meaning of social well-being of aging people, including people with dementia, is reviewed; next, the difficulties faced by people with dementia in social interactions are discussed; finally, interventions and environmental arrangements are explained.

#### Social well-being

The World Health Organization defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity," 11 and it is recommended that aging adults improve their social well-being, because it can be modified, whereas their physical and mental health tends to be vulnerable. 12 Aging adults can directly benefit from positive social interactions, 13,14 and reciprocal relationships can significantly enhance their sense of self-worth. 15 A systematic review and correlational meta-analysis reported that factors reflecting relationships and social engagement were associated with better quality of life (QoL) for people with dementia. The study also reported that poor well-being of the caregiver is associated with lower QoL. 16

Furthermore, in their systematic review, O'Rourke *et al.* identified four factors that affect QoL of people with dementia: (i) relationships (together *vs* alone); (ii) agency in life today (purposeful vs. aimless); (iii) wellness perspective (well *vs* ill); and (iv) sense of place (located *vs* unsettled). They emphasize the importance of these factors as potentially modifiable areas where QoL can be improved for those with deteriorating cognitive function.<sup>17</sup>

However, when they experience a decline in their capacity, maintenance of social networks becomes difficult, and at times they even diminish.<sup>18</sup> This is especially true after a diagnosis of dementia.<sup>19</sup> It is therefore desirable to provide appropriate support for people with dementia to ensure social participation.

Operational definition of social health according to the Early, Timely and Quality Psychosocial Interventions in Dementia Social Health Taskforce

As social health is particularly important for aging people, including those with dementia, the pan-European network of researchers collaborating in research on and dissemination of the Early, Timely and Quality Psychosocial Interventions in Dementia (INTERDEM) Social Health Taskforce, proposed an operational definition of social health. The definition was based on the three social health dimensions described by Huber *et al.*: (i) capacity to fulfill one's potential and obligations; (ii) ability to manage life with some degree of independence; and (iii) participation in social activities. These three dimensions appear relevant to the difficulties that people with dementia encounter in everyday life. Therefore, developing insight into the relevant themes within these three dimensions can be beneficial for providing support and care to promote their social health, and optimize care and support systems. The second of the participation of the providing support and care to promote their social health, and optimize care and support systems.

For the first dimension, the INTERDEM Social Health Task-force identified that the capacity to exercise choice and autonomy, to maintain own identity (personhood), to participate and contribute to communities, to give and receive support (reciprocity), to collaborate with professionals and informal carers, and to participate in shared decision-making related to a micro level. The capacity to participate and contribute to communities was identified to be related to a macro level. To fulfill their potential and obligations, developing interventions is required to optimize and promote the preserved capacity of people with dementia.<sup>7</sup>

The second dimension was 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." The operational definition emphasizes self-management and emotional control. In the action phase, autonomy is emphasized, and it is recommended that the person living with dementia be involved in meaningful activities.

The third dimension reconfirms the importance of social ties and relationships. Here, people with dementia might feel insecure participating in maintaining social relationships, owing to difficulties in communication as a consequence of their cognitive ability.<sup>7</sup>

In sum, social participation is based on reciprocal, cobeneficial relationships. People with dementia are expected to fulfill their potential and obligations by reciprocating and participating in community life with the appropriate support. Hence, merely promoting DFC without appropriate support will not be beneficial. Finding innovative ways to provide support for them to continue to participate socially should be addressed seriously. Thus, in this article, difficulties experienced by people with dementia during social interactions are explained briefly to clarify issues in social participation.

#### Disease-related barriers for social participation

#### Decline in social cognition

Dementia affects an individual's independence, owing to cognitive decline that can result in social maladaptation. Given the cognitive decline in people with dementia, the more they require support, the more they tend to become socially maladaptive.

Among the cognitive functions, deterioration of social cognition can lead to social maladaptation. Social cognition is a newly recognized cognitive domain in the *Diagnostic and Statistical Manual of Mental Disorders*, 5th edition;<sup>1</sup> previous diagnostic criteria referred to it as personality change.<sup>21,22</sup> Social cognition broadly refers to the processing of social information in the brain, and social cognitive skills are critical for social communication and interaction.<sup>23</sup> In Alzheimer's disease dementia (ADD), the most common cause of dementia, deterioration of social cognition, is related to problems with managing treatment and behavior, as well as poor interpersonal relationships. Thus, basic social perceptual functioning should be considered when developing interventions.<sup>23</sup>

Diagnostic and Statistical Manual of Mental Disorders, 5th edition exemplifies the theory of mind reasoning, recognition of emotions and insights as social cognition. 1,21 Theory of mind reasoning is the ability to infer the mental states of others, including others' intentions, thoughts and emotions. To ensure smooth social interaction, one might try to infer the mental states of others, predict their actions and respond accordingly. Theory of mind reasoning is utilized through this interaction process. Deterioration of this ability is reported in people with ADD and behavioral variant frontotemporal dementia (bvFTD). 24-26 Regarding recognition of emotions, change in empathy has been discussed; empathy can be broadly defined as the ability to understand what others feel (cognitive empathy) and feel what others feel (affective empathy). Change in empathy is controversial; impairments in cognitive empathy, but not affective empathy, have been reported in people with ADD,<sup>27</sup> whereas even in the prodromal stages of ADD and bvFTD, socially inappropriate behaviors, such as lack of empathy, inappropriate affect and disinhibition are reported.<sup>28</sup>

The concept of mild behavioral impairment (MBI) has also been proposed: MBI defines a late life syndrome with prominent psychiatric and related behavioral symptoms in the absence of major cognitive symptoms during a transitional state between normal aging and dementia.<sup>29</sup> MBI has been proposed as a diagnostic construct to identify patients with an increased risk of developing dementia. The behavioral changes are divided into the five MBI domains: (i) decreased motivation; (ii) emotional dysregulation; (iii) impulse dyscontrol; (iv) social inappropriateness; and (v) abnormal perception or thought content. 30,31 In the concept of MBI, deterioration of social appropriateness is regarded as one of the domains to identify the risks of developing dementia. As stated above, difficulties in social interaction might begin in the early or even prodromal stages of dementia; thus, appropriate support based on understanding social cognitive decline is required to continue meaningful social interaction.

Regarding insights, deterioration of self-monitoring and self-control abilities are recognized as typical symptoms of ADD and bvFTD, <sup>32–38</sup> with lack of self-control also being observed even in prodromal ADD and bvFTD. <sup>28</sup> In addition, deterioration of the self-monitoring ability can be the main cause of miscommunication and caregiver burden, even in mild cognitive impairment (Fig. 1). <sup>39,40</sup>

In social communication, it is desirable to infer others' thoughts and feelings, predict their actions, respond accordingly, monitor one's own behaviors and others' reactions, and manage

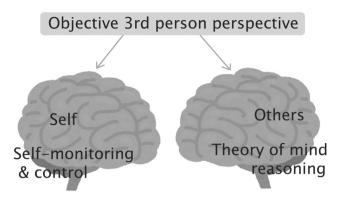


Figure 1 Inference of others' thoughts and self-monitoring. Inference of others' thoughts (theory of mind reasoning) is hypothesized to be subdivided into three distinct components: (i) representation of reality; (ii) belief inference of others from others' perspective; (iii) and self-perspective inhibition. In contrast, in objective self-monitoring and self-reflection, others' perspective needs to be considered, inhibiting selfperspective. Thus, taking an objective third-person perspective and inhibiting self-perspective can be the common factor between inference of others' thoughts (theory of mind reasoning) and reflecting and monitoring oneself. Both inferring others' mental states and reflecting and monitoring oneself play important roles in maintaining social relationships, which become difficult for people with dementia. When assessing the individual's social functioning, it could be effective to evaluate whether one has difficulties in taking an objective third-person perspective and inhibiting self-perspective. By understanding that taking the first-person perspective is due to a decline in social cognition, the misunderstanding of selfishness might be avoided.

one's behavior for mutual understanding.<sup>7</sup> In dementia, it might become difficult to infer others' thoughts and feelings as a result of declining theory of mind reasoning.<sup>24–26</sup> Consequently, it becomes difficult to predict others' reactions and respond accordingly because of the deterioration of thinking abilities. Monitoring and managing one's own behaviors also becomes difficult, owing to the deterioration of self-monitoring and self-control abilities.<sup>32–38</sup>

Although people with dementia experience social maladaptation, it becomes difficult for them to self-reflect and resolve conflicts. It might also become difficult for them to understand the consequences of their actions, even when they cause some trouble. However, they do feel a vague sense of maladaptation, which could induce anxiety. Therefore, social adaptation of persons with dementia could further be compromised because of increased anxiety.

People with dementia often tend to dissociate from others, this is often attributed to changes in personality or loss of motivation, whereas decline in social cognition might be overlooked. <sup>42</sup> Basic social functioning should be considered when assessing the background of changes of behavior in dementia. <sup>23</sup>

#### Social reserve

To overcome the decline in social cognition, the concept of social reserve has been proposed.<sup>43</sup> Social reserve is regarded as one domain of cognitive reserve, which refers to the discrepancy between the degree of brain damage and the severity of cognitive decline.<sup>44</sup> In dementia, cognitive reserve is also referred to as resil-

ience, which is defined as cognitive functioning at a level higher than that expected after a brain injury.<sup>45</sup>

The level of social cognition decline differs in individuals, and the severity of dementia does not always explain clinical manifestations. Social reserve is utilized as a term explaining certain underlying compensatory mechanisms that allow some people to manage the difficulties associated with dementia. Based on clinical experience, social cognition varies greatly among individuals compared with other cognitive functions, such as memory. For example, some individuals show a high degree of social adaptation until the advanced stages of dementia.

Studies have suggested interventions to improve cognitive reserve. 46,47 However, a better understanding of the biological mechanisms of cognitive reserve or resilience, which remains poorly understood, is required to help develop effective preventive and treatment strategies. 48 Furthermore, it is necessary to devise effective support to improve social reserve, as support to increase social reserve can be one of the key factors to enhance social wellbeing. In some cases, social function could be spared through compensation, which might involve using memories of life experiences. For others, the motivation to maintain interactive relationships could contribute to the retention of social function. 49,50 Generally, support starts with one's own motivation to achieve a goal, and motivation is important for engagement in the intervention. 51,52

Although it is important to think about how to intervene, it is also important to accept the decline in social cognition of a person with dementia who has difficulty with social adaptation. It is necessary to promote the understanding that social maladjustment can be caused by cognitive decline, which can be difficult to overcome on their own.

#### Intervention for social participation

Empowerment support for self-help attitudes

In the position paper of INTERDEM, autonomy and self-management, including emotional control, is emphasized.<sup>7</sup> It is important for people with dementia to have the opportunity to maintain an active and meaningful life despite the disease.<sup>53</sup> Empowerment support is desirable in maintaining such motivation to design their own lives even after developing dementia.<sup>49</sup>

The early stages, during which the abilities of inferring others' feelings and thoughts, self-monitoring, and self-control are preserved, are critical to improving social adaptation. There is controversy in the early diagnosis of dementia, as there is no cure for many causative diseases of dementia. This means that early intervention does not always result in recovery.<sup>54</sup> However, if a person with dementia is willing to maintain their social relationships, it is worthwhile to address the condition at an early stage;<sup>49</sup> Alzheimer's Disease International states that one of the benefits of early diagnosis is providing an opportunity for the person to explain their condition to their family, friends and colleagues. 55,56 Here, it should be noted that although the majority of people with dementia are in favor of open disclosure, 57 receiving a diagnosis of dementia is associated with negative emotions, such as shock, fear and sorrow.  $^{\rm 58-61}$  Thus, mental support when receiving a diagnosis is important; for example, the importance of physicians offering hope is also emphasized.<sup>62</sup> People with dementia are required to re-establish human relationships, which continue to be affected by the condition over time. Even after diagnosis, it is recommended that they take initiatives to rebuild relationships with others and expand the circle of support by themselves. 42,56,63 It requires courage to accept one's own cognitive decline and to seek support; therefore, adequate support should be provided to empower people with dementia.<sup>49</sup>

#### Self-management intervention

Self-management interventions are increasingly offered to people with chronic health conditions. A study has examined the applicability of such an approach for people with early stage dementia. Self-management programs, which encourage people with dementia to learn to manage their conditions and optimize their own well-being, have likewise been proposed. These programs aim to enhance self-regulation, a sense of self-efficacy and problemsolving skills by focusing on the relevant aspects of daily living.

Support programs for people with dementia and their caregivers are also proposed. For example, the Meeting Centers Support Program was developed in collaboration with people living with dementia and their caregivers. The program provides opportunities to promote social participation in local community centers. In the program, people with dementia and their carers are required to cope with adaptive tasks; for example, dealing with disabilities, retaining social relationships, and maintaining an emotional balance and positive self-image. The program aims to help people deal with the changes dementia brings to their life and to support them in living well. People living with dementia and their caregivers are expected to re-establish the relationships that have been affected by dementia during the developing process of Meeting Centers Support Program. <sup>70–73</sup>

#### Self-prevention of behavioral and psychological symptoms of dementia in the early stages of dementia

As recommended in the position paper of INTERDEM, emotional control is also important in the early stages of dementia. The current guidelines for the management of behavioral and psychological symptoms of dementia, such as disturbed emotions, mood, perception, thought, motor activity and altered personality traits, recommend non-pharmacological interventions as first-line treatment, as severe side effects might result from pharmacological interventions. T4,75 Empowerment support for emotional control is one example of a non-pharmacological approach for treatment in the early stages of dementia.

It is desirable to acquire emotional management strategies and make them habits of their own. Within the authors' review of previous research, there has been no study of anger management in people with dementia, but a previous study reported the efficacy of an intervention to improve anger control in people with intellectual disabilities. Thus, anger management intervention can possibly be applied to people with dementia in early stages. Behavioral and psychological symptoms of dementia can lead to miscommunication with family members and increase caregiver burden. These motional control strategies in the early stages to maintain good communication with others.

#### Support in advanced stages

While the ability of self-reflection is preserved, support should be provided to enhance their self-management ability to be more resilient. However, in advanced stages, a person with dementia might find it difficult to self-reflect and remain motivated to change their behaviors. <sup>81</sup> In such cases, people around them should provide special consideration so that maladaptive behaviors do not become apparent. <sup>81</sup>

Ideally, support is devised in an individualized tailor-made manner.<sup>81</sup> In addition to the customized approach for each person with dementia, it is also important to communicate with those

involved in order to better understand the specific difficulties each person with dementia faces. In the event that the person with dementia is unable to deal with these difficulties by him/herself, the people involved might be required to provide special consideration for them. 82

Communication difficulties for people with dementia can particularly cause relationship stress, even for the family and professional carers. A systematic review evaluated the effectiveness and acceptability of training interventions with communication, and reported that the interventions were beneficial to improve carer knowledge and communication skills, but not caregiver burden. For the promotion of social participation of people with dementia, further practice and research are required to devise more effective interventions. §3,84

#### **Environmental arrangements**

Raising awareness: Dementia supporters and dementia friends
The provision of a social environment can be effective in promoting DFC. In particular, social capital has been defined as the resources available to individuals and groups through membership in social networks.<sup>85</sup> It is reported that people can continue to live in communities with high social capital, even after they experience cognitive decline.<sup>86</sup>

In Japan, a national campaign of "Dementia Supporter Caravan" was launched in 2005 with the purpose of raising awareness of dementia, and to train various groups and individuals in their personal or professional capacities to best support people with dementia and caregivers to live well in their community.<sup>87</sup> As of March 2019, >11 million supporters are active in communities, schools and industries.<sup>87–89</sup> The movement has expanded to other countries including the USA, Canada, Germany, Taiwan and Thailand, while in the UK, "Dementia Friends," which was launched in 2013, is now a rapidly growing movement.<sup>87–90</sup>

#### Informal support

Informal support is desirable to match individuals' needs in daily living and support; the support to continue community life as it was before the onset of dementia, rather than doing anything special. This involves continuing being friends with the person with dementia, not leaving them after the onset, and supporting those who are living alone. However, it is sometimes difficult to maintain relationships with people with dementia in the same way as before, even after the onset. Thus, changes in relationships can lead to isolation, withdrawal and depression. Furthermore, lone-liness might be a risk factor of developing dementia 1-94 and the progression of dementia. The purpose of learning about dementia should not be to increase one's knowledge of the disorder to manage the symptoms, but to understand the needs of each person with dementia and devise the support to meet such needs.

Sharing the burden of care from the perspective of the society as a whole

From the perspective of society, more discussions on how to share the socioeconomic burden by various stakeholders to promote DFC are required. Social and human resources are limited, and need to be shared with other requirements, including support for others. There is a need for more open discussions, including people with dementia and informal carers, such as family members. Dementia is part of the society's diversity. The well-being of the society can be improved by balancing these diverse aspects. At the same time, practical discussions about issues of cost, including manpower, to ensure sustainable support can be provided.

#### Possibility of peer support among people with dementia

Peer support group

Although peer support for caregivers has long been implemented, the practice and verification of peer support for people with dementia has only just begun. A previous review reported that participating in peer support groups might bring about psychological benefits to people with dementia by reducing depression, and improving QoL and self-esteem; however, the review commented that no conclusion was delivered, owing to the small sample size and heterogeneous characteristics. <sup>97</sup> Furthermore, qualitative studies have reported subjective benefits for participants, but quantitative evidence is lacking. <sup>98</sup> Further research is required to conclude the efficacy of such methods.

When considering the function of peer support among people with dementia, it is important to consider two issues. The first is that dementia is a progressive disorder. The difficulties experienced in the early stages are different from those experienced in the advanced stages, and there are large individual differences, especially in the early stages. Thus, remarks of those in the earlier stages do not necessarily represent the whole of dementia. The second issue is that because of the decline of cognitive function, it might be difficult for people with dementia to acquire skills in order to support others, even though it is preferable for the supporter to receive training about the disorder, interpersonal communication and so on. 99 Skills to resolve issues and conflicts might also be required. Furthermore, it might become difficult for them to facilitate and manage the meetings and build constructive consensus. It might be necessary to reconsider the aim of peer support groups and determine the extent that peer support can contribute to mitigating symptoms. The authors consider that the essence of group meetings among people with dementia is to share the experiences of living with dementia, which can only be shared among those living with dementia. Furthermore, the peer support groups have the purpose of asserting rights in society. The Japan Dementia Working Group aims "to represent the voices of people with dementia throughout Japan" and "to make proposals to and monitor measures and policies that affect people with dementia."96 To accomplish this significant mission and represent the voices of people living with dementia, it is desirable to formulate and provide effective support.

#### Dementia café

Dementia café aims to provide a social setting where people with dementia and their caregivers can meet others in a similar situation and feel supported and encouraged. <sup>100</sup> In Japan, various people including healthcare/medical professionals, local government staff, volunteers (including Dementia Supporters), students, and people with dementia and their family members participate in dementia cafés. Dementia cafés could be a suitable social setting to meet the needs of people with dementia and provide support, wherein healthcare/medical professionals can act as coordinators.

#### Support to engage in socioeconomic activities

In everyday situations, such as neighborliness, the tailor-made individualized situation can be set according to the requirements of each person with dementia, while they are required to meet predefined requirements and participate in socioeconomic activities.

The European Union's Joint Action on Dementia emphasizes the importance of opportunities for people with dementia to "participate in and contribute to mainstream community life" (i.e. not just in the separate, specialized activities). Although people with dementia are a heterogeneous group with a wide range of capacities,

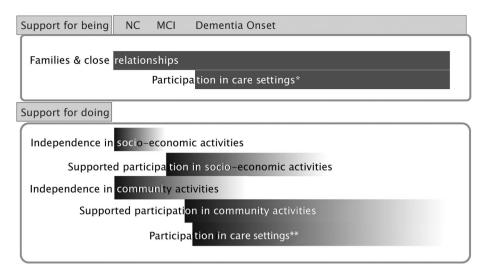


Figure 2 Styles of social participation according to the stages. Accepting the person with dementia in his or her current state: Support begins by accepting the person with dementia in his or her current state, as persons with dementia need to be accepted unconditionally, including any declines and deficits. They experience loss of prior functional capacity; in that they could once recognize their social selves through specific abilities and achievements, but are now confronted with being dependent. Furthermore, they might feel anxious about losing these abilities and consequently could lose motivation in everyday living. Such anxiety and reduced motivation might affect the manifestation of cognitive functions. Thus, feeling accepted by others in this new reality is necessary. This acceptance is often assumed to be important in advanced dementia, but such acceptance is essential during the early stages, as this is when the person with dementia most clearly recognizes the deterioration. Even if one makes a mistake, it is critical not to evaluate the related behavior, but instead to accept the person's value regardless of the attempt's success or failure. Furthermore, persons with dementia are inevitably confronted with their weaknesses, which they might want to hide from others. However, they need to expose their weaknesses to others in order to ask for support. Thus, providing an absolute sense of security is desirable. Communication should be based on a profound confidential relationship, and the purpose of communication can be to confirm this mutual co-beneficial relationship. Care settings basically aim to provide support to respect as one is. Furthermore, it is desirable to provide support and to respect an individual as they are in the community setting. Social participation with some specific roles: in everyday life situations in families and the community, a tailor-made, individualized situation can be set according to each person with dementia, whereas participation in socioeconomic activities requires one to meet predefined requirements. Also, in order to join in some activities with specific roles, it is sometimes necessary that one meets the requirements to carry out the roles. Care settings aim to provide support to respect individuals as they are (\*), while it might also be required to provide support to enhance function and/or to arrange the environment to participate in socioeconomic activities (\*\*). Even when it becomes difficult to participate in socially proactive activities, certain groups or organizations, such as day-care services, can provide such opportunities. In Japan, many day-care services try to provide opportunities for social interaction in the community rather than to provide care that isolates people with dementia from their community lives. Through day-care programs, people in advanced stages of dementia have opportunities to participate in and contribute to community activities. MCI, mild cognitive impairment; NC, normal cognition.

styles of social participation might be changed according to the capacities in the community. One of the most basic and essential needs is support to engage in socioeconomic activities; with adequate support, people with dementia might go shopping, do banking and use public transportation (Fig. 2). Thus, Dementia Supporter and Dementia Friend programs are being carried out to improve the understanding of dementia among staff members in organizations, such as retail shops, banks, public transportation and public facilities, to support the daily socioeconomic activities of people with dementia. Such small actions make the community more dementia-friendly and provide support to people with dementia to carry out everyday life activities. <sup>101</sup>

This is not only task-shifting, which aims to meet the shortage of medical/healthcare professionals and to train volunteers to support people with dementia, <sup>102</sup> but also provides support for people with dementia to participate in socioeconomic activities to explore new values that meet the needs of a super aging society. <sup>103</sup> In order not to exclude people with dementia from socioeconomic activities, more discussion is required to understand ways to protect their rights and ensure access to activities. <sup>104</sup>

### Promoting community inclusion through dementia prevention

Primary prevention of dementia has been promoted through a multidomain intervention of lifestyle management. In Japan, community-based dementia prevention is being promoted through interventions of lifestyle modification. It is suggested that lifestyle management might reduce the risk of dementia, although complete dementia prevention is not possible. It has been pointed out that a false understanding exists that dementia can be prevented by lifestyle practices, leading to eliminating the disorder, and developing dementia is a result of one's own actions. Here, prevention of progression in the tertiary prevention <sup>12</sup> as well as primary prevention of developing dementia, should be promoted in accordance with awareness raising of dementia, which might lead to promoting social inclusion of dementia.

#### Limitation

Innovative practices promoting DFC are reported, but research evidence on their effectiveness is lacking. Thus, it should be

effective to provide consensus-based concepts of DFC, as well as insight into practices and the effectiveness of interventions, such as the position paper of INTERDEM.<sup>7</sup> Furthermore, there is a lack of standardized measures of social health and social wellbeing. Improved measures of social health can contribute to deepening the discussion about how people with dementia can live better lives.<sup>9</sup>

#### Conclusions

DFC is based on human relationships in the community. Its purpose is to create a sustainable society and improve the well-being of the community as a whole. Dementia essentially affects the independence and social adaptation of people. It is worthwhile to proactively support people with dementia and collaborate with them to improve the well-being of the community; thus, discussions including people with dementia and their carers should be encouraged. Through in-depth discussion considering both the positive and negative aspects, it can be expected that a society, including socially vulnerable people, can be a rich society and effectively improve the well-being of the whole society.

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The authors declare no conflict of interest.

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