

Proposal for the empowerment of interdependent self-management support for people with dementia

Yohko Maki

Abstract

The concept of 'living well' varies among individuals, and such diversity should be valued. However, maintaining co-beneficial relationships is critical for all the persons with dementia to live well with dementia, since dementia gradually affects independence in daily living. From practical experience, there can be at least five key factors that help preserve social function: 1) focusing on individuals' preserved functions and strengths rather than their deficits; 2) providing shared decision making; 3) ensuring their initiative in decision making; 4) working towards autonomous interdependence, and 5) maintaining reciprocal, beneficial, and grateful relationships. This manuscript proposes a method of self-management support called 'Self-Management of Autonomous Interdependent Life Empowerment' (SMILE). The goals of SMILE are: 1) to strengthen reciprocal relationships in people with dementia; 2) to make people with dementia feel needed, and 3) help people with dementia sense their own existence in their relationships.

Key words

dementia, self-management, autonomy, interdependence, shared decision making, gratitude

Introduction

'Living well' is prioritised as a goal of dementia support. Well-being depends on the individual, and such diversity should be valued. However, a common characteristic of dementia is the gradual deprivation of independence. Therefore, people with dementia need support and inevitably live interdependently with others from the early stages of the disease. Unfortunately, although the deterioration of independence causes people with dementia to need others' support and assistance increasingly as the disease progresses, a decline in social function, which affects interaction with others, is one of the typical symptoms of dementia. The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, published by the American Psychiatric Association and revised in May 2013, mentions *social cognition* as one of

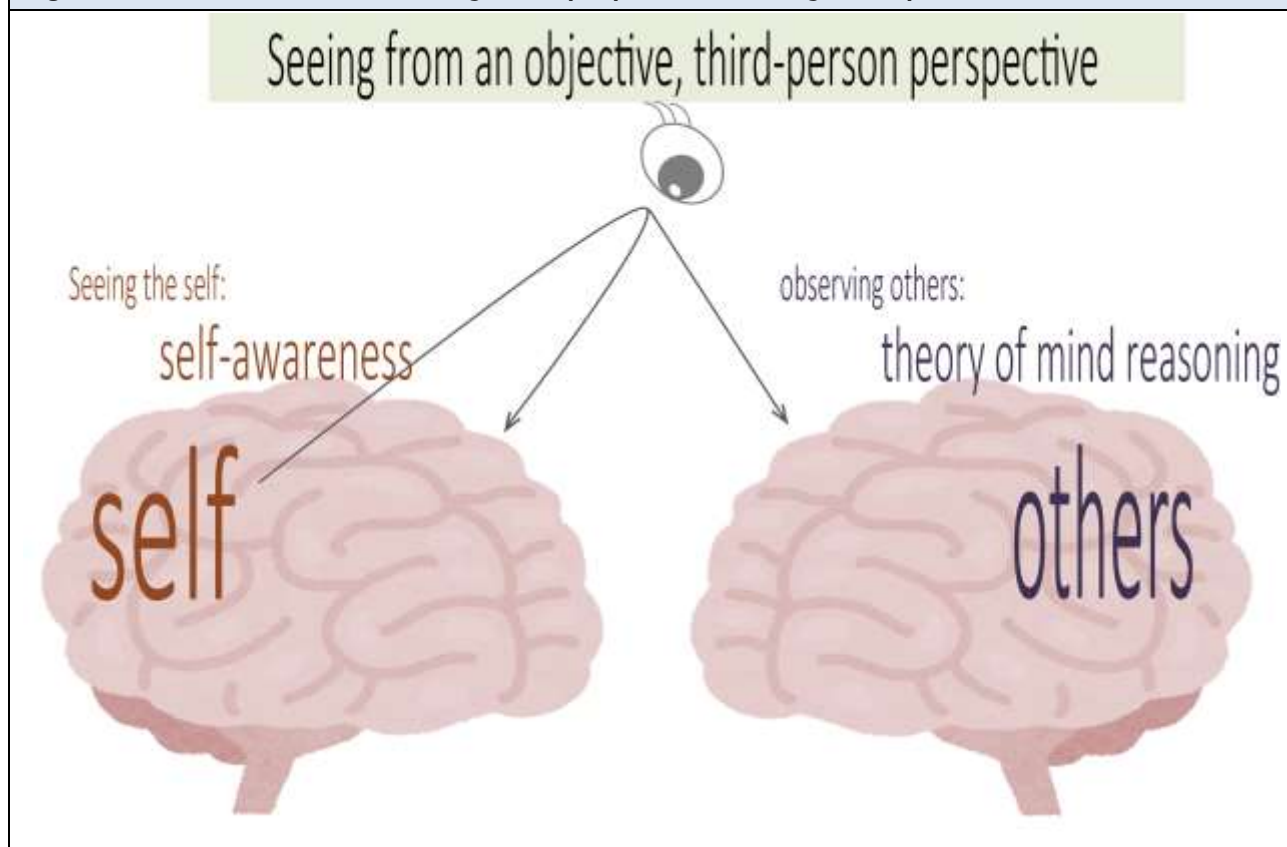
six independent cognitive domains in the diagnostic criteria for major neurocognitive disorder (previously *dementia*), alongside learning and memory, language, executive function, complex attention, and perceptual-motor function.¹

Social cognition refers to cognitive function involving *knowing oneself and others*. The ability to *know others* is explained by theory of mind, a cognitive skill that considers the mental states of others (monitoring) and uses this information to predict behaviour (control).^{2,3} Inferring others' thoughts and feelings, predicting their actions, and responding accordingly are important components of smooth social interaction. Theory of mind declines in Alzheimer's disease dementia (ADD), as shown in previous meta-analyses.^{4,5} With respect to *knowing oneself*, self-recognition and self-monitoring begin to deteriorate from the early stages of ADD, and it becomes difficult for people with the disease to assess their cognitive deficits objectively and appropriately monitor their own behaviour (i.e. anosognosia).⁶ Inferring mental states, predicting behaviour, and reflecting on and monitoring oneself are important abilities in maintaining good relationships with others in society (Fig 1).

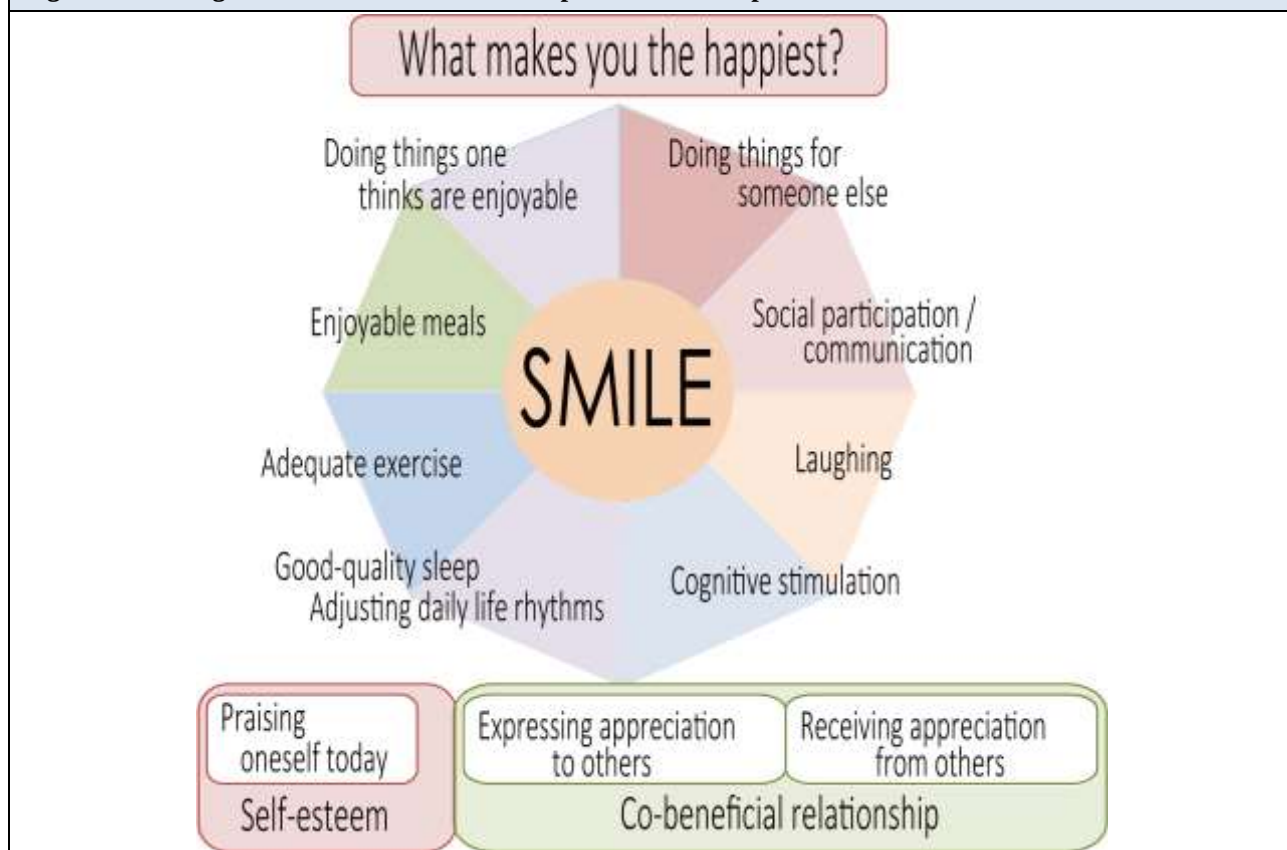
The decline of other cognitive functions also manifests as social difficulties. For example, one of the most common disorders associated with ADD involves the memory and manifests as an inability to recall promises, future appointments, and previous conversations. This deficit creates difficulties in individuals' social lives.

As mentioned above, people with dementia gradually lose their independence since their social function deteriorates as the disease progresses, thus, support from others is inevitable. Support to spare social cognition and/or enhance compensation for the decline of social function is fundamental for people with dementia to live well interdependently with others.

In this manuscript, *society* is considered as the totality of an individual's relationships with others, including family members and caregivers. Therefore, even in cases in which individuals' independence is deteriorated, they continue to retain some type of relationship with *society* until the terminal stage of the disease.

Fig 1. The relation between *mental recognition of self* and *mental recognition of others*

Taking an objective third-person perspective is the common factor between self-awareness and theory of mind reasoning. Seeing the self from an objective, third-party perspective is *self-awareness*, and observing others is the *theory of mind reasoning*

Fig 2. Self-Management of autonomous Interdependent Life Empowerment

Social reserve

The concept of *social reserve* was proposed recently.⁷ Within the concept of *cognitive reserve*, which refers to the ability to overcome cerebral atrophy and decreased cognitive function, a hypothesis defines reserves of social cognition as *social reserves*.⁷ Based on the author's practical experience, there are considerable individual differences in the decline of social cognition. Some individuals display a high degree of social adaptation until the advanced stages of dementia. In some cases, social function can be spared through compensation, which may involve the use of memories of life experiences. Moreover, in other cases, the motivation to maintain interactive relationships with others could contribute to the retention of social function. Therefore, support that increases an individual's social reserves is one of the key factors in living well with dementia in social interactions.

Based on the author's practical experience, there are at least five key factors in the preservation of social function:

- 1) Focusing on individuals' spared function and strengths rather than their deficits
- 2) Shared decision making
- 3) Ensuring that people with dementia take the initiative in decision making,
- 4) Autonomous interdependence
- 5) Maintaining reciprocal-beneficial and grateful relationships

Focusing on individuals' spared function and strengths rather than their deficits

Conventional support considers areas in which people with dementia experience difficulties, such as maladaptive behaviour, and focuses on techniques to manage these symptoms. This perspective is a *medical concept* emphasizing deficits, rather than the whole person, with the goal of regaining a *normal state*. However, there is no cure for dementia, and the disease is progressive in nature; therefore, people with dementia inevitably continue to live with declining functions, which makes it impossible to regain a *normal state*. In contrast, the *care concept* should focus on the whole *person*, who lives autonomously with dementia. Also, support should focus on individuals' strengths and residual function rather than their deficits. This is the fundamental concept of the International Classification of Functioning, Disability and Participation.⁸ Furthermore, regaining a *normal state* is not always a goal in medical care. In 1986, the Ottawa Charter of the World Health Organization stated that 'Health is seen as a resource for everyday life, not the objective of living'.⁹ In addition, rather than living each day only to overcome deficits, it is desirable that people with dementia live each day with a purpose, and support may be required to utilize their strength and prevent *being with dementia* from becoming a hindrance to meaningful daily life.

Shared decision making

Because of their declining cognitive function, people with dementia need support in decision making. In addition, their lives involve continuous collaboration with others, as they need increasing support as the disease progresses. Therefore, decision making by those with dementia is inevitably shared decision making in collaboration with others.

Conventional thinking tends to focus on the debate of *how to provide care*; consequently, it considers people with dementia as passive *care recipients*. However, the focus on areas such as end-of-life care has recently shifted to the importance of supporting the decision-making process for people with dementia. Decision making is no longer restricted to choices as to how medical treatment and care should be provided. Rather, action and behaviour are related to individuals' free choices; therefore, daily life involves a continuous string of decisions. As long as people with dementia are alive, decision making in everyday life remains an important activity.

It is desirable for people with dementia to take the initiative, and their free choice should be respected to the maximum extent possible. Support provided during daily life should assist individuals in forming the best possible social relationships and making decisions that increase social interaction to maintain social reserve.

This support requires cognitive empathy. Empathy has both affective and cognitive aspects, and cognitive empathy involves the ability to analyse and consider the contextual factors behind people's actions¹⁰; in cases involving support for people with dementia, the factors underlying behaviour, including the decline of cognitive function, and environmental and individual factors, should be considered. Although the ability to express thoughts in words declines as dementia progresses, people with the disease can still delineate their thoughts, convince themselves, and make their own decisions with appropriate support involving cognitive empathy.

People with dementia taking the initiative in decision making

It is desirable for people with dementia to take the initiative in shared decision making; however, support should be provided to ensure that their words are heard, that the factors underlying their words are comprehended, their intentions are understood, and sufficient meaning is attached to their words when they are unable to organize vague ideas sufficiently.

It is particularly important to attach positive meaning to these words. Thoughts have both good and bad aspects. However, even if people with dementia reveal socially deviant thinking, it is desirable to wait and provide support until they notice this and change their minds, rather than managing or restricting their behaviour. Other than maintaining confidential relationships, there are no techniques via which this can be achieved. Even when people with dementia present a danger to themselves or

others, it is necessary for them to change their minds themselves, and managing or restricting their behaviour may not produce favourable results. Therefore, confidential relationships are of greater importance to the maintenance of communication.

Autonomous interdependence

As mentioned above, it is desirable for people with dementia to make their own decisions with appropriate support, while all activities in everyday life involve collaboration with others as the disease progresses. Therefore, self-management (i.e. living according to one's own decisions) in dementia should be supported from disease onset, with the aim of ensuring interdependence rather than independence.

Individuals' lives always involve interdependent relationships with others, even if they are able to live independently, because it is impossible to live a life that is wholly free of providing and receiving help from others. Therefore, given that dementia onset leads to the deterioration of independence, interdependence becomes increasingly important.

The critical factor in relationships with others is autonomy (i.e. self-determination) rather than independence. Therefore, *autonomous interdependence* is important. As dementia leads to the deterioration of independence, even if self-management that aimed to ensure independence were possible, this self-management would be limited to only the earliest stages of the disease; eventually, the independence would become impossible.^{11,12} In dementia, the provision of support for *interdependence* is important from disease onset, to enable people with dementia to achieve what they are capable of achieving and receive assistance from others in accomplishing actions that cannot be achieved alone, to allow them to enjoy life. Therefore, living well with dementia is accomplished by maintaining interdependent relationships.

Maintaining reciprocal-beneficial and grateful relationships

As fundamental dysfunction in dementia involves difficulties in social relationships and interactivity, interdependency, and co-beneficial relationship-based care should be emphasized.¹³ Therefore, support should be designed to re-establish social relationships rather than improve cognitive function. As dementia is a life-changing disease, and relationships with others inevitably change, gratitude and appreciation for support could connect people with dementia to others. Relationships with others are based on the reciprocal exchange of support, but people with dementia inevitably receive increasing support as the disease progresses. However, until just before they fall into a coma, people with ADD retain the ability to smile at others¹⁴; therefore, they could remain able to express their gratitude and appreciation to others in the advanced stages. The receipt of gratitude and appreciation is regarded as a social reward¹⁵; therefore, for those with dementia, the exchange of appreciation and

gratitude could be an important factor in re-establishing co-beneficial relationships with others. For those around people with dementia, providing support is not always a burden; rather, it can be perceived as a social reward.¹⁵ Tomasello showed that altruistic behaviour could be an innate desire in human beings.¹⁶

Proposal of Self-Management of autonomous Interdependent Life Empowerment (SMILE)

The author proposes the 'Self-Management of autonomous Interdependent Life Empowerment' (SMILE) as a method for self-management support (Fig. 2). SMILE is a support method designed from practical observations to enable people to identify everyday living as a goal and enjoy each day. The name SMILE is derived from Stage 7e of the Functional Assessment Staging of Alzheimer's disease, which is the stage prior to coma—namely, *loss of the ability to smile* (i.e. the ability to smile is maintained until immediately before coma, when patients approach the terminal stage of ADD).¹⁴ SMILE is designed to allow people with dementia to lead meaningful lives each day within interdependent relationships, find enjoyment in life, and improve their own mental and social health.¹⁷

Simultaneous multi-domain interventions and reviewing one's lifestyle are recommended for the prevention of dementia and disease progression. One of the representative initiatives is the Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability,¹⁸ which involved simultaneous multi-domain interventions wherein participants were 'provided' with appropriate individualized programs (based on prior assessment) and the researchers supervised compliance with these programs. In contrast, SMILE respects self-determination and autonomous management, encouraging people with dementia and their family members to identify goals related to daily life and engage in autonomous consideration of how to incorporate eight items in their daily life to ensure that each day is enjoyable.

For example, if people with dementia express the desire to cook meals for the family, the goal to enjoy life is fulfilled via their making preparations for the family (doing something for others), cooking (engaging in an enjoyable activity), enjoying meals with the family (social participation/communication), laughing at the dinner table (laughing), enjoying meals (SMILE places more importance on enjoying meals than on nutrition), devising each day's menu (cognitive stimulation), going shopping in preparation for food (exercise), and sleeping well as a result of consuming a well-digested meal (high-quality sleep). This goal directs people with dementia in organizing their lives and incorporating the eight elements into everyday life. In cases in which difficulties related to dementia are obstacles to daily living, support can be provided to devise individualized strategies to cope with or manage difficulties. These strategies should be individualized, as ways of life differ between individuals.

As advocated in the Ottawa Charter, the goal should not be health itself.⁹ If one's objective in life is to prevent dementia, onset progression leads to a life ruled by dementia. Living a rich life every day by accepting the challenge of what one wants to do without using dementia as an excuse could lead to the effective prevention of dementia progression.

Therefore, even if dementia progresses, the individual could continue to live a rich life. In cases involving progressive dementia, the present is the time during which various functions remain at their highest levels. This irreplaceable time should not be saved for the future, when dementia progresses; rather, leading a rich life by enjoying the present allows people to live enjoyable lives with dementia.

The empowerment aspect of SMILE places importance on self-affirmation, reciprocity, and gratitude. As part of the support provided by SMILE, at the end of each day, people with dementia and their family members review the day's events and record instances in which they praised themselves, they were grateful to others, and others thanked them. Importance is attached to how time was spent enjoyably with others rather than achievements. The specific goals of SMILE are as follows:

- (1) People with dementia experience strengthened reciprocal relationships as a benefit of mutual appreciation.
- (2) People with dementia feel that others need them.
- (3) People with dementia sense their own existence in their relationships with others.

Others' acceptance is experienced as a social reward that increases the will to live.^{19,20} Therefore, SMILE supports the efforts of people with dementia who endeavour to live their lives through their relationships with others, allows them to confirm those relationships to themselves, and enables them to find ways of expressing appreciation for others.

Although dementia support does consider a person's *identity* important, this type of self-reflection, in which individuals see themselves in an abstract psychological manner, is difficult even for people without dementia. Psychological reflection is considerably more difficult in dementia, as social cognition, including the ability to engage in self-monitoring, has declined.

In SMILE, instead of engaging in abstract reflection, individuals are required to reflect on their daily lives within the context of their relationships with others. Daily life consists of one's relationships with others; therefore, observing the details of one's actual everyday life, rather than observing oneself, leads naturally to the observation of one's current relationships. Currently, interventions are increasingly emphasizing the relevance of daily living, given that it helps people with dementia to maintain motivation to live well.²¹⁻²³

Various hindrances to daily life, which are not experienced by those without dementia, occur for those with dementia. However, SMILE does not attach importance to methods of solving difficulties that arise during everyday life; rather, it is concerned with the sense of trust between people with dementia and those around them. Both persons with dementia and their caregivers, including their families, might think: 'No matter what happens in the future, I can ask the people around me for support and social support to resolve any issue; therefore, I don't have to do it on my own. I can overcome anything with others around me'. When difficulties arise, people with dementia take the initiative to request assistance. It is also desirable for caregivers to proactively ask for the necessary support, which helps them avoid unnecessary worry or burden and increasing isolation from society. The circle of support should begin with the person with dementia and expand outwards, and such expansion of circle of support starting from one specific person is the essence of dementia friendly society. Although it is impossible to prepare for all potential hindrances to daily life, as long as this trust exists, people with dementia, caregivers and family members are well-equipped to actively seek methods of resolving problems that arise. This support may increase quality of life for people with dementia and those around them including their family members.

Conclusions

Because of the gradual decrease in independence in people with dementia, maintaining co-beneficial relationships is critical for people to live well with the disease. Others close to them should be expected to accept them for who they really are, even including their declining functions, instead of hoping that they will become as others wish them to be. If people with dementia feel that others need them just as they are, they may regain their peace of mind, and they may sense their own existence in their relationships with others. SMILE can have the potential to enhance well-being (particularly social well-being) through its focus on establishing co-beneficial interdependent relationships.

Acknowledgement

The author is grateful for the people with dementia and their family members who have inspired me. This research was supported by the National Center for Geriatrics and Gerontology (Research Project Number 30-26).

Author information: Yohko Maki, PhD, National Center for Geriatrics and Gerontology, 7-430, Morioka, Obu, Aichi 474-8522 Japan; Email: makiyk@ncgg.go.jp

Correspondence: Yohko Maki, PhD, National Center for Geriatrics and Gerontology, 7-430, Morioka, Obu, Aichi 474-8522 Japan; Email: makiyk@ncgg.go.jp

Competing interests: None.

Received: 1 November 2018; **Revised:** 7 January 2019; **Accepted:** 12 February 2019

Copyright © 2019 The Author(s). This is an open-access article distributed under the terms [CC BY-NC] which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

Citation: Maki Y. Proposal for the empowerment of interdependent self-management support for people with dementia. *Journal of Geriatric Care and Research* 2019, 6(1): 3-8.

References

- American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders, 5th ed. (DSM-5). Arlington, VA: APA Publishing; 2013.
- Frith CD. The role of metacognition in human social interactions. *Philos Trans R Soc Lond B Biol Sci.* 2012; 367(1599):2213-2223.
- Frith CD, Frith U. Interacting minds: a biological basis. *Science.* 1999;286:1692–1695
- Bora E, Walterfang M, Velakoulis D. Theory of mind in behavioural-variant frontotemporal dementia and Alzheimer's disease: a meta-analysis. *J Neurol Neurosurg Psychiatry.* 2015;86(7):714-9.
- Sandoz M, Demonet JF, Fossard M. Theory of mind and cognitive processes in aging and Alzheimer type dementia: a systematic review. *Aging Ment Health.* 2014; 18(7):815-27.
- Maki Y, Ymaguchi T, Yamaguchi H. Anosognosia in Alzheimer's disease dementia. In: Howell B, editors. *Alzheimer's disease: Risk factors, diagnosis, coping and support.* New York: Nova Science Publishers, Inc; 2015. p. 1-18
- Fliss R, Le Gall D, Etcharry-Bouyx F, Chauviré V, Desgranges B, Allain P. Theory of Mind and social reserve: Alternative hypothesis of progressive Theory of Mind decay during different stages of Alzheimer's disease. *Soc Neurosci.* 2016;11(4):409-23.
- World Health Organization. International Classification of Functioning, Disability and Health [Internet]. Geneva: World Health Organization; 2018 [Cited 2018 Nov 1]. Available from: <http://www.who.int/classifications/icf/en/>.
- World Health Organization. The Ottawa Charter for Health Promotion [Internet]. Geneva: World Health Organization; 1986 [Cited 2018 Nov 1]. Available from: <http://www.who.int/healthpromotion/conferences/previous/ottawa/en/>.
- Decety J, Yoder KJ. Empathy and motivation for justice: Cognitive empathy and concern, but not emotional empathy, predict sensitivity to injustice for others. *Soc Neurosci.* 2016; 11(1):1-14.
- Mountain GA, Craig CL. What should be in a self-management programme for people with early dementia? *Aging Ment Health.* 2012; 16(5):576-83.
- Sprange K, Mountain GA, Shortland K, Craig C, Blackburn D, Bowie P, et al. Journeying through Dementia, a community-based self-management intervention for people aged 65 years and over: a feasibility study to inform a future trial. *Pilot Feasibility Stud.* 2015; 1:42.
- Maki Y, Sakurai T, Toba K. A new model of care for patients with dementia: Japanese Initiative for Dementia Care. In Michel JP, Lynn Beattie B, Martin FC, Walston JD, editors. *Oxford textbook of geriatric medicine.* 3rd ed. Oxford: Oxford University Press; 2018.
- Reisberg B. Functional assessment staging (FAST). *Psychopharmacol Bull.* 1988;24(4):653-9.
- Rademacher L, Schulte-Rüther M, Hanewald B, Lammertz S. Reward: from basic reinforcers to anticipation of social cues. *Curr Top Behav Neurosci.* 2017; 30:207-21.
- Tomasello M. *Why we cooperate.* Boston: The MIT Press; 2002.
- World Health Organization. World Report on Ageing and Health. [Internet]. Geneva: World Health Organization; 2015 [Cited 2018 Nov 1]. Available from: http://apps.who.int/iris/bitstream/handle/10665/186463/9789240694811_eng.pdf;jsessionid=3F47893318BF9CA272FC0ECCB753778A?sequence=1
- Ngandu T, Lehtisalo J, Solomon A, Levälähti E, Ahtiluoto S, Antikainen R, et al. A 2 year multidomain intervention of diet, exercise, cognitive training, and vascular risk monitoring versus control to prevent cognitive decline in at-risk elderly people (FINGER): a randomised controlled trial. *Lancet.* 2015;385(9984):2255-2263.
- Foulkes L, Viding E, McCrory E, Neumann CS. Social Reward Questionnaire (SRQ): development and validation. *Front Psychol.* 2014; 5:201.
- Perry DC, Sturm VE, Wood KA, Miller BL, Kramer JH. Divergent processing of monetary and social reward in behavioral variant frontotemporal dementia and Alzheimer disease. *Alzheimer Dis Assoc Disord.* 2015; 29:161-4.
- Clare L, Bayer A, Burns A, Corbett A, Jones R, Knapp M, et al. Goal-oriented cognitive rehabilitation in early-stage dementia: study protocol for a multi-centre single-blind randomised controlled trial (GREAT). *Trials.* 2013; 14:152.
- Clare L. Rehabilitation for people living with dementia: A practical framework of positive support. *PLoS Med* 2017; 14:e1002245.
- Maki Y, Sakurai T, Okochi J, Yamaguchi H, Toba K. Rehabilitation to live better with dementia. *Geriatr Gerontol Int.* 2018; 18(11):1529-36.