



Short Communication

Co-beneficial relationship-based care for persons with dementia

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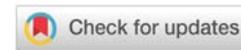
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Abstract

Co-beneficial relationship-based care has been proposed as a basic concept of dementia care to improve the social well-being of persons with dementia and those close to them, including family members and caregivers. The aim is to empower persons with dementia to manifest their innate altruism, which is intact until the end-of-life period. As dementia may change relationships even among family members, it is desirable for persons with dementia and those close to them to make efforts to maintain mutually beneficial relationships in their daily lives.

Abbreviations

AD: Alzheimer's Disease; bvFTD: Behavioral-variant Frontotemporal Dementia

Co-beneficial relationship-based care

Why prosocial relationships are essential

The authors propose co-beneficial relationship-based care to improve the social well-being of persons with dementia until the end of life [1]. Co-beneficial relationship-based care is a simple concept that aims to maintain mutually prosocial relationships between persons with dementia and those close to them, including family members and caregivers. Maintaining co-beneficial relationships can become one of the motivating factors for persons with dementia to live well in their old age. This inference is logical considering that the human brain has developed to survive under complex social conditions and that social cognition, as a form of metacognition, is positioned above cognitive modules, including memory.

Innate altruistic tendencies as the goal of dementia care

It has been proposed that altruism is innate, based on

findings that infants and toddlers behave altruistically even when they are not taught to do so [2-4]. Infants require others' support to survive; therefore, it has been hypothesized that they behave altruistically to maintain good social relationships. Interestingly, in one study, if 20-month-old infants performed altruistic actions and received a material reward, they subsequently would not perform altruistic actions without material rewards [5]. Therefore, the driving force of innate motivation is replaced by the expectation of material rewards. However, if there is no material reward or if they receive social rewards, such as gratitude, infants will continue to spontaneously engage in altruistic behaviors [5]. This may serve as a goal for improved dementia care; even when one has been deprived of what they have learned, inherent altruism may emerge, in expectation of social rewards. Dementia, in one sense, can be described as the process of gradual deprivation of what has been learned; thus, dementia may also result in the deprivation of the expectation of material rewards, returning persons with dementia to their original state of spontaneous altruism, which may be encouraged by the social reward of gratitude. According to the Functional Assessment Staging of Alzheimer's Disease (FAST), persons with Alzheimer's Disease (AD) retain their ability to smile until they fall into a coma [6];

smiling is typical non-verbal altruistic communication. Thus, the goal of dementia care should be to empower the physical manifestation of innate altruistic tendencies [1].

Identity nurtured in relationships

Person-centered care is a mainstream concept in dementia care that supports the dignity of persons with dementia as living human beings. It was proposed in the 1970s when persons with dementia were not always respected as individuals with dignity [7]. While person-centered care is still the central concept in dementia care, it is based on the premise that individuals are social beings, rather than individuals who exist by themselves. More recently, the relationship-centered approach has been emphasized, especially in community settings [8]. This trend is reasonable since identity is continuously being cultivated through interactions with people close to persons with dementia, both before and after its onset. In fact, there are many persons with dementia who, after onset, show their hidden potentials; they continue to move on, realizing new selves and building new lives.

Focusing daily living

As mentioned above, identity is continuously nurtured through everyday living. Persons with dementia are not shadows of who they once were but individuals constantly living new everyday lives with the people close to them. Although dementia support emphasizes the importance of a person's identity, the kind of self-reflection that involves viewing oneself in an abstract manner is difficult even for a person without dementia. Therefore, in daily living, it is more feasible for persons with dementia to reflect on their relationships, rather than engaging in abstract reflections on their identity.

Dementia care is about weaving a narrative on how the person continues to engage in mutually beneficial relationships with close ones. It is about continuing to rebuild relationships with persons with dementia in their daily lives. The progression of dementia brings with it difficulties in daily living, necessitating more support from others. This leads to changes in relationships; therefore, rather than a futile resistance against the inevitable, persons with dementia and those close to them are expected to accept these changes and continue to try to rebuild better relationships. This process of rebuilding is mutually beneficial; the manifestation of innate altruism, which benefits all parties in the relationship, can be the goal of dementia care.

Importance of maintaining social well-being until the end-of-life period

Social well-being: The outcome of co-beneficial relationship-based care is the overall improvement in 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" [9]. In dementia, while physical and mental health may be compromised, social well-being can be maintained until the end-of-life stage. Communication is an integral aspect of society, and dyadic

interaction—that is, communication within a pair—can be considered one of the most basic types of relationships. Just as infants can communicate with their parents from birth, persons with dementia can communicate with their families and close associates until the end of their lives.

Regarding social well-being, co-beneficial relationships are critical since society is based on interpersonal relationships. At certain times, having a social role is emphasized in the context of social health; it is true that what one can accomplish and how one can contribute to society are important for enhancing self-esteem, and therefore, praise for such achievements may be perceived as social rewards [10]. However, ascribing too much value to individual abilities and achievements may lead to the exclusion of persons with impaired independence, including those with dementia. Each person should be valued not merely for what they have accomplished but for their very existence; therefore, in reciprocal relationships, it is desirable to value others, not in terms of "doing" (e.g., one's abilities) but in terms of "being" (i.e., their relationships and existence itself). A relationship in which "being" is respected is a relationship of equality, regardless of differences in ability. Society is an accumulation of relationships, and cooperation based on altruistic thinking can be one of the basic building blocks of an equal society.

Emphasizing interdependence and improved social well-being

As mentioned above, valuing each other's relationships and existence itself can be the driving force for *living well with dementia*. It is obvious that living well is highly individualized, and diversity should be respected. However, the common factor in well-being for those living with dementia is maintaining good relationships with others, since it is necessary to consider *living well with dementia* on the premise that persons with dementia are not *independent* persons who can act on their own; they are in need of support for daily living and must inevitably live interdependently with others from the early stages of dementia.

Thus, as stated before, ascribing a disproportionate value to independence may also lead to the exclusion of persons with dementia. The progression of dementia necessitates more support in daily life. While emphasizing independence tends to focus on the negative aspect of being unable to do much without assistance, emphasizing interdependence can be viewed positively, since relationships may deepen and social well-being may increase despite the progress of dementia.

Social rewards as a driving force to improve social well-being

To reinforce this tendency, social rewards can be the driving force behind conscious behavior. Clinical experience shows that while material and financial rewards become incomprehensible as dementia progresses, social rewards remain comprehensible. Furthermore, as mentioned above, studies have reported that although infants spontaneously manifest innate altruistic tendencies while receiving social

rewards, in the case of material rewards, the created expectation becomes the underlying motivation [5]. Gratitude and appreciation are regarded as social rewards; thus, even until the point of falling into a coma, persons with AD retain the ability to smile at others [6]. Therefore, it can be inferred that they can express their gratitude and appreciation to others in the advanced stages of dementia.

How altruistic tendencies remain even when social cognitive functioning is impaired

Deficits in social cognition: As the progression of dementia impairs social adaptation, maintaining social relationships is critical to living well with dementia. Social communication becomes severely impaired because of impaired language skills, memory function, and other cognitive abilities. Furthermore, the deterioration of social cognition, which is an ability required to lead a social life, accelerates the difficulties in social adaptation. Social cognition is one of six independent cognitive domains included in the diagnostic criteria for “major neurocognitive disorder” (previously referred to as *dementia* in the diagnostic criteria): “learning and memory, language, executive function, complex attention, perceptual-motor, and social cognition” [11].

Theory of mind (ToM) reasoning, which is the ability to infer the minds of others, is a typical ability in terms of social cognition [12]. Although clinical observations have suggested that social cognition is impaired in behavioral-variant Frontotemporal Dementia (bvFTD) and not in AD, recent meta-analyses have reported that social cognition is also impaired in AD [13,14]. ToM reasoning is explained as follows. First, it represents the reality corresponding to the subject’s own belief, that is, comprehending external stimuli from their own perspective. Second, when inferring someone else’s belief, the subject takes others’ perspectives into account while considering the stimuli interpreted from one’s own perspective. Third, when there is a discrepancy between one’s own belief and the other person’s belief, adopting someone else’s perspective requires inhibition of one’s own perspective [15–23]. The main factor that may be compromised in AD is the function of adopting an objective perspective (deficits in the second point above). In other words, the difficulty for persons with AD lies in adopting an objective perspective, and as a result, they tend to act based on their subjective perspective without objectively examining their own subjectivity. Persons with bvFTD are capable of taking another person’s perspective into account when considering the stimuli interpreted from their own perspective, inferring someone else’s belief. However, when there is a discrepancy between subjective and objective perspectives, it becomes difficult for them to inhibit the subjective perspective (deficits in the third point above). As a result, the subjective perspective takes precedence over the objective perspective. Thus, both those with AD and those with bvFTD tend to act from a subjective perspective, but the mechanism is different [15] (Figure 1a).

Social reserve: In practice, it has been observed that there are wide individual differences in social adaptation, and in this regard, the concept of “social reserve” has also been proposed [24]. It can, therefore, be assumed that in some cases, the social

function of persons with dementia may be spared through compensation using semantic memories from life experiences; however, the mechanisms or neural basis for this process have not yet been elucidated. Consequently, there are no established methods of training to maintain social reserves.

It is important not to provide training to enhance social adaptation to persons with dementia but to provide appropriate support for social interaction tailored to each individual’s preserved function. Care is not the provision of training, but the process of living together in daily life and providing appropriate support. The goal of dementia care should be then to empower persons with dementia to return to their innate altruism, even if everything they have learned and remembered fades.

Not confusing altruistic thoughts and theory of mind

It is important not to confuse altruistic thoughts and ToM (Figure 1b). Even if ToM is compromised, innate altruism remains even in persons with advanced dementia. It must be noted that ToM and altruism can be incompatible. ToM reasoning can work negatively, for instance, in the act of deceiving. Before the onset of dementia, at the stage of mild cognitive impairment, it becomes more difficult to recognize the deceptive intentions of others [25,26]. In other words, it becomes more difficult to deceive but is easier to be deceived. It is important to note that altruism is essential and required to achieve social well-being, which can be improved by exercising altruism appropriately with support to compensate for deficits in social cognition. In AD, difficulties in considering perspectives that are different from one’s own can be an obstacle to social adaptation; therefore, support for considering different perspectives is required. In general, to proceed with a conversation while understanding the other person’s intentions, sharing a point of view is a prerequisite. In a conversation between those capable of having an objective perspective, both parties can try to infer the other person’s state of mind. If the person with dementia finds it difficult to have an objective perspective and speaks only from their own perspective, it is simply that the other party takes the first-person perspective of the person with dementia, just like *putting their feet in the shoes* of the person with dementia, to continue the conversation.

As mentioned above, the decline in cognitive function in AD includes impaired social cognition. However, innate altruistic tendencies remain regardless of deficits in social cognition. It is critical to distinguish between social cognitive decline and altruism, and then consider that it is possible to maintain altruistic relationships with others until the end-of-life period, which manifests in certain acts including persons with dementia smiling until they reach the end-of-life stage, as observed by FAST [6]. In other words, altruistic communication is the last remaining function. Even in bvFTD, it has been reported that self-centered altruism remains until the end of life [27].

Support for persons with dementia

Prosocial behaviors and trying to live well every day: It is recommended that people should attempt to consciously find

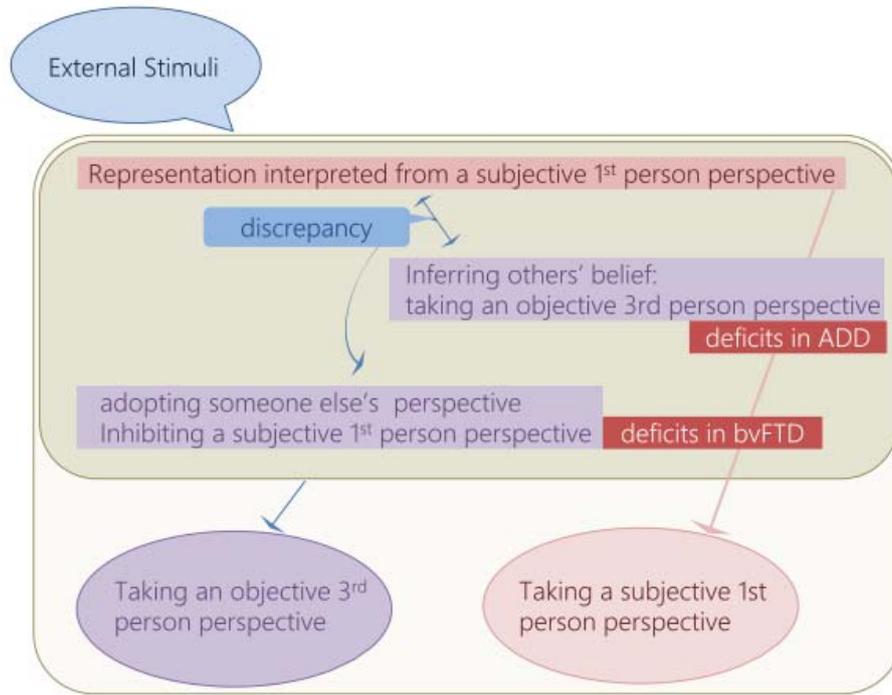


Figure 1a: The multi-level theory of mind offers the following explanation [15–23]. The representation of external stimuli is created based on a person's subjective perspective. Next, others' thoughts and beliefs are inferred from considering another person's perspective (i.e., objective perspective). If there is any discrepancy or conflict between the subjective and objective perspectives, and one decides to adopt an objective perspective, the subjective perspective is inhibited. In Alzheimer's Disease (AD), it becomes difficult to take an objective third-person perspective; therefore, the behavior of persons with AD tends to be based on their own subjective perspective. Persons with behavioral-variant frontotemporal dementia (bvFTD) are capable of taking an objective third-person perspective, but when there is a discrepancy between the subjective and objective perspectives, it becomes difficult for them to inhibit the subjective perspective. As a result, the subjective perspective takes precedence over the objective perspective. As above, although the mechanism is different, both AD and bvFTD tend to act from a subjective perspective.

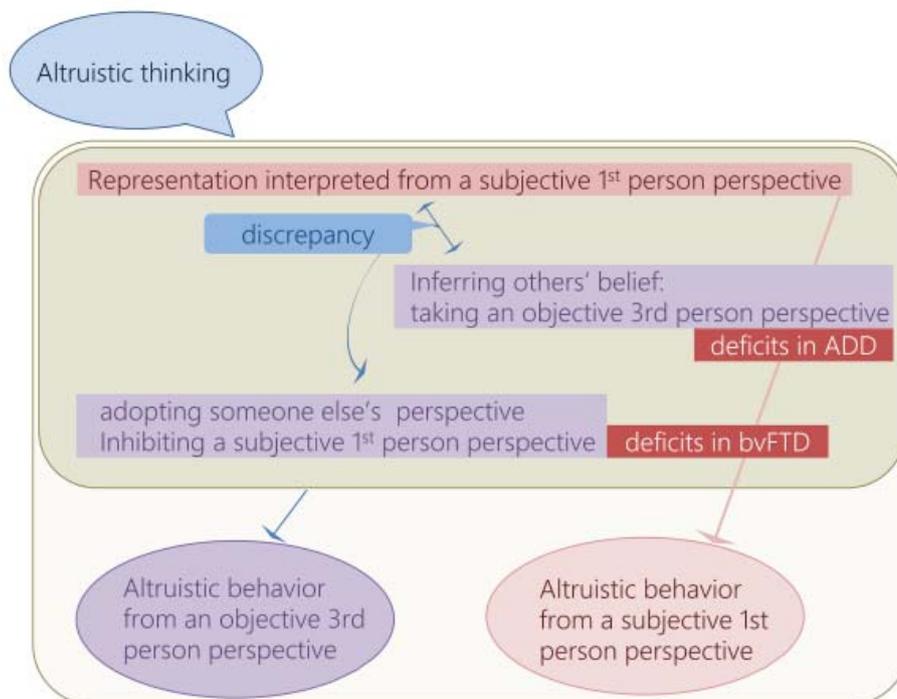


Figure 1b: The same can be said for spontaneous internal thoughts. As for altruistic thinking, when one has an altruistic idea, it is examined from an objective perspective to see if it is in line with others' wishes, and if not, the idea may be suppressed. As explained above, in AD, it becomes difficult to take an objective third-person perspective, while in bvFTD, although it is possible to take an objective third-person perspective, it becomes difficult to inhibit one's own perspective. As the subjective perspective takes precedence over the objective perspective, the behaviors of persons with bvFTD tend to reflect their subjective perspective. As above, both those with AD and those with bvFTD act from a subjective perspective and may spontaneously perform whichever altruistic action comes to mind.



value in collaboration with others, rather than just aiming for independence, from the early stages of dementia [28,29]. It is expected that being aware of the altruism within oneself can be achieved by actively receiving support from others as well as actively living together. Creating narrative life stories between persons with dementia and the people close to them is recommended. There are many who lament the decline of their cognitive functions and feel hopeless about the increasing number of things they cannot accomplish without assistance. However, it is recommended that they appreciate what can be done with the support of those close to them, and foster gratefulness for that support.

Support for those living with persons with dementia

Support manifested in “being,” not “doing”: It is critical to support “being,” not “doing.” During the evaluations of persons with dementia, they should be assessed in terms of their relationships, not merely their abilities. For instance, if a person with dementia cooks meals, aside from observing objective criteria like cooking ability and the taste of the food, it is of the utmost importance to acknowledge the person's desire to cook and their intention to share food with those who are close to them. Dementia care is the process of *creating an appreciation for narrative stories of everyday acts*, such as eating well together.

Cognitive empathy

Since social cognition deteriorates during dementia, and persons with dementia tend to think from their own subjective perspective, it is desirable to try to understand how persons with dementia think. Such support requires the ability for cognitive empathy.

Empathy, the ability to experience and understand what others feel without confusion between oneself and another person, is a multidimensional construct comprising affective and cognitive components. Affective empathy is a response that stems from the comprehension of another person's emotional state or condition. Cognitive empathy is the ability to imagine another person's perspective to infer their mental state, involving self-other differentiation and the ability to decode emotional and situational cues [30]. In the case of support for a person with dementia, it is necessary to consider the background factors of behaviors, including the decline of cognitive functions, environmental factors, and individual factors. Knowledge about dementia is an essential element to analyze the background of the person's words and behaviors. In other words, knowledge of dementia should be used not to manage the behavior of persons with dementia but to understand the background of their words and behaviors. Although the ability to express their thoughts in words declines as dementia progresses, persons with dementia can be assisted in delineating their thoughts and making decisions on their own, with appropriate support utilizing cognitive empathy.

Care burden

Reducing the burden of care is one of the main issues in dementia care. Caregivers of persons with dementia are

often referred to as the second patients, and reducing their burden should be a major point of discussion since dementia caregiving can be accompanied by negative physical health consequences [31]. Making efforts to proactively give meaning to the lives of persons with dementia may also help reduce these psychological burdens. Relationships are reciprocal in nature, and the social well-being of persons with dementia should ideally not be improved at the expense of those close to them. Therefore, efforts should be made to maintain mutually beneficial relationships.

Dementia care is a continuous effort

Dementia care is not a form of training but a continuous effort to live well together. Therefore, co-beneficial relationship-based care encourages living better every day and continuously re-establishing relationships together. Co-beneficial relationship-based care is one concept of dementia care, not a how-to methodology; it is the continuous engagement that manifests altruism.

Conclusion

Dementia may change the framework of social relationships, even among family members. In this context, persons with dementia are expected to try to lead better lives despite their condition. For those who are close to persons with dementia, including family members, it is desirable to educate themselves about dementia to provide appropriate support. A combination of these acts will encourage persons with dementia and those close to them to sustain their efforts to maintain mutually beneficial relationships in their daily lives, until the end-of-life period.

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