

Accepting a Dementia Diagnosis: Support for Daily Living as a Non-Pharmacological Approach



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Abstract

Dementia is a life-changing disease, even in areas that affect the personal relationships. While the early detection and diagnosis of dementia is advocated, no fundamental medical cure for the disease is currently available, and persons with dementia gradually lose independence as dementia progresses. Since they inevitably live interdependently, maintaining social relationships should be considered a central pillar of support as non-pharmacological treatment. Herein, living well with dementia does not always mean living independently as much as possible, but rather, the quality of life of persons diagnosed may be enhanced within the context of their interpersonal and cooperative relationship with others including their family members. The author emphasizes the importance of providing support at each time they face new challenges due to dementia.

Persons with dementia and their family are faced various challenges in their daily life, and the support is desirable to think together about how to respond to such challenges and how they could make their lives work under such circumstances. Through the process of facing and dealing with the challenges, it is hoped that dementia comes to be gradually and naturally accepted through a process to cope with the challenges. The support should be provided until they come to terms with the fact that they live within the context of their interpersonal relationships. If the persons with dementia and their family members succeed to find meaning in the interdependent relationship, they may find meaning as they live with the realities of dementia.

Keywords: Dementia, Acceptance of dementia, Living Well with Dementia, Living Proactively with Dementia, Interdependency, Coexistence, Social Reserve, Non-Pharmacological Approach

Introduction

The need to provide support following a dementia diagnosis. Dementia is a life-changing disease wherein the person diagnosed must change or modify their way of life, including in areas that affect their personal relationships. While the early detection and diagnosis of dementia is advocated, no fundamental medical cure for the disease is currently available. As such, it is at times referred to as early detection, early despair. The probability of progression can be accelerated if depression or apathy set in after the diagnosis, because depression and/or disuse syndrome (related to apathy) are recognized risk factors for dementia progression. To prevent early detection from leading to feelings of early despair, support needs to be provided to the person diagnosed with dementia in order to encourage their acceptance and to take necessary steps to modify their daily lives. Support for daily living is critical in providing overall support following the diagnosis.

The main objective of early diagnosis is not to slow down the progression of dementia, but rather to better identify health resources for everyday life. While one may have dementia, beyond this, they require support to live a rich and fulfilling life. Cases

exist in which people diagnosed with dementia search for ways to recover from the disease; for example, they may try various kinds of brain training exercises or similar activities and their entire lives became dominated by trying to overcome dementia. As mentioned in the Ottawa Charter: Health is, therefore, seen as a resource for everyday life, not the objective of living. Health is a positive concept emphasizing social and personal resources, as well as physical capacities. Therefore, health promotion is not just the responsibility of the health sector but goes beyond healthy life-styles to well-being.

For a person with dementia to best adjust to their life following diagnosis, it is desirable to receive this diagnosis while still in the early or mild stages, when judgment and cognitive abilities are still intact. People diagnosed with dementia are encouraged to accept their disease and understand what it means to live a life with dementia. As no fundamental medical treatment is currently available for this disease, it is not easy for a person to accept progressive dementia, which involves the gradual loss of function. Because dementia is a continual process of overcoming one challenge and then facing another, support

should be provided in such a way that it will assist in all aspects of their daily life, including their relationships with others. The objective of support for progressive dementia is not for the person with dementia to acquire or recover functions; rather, it is to support the person through their process of losing their functions and, ultimately, their independence.

The objective of support is not to prevent the progression of dementia but to help people live happily following diagnosis: Conventionally, rehabilitation for dementia has included various brain training exercises with the objective of improving cognitive function at the levels defined in the International Classification of Functioning, Disability, and Participation (ICF) [1]. Reminiscence and music therapy are also conducted with the objective of improving cognitive function; however, clinical experience has indicated that results of cognitive function training, even if the person's cognitive test score on the Mini-Mental State Exam (MMSE) improves, this does not necessarily indicate a general improvement of the person's daily life performance. Also, most dementia diagnoses, including Alzheimer's disease dementia (ADD), are progressive, and so it is difficult to expect a long-term improvement even after the person with dementia undergoes functional training. Therefore, improvement and recovery from dementia is not considered an appropriate long-term goal, though factors related to these goals may be achieved in the short-term.

Dementia is a disease wherein the person receiving the diagnosis should inevitably change their way of life, including their interpersonal relationships, such as those with family members. After the onset of dementia, the person diagnosed needs to accept the difficulties they will face in their daily life as well as to their social relationships due to challenges related to the disease. They require support that can enable them to feel undefeated by dementia and to live their lives as their true selves. This stance of being undefeated by dementia is not a stance in which the person with dementia leads their daily life with the objective of improving their cognitive function and achieving recovery; rather, it is a stance wherein they can strive to fulfill the things they wish to do despite having this disease. Supporting in their daily lives becomes meaningful when the people involved with the person with dementia work together so that the disease does not hinder them from feeling fulfilled and happy.

Supporting the Process of Accepting Dementia

A person with dementia may consult a doctor for a diagnosis as they, and others around them, become aware of cognitive issues. In fact, in many cases, even before the person is diagnosed with dementia, that person and their family experience concern and confusion due to a variety of issues that may be affecting the social relationships of the person with dementia. Although some cases exist in which the person with dementia and/or their family realizes that the issues may originate from dementia and they feel reassured after receiving this diagnosis, there are

other cases in which the person with dementia and their family are experiencing emotional turmoil, do not have the capacity to accept advice from others, and their lives become even more disrupted following the diagnosis.

The period of psychological confusion following diagnosis requires psychological support more than anything else. Despite the great differences among individuals' reactions to receiving and ultimately accepting their diagnosis, it is necessary in all cases to wait for the person with dementia and their family to become mentally prepared to live their lives as being affected by dementia before effective support can begin. The person diagnosed and their family must tackle the everyday issues of life together as they arise, one after another. The expectation is to provide support in such a way that involves both the person with dementia and their family members so that they can identify confusions that may occur in the person's daily life due to dementia, consider solutions together, and try out those solutions; in so doing, they can start to untangle each of the confusions one by one. The person with dementia and their family are hoped to gradually come to understand dementia through this process. For example, when a problem involving money management occurs, the person with dementia and their family may not understand why such a problem is occurring, and this can result in emotional conflict. The issue cannot be fundamentally solved by only addressing feelings; rather, effective support will assist them in finding where the problem lies, clarifying why money management is becoming difficult; identifying which process is being hindered; and waiting until the person with dementia and their family can objectively acknowledge and address the situation. Next, support can be provided that considers a strategy to handle difficult situations and tackle them through trial and error along with the person with dementia and their family, so the person with dementia can consent, and their family can also feel reassured and knowledgeable. This support is not determined unequivocally but rather includes various options to support the person with dementia and their family's processes to independently tackle issues and create their own solutions in harmony with their lifestyles. Although this can be a time-consuming process, the person with dementia and their family will obtain a better understanding of dementia in conformity with their lifestyle.

Overall, the support provided for one's daily life emphasizes shared decision-making and respect for the person with dementia and their family's independence. Support becomes effective not when medical service provides one-side strategies and provides training in accordance with these strategies, but when those providing support wait for the person with dementia and their family to develop awareness and self-determination to live with the effects of this disease. Ways of life are diverse, and families each have their own history.

Having dementia is only a part of the person with dementia; it is not their true nature; therefore, even if an optimal method

of medical support exists for treating the disease, it would not be the appropriate support if it does not fit the lifestyle of the person with dementia and their family. There are cases in which medical support has been forcefully provided, and in which relationships among family members has been strained. The person with dementia and their family members are at the center of the lives affected; hence, it is important for them to be proactively find methods to deal with their concerns within the context of their daily lives. In many cases, it is more desirable for them to come to terms with the challenges and develop a flexible stance toward their day-to-day living rather than trying to finitely solve all concerns at one time.

Objective assessment is critical for such support because it evaluates the cognitive function of the person with dementia, analyzes actions subject to the assessment, and clarifies at which point the disability is being manifested. In many cases, support should not focus on training to improve related cognitive functions, but rather be suggestions toward identifying substitute measures. These substitute measures include accepting support from others as well as various solutions that can be provided to and conducted together with the person with dementia and their family. It is important to note that, during this process, the goal is not for the person with dementia to be able to perform these actions by themselves, but for them to share with others the difficulties they are facing due to dementia and to rebuild relationships by working together.

Accepting dementia is not about accepting the disease in an abstract sense but rather how it will affect them directly; In addition, decision making is not limited to considering what kind of care can be received in preparation for the future. Life is a perpetual process of self-determination, and the person with dementia and/or their family are hoped to gradually accept the disease and to focus on overcoming difficulties in their daily lives. This can be achieved by contemplating why they consider each issue as a difficulty when it occurs, and what measures should be taken at present and in the future, when and if it occurs again.

The difficulty in accepting dementia is that it is a progressive and disease. Dementia causes a series of challenges where, even after one challenge is overcome, functional declines cause another life-challenging disability to arise. As such, it is meaningful for the person with dementia and their family to admit to difficulties and implement coping methods proactively. Even if a method is not medically optimal, if the person with dementia and their family can make appropriate compromises in their daily lives, this method is optimal for the person with dementia, and their own decisions should be respected. In some cases, a person with dementia and their family have gained a stronger sense of unity after overcoming an obstacle and grow both individually and as a family unit. There are families who say, "We do not feel as though we are providing care; rather, we feel that we are simply living together with the person with dementia."

Providing coping methods in the form of instructions are nothing more than paternalistic support, and such instructions are often taken as how-to methods. When this type of support is offered, the person with dementia and their family may implement these methods without considering their purpose or meaning. Ultimately, this type of support is not conducive for anyone involved in acquiring the capacity to handle and deal with series of life-challenging disabilities, as a result of dementia, that will arise one after another.

Thus, it is hoped that dementia comes to be gradually and naturally accepted through a process in which the person with dementia and their family face challenges in their daily lives caused by dementia, and then think together about how to respond to such challenges and how they could make their lives work under such circumstances as they receive support from medical practitioners. This accumulation of cooperative experiences is what leads the person with dementia and their family to find peace as they live with the realities of the disease. Dementia hinders independence, and so the person with dementia will ultimately begin to rely on their relationships with other people as protection from harm and negative consequences.

Support to Heighten Social Reserve in a More Positive Manner

Living well with dementia is a challenge for all persons concerned. The ideal type of support will assist the person with dementia and their family with accepting the disease by facing and dealing with the challenges in their daily life, and to assist in living more positively despite being diagnosed with this disease. Living proactively with dementia, as mentioned above, does not necessarily mean that the person with dementia will become or remain independent (i.e., independence is limited to the very early stages of dementia). If viewed as a cycle, people begin their lives in interdependent relationships, and if they are diagnosed with dementia, it is once again vital for the person to live their life in interdependent relationships. Furthermore, when the memory of the person with dementia is hindered, it becomes difficult for them to confirm their identity and retain autobiographical memories; however, it is possible for them to confirm their sense of self, moment to moment, within a given relationship. If a person with dementia can find contentment or a sense of subjective well-being within each of their relationships and affirm their own existence in those moments, this can be a factor that leads to happiness.

Social Reserve

Maintaining social relationships should be considered a central pillar of non-pharmacological treatment. In the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), cognitive functions for dementia were defined by six domains, of which social cognition is one [2], Social cognition is defined as the ability to understand self and

others, and is a cognitive function required in the maintenance of social relationships. Systematic review and prior experiments have shown that cognitive functions, particularly the theory of mind (the ability to infer the mental states of others [3])-a representative ability for one to understand others-decline in the early stages of dementia, even in ADD [4,5]. As the degree of this disability varies greatly depending on the individual, social reserve is advocated to help overcome declining cognitive function and maintain high sociability. Such support that can help one retain their social reserve is precisely the type of support that is required of non-pharmacological treatment for dementia. This type of support can be provided throughout the process in which the person with dementia reflects on his or her daily life, as well as their own disabilities, until one comes to terms with the fact that they live within the context of their interpersonal relationships. Even if the person with dementia requires physical assistance with their overall daily life, this does not mean that they are passive care-recipients; rather, this is a cooperative act based on shared decision-making with other people. If the person with dementia can continue to feel gratitude toward living their lives within these relationships, this may help to lead them to live at peace with their disease.

Conclusion

Non-pharmacological treatment for people with dementia should focus on assisting the person diagnosed and their family with reconciling each of the disabilities that arise one by one, and to overcome these challenges through methods that work for that person and their family. While cognitive and physical function will decline as their dementia progresses, it is desirable to provide support so that each time they face new challenges, they are able to flexibly and gradually change their ways of life. In addition, while reflecting on their relationships with other people, the person diagnosed can consider ways to live well despite having dementia. Living with dementia does not mean living independently; rather, the person diagnosed can live within the context of their interpersonal relationships. Relationships between persons with dementia and the family and others should not be viewed as being between a care-provider and care-recipient, but rather that it is a cooperative relationship to enhance quality of living. Finding meaning in this coexistence may help to lead people with dementia and their families toward happiness and positive experiences as they live with the realities of dementia.

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Conflict of Interest

The author has no economic interest or any conflict of interest.

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