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Progression of dementia symptoms in old patients because of confinement in the COVID-19 pandemic era: challenges for mental health workers and caregivers

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ABSTRACT

Currently, the whole world is experiencing a COVID-19 pandemic. The elderly are one of the populations with a high physical and mental risk of being affected by covid-19. Dementia is a psychiatric disorder that is often experienced by the elderly. We describe two cases of dementia that occurred during the COVID-19 pandemic situation. Both cases explain the condition of dementia patients during quarantine due to the implementation of the PSBB (confinement). Dementia patients have difficulty in understanding and complying with health protocols. The emergence of exacerbation symptoms and education on health protocols are challenging for caregivers during the COVID-19 pandemic. The role of mental health workers is important to help caregivers understand the causes of worsening symptoms of dementia patients because of changes in environmental conditions during the COVID-19 pandemic situation and provide examples for caregivers on how to educate patients with appropriate health protocols. Modification of activities during a pandemic and regular communication with caregivers can be a solution to addressing challenges.

Keywords: *dementia, confinement, covid-19 pandemic, mental health, caregivers*

INTRODUCTION

The COVID-19 pandemic has shown an increasing number of cases globally, including in Indonesia.¹ National data in September 2020 showed more than 270,000 cases, with Jakarta as the city holding the most cases.¹ To slow down the fast-paced spread of the virus, Jakarta's local authority has mandated intermittent confinement to all its residents since April 2020, including senior citizens, given alongside public education to maintain physical distance, implement hand hygiene, and wear a face mask.

Older adults are a population group with a high risk of being greatly affected by COVID-19.² Mortality rate due to COVID-19 has shown to be the highest in this age group.⁴ Besides physical risks, seniors with psychiatric and neurocognitive problems before COVID-19 are also at risk of exacerbating their conditions. This exacerbation, to number few, can be influenced by confinement and the caregiver's attitude toward dementia patients during the confinement.²

One of the psychiatric disorders that are often experienced by the elderly is dementia. Dementia is a neurodegenerative syndrome, usually chronic and progressive, accompanied by impaired cognitive function beyond age, such as memory, orientation, comprehension, calculation, learning capacity, language, and decision-making. Consciousness is not compromised. Impaired cognitive function is usually accompanied by deterioration of emotional, behavioral, and motivation control.

Symptoms of dementia can interfere with a patient's ability to accept and process new information and eventually to practice instruction within the new information, including education about hygiene, physical distancing, and confinement. This difficulty in understanding and practicing prevention methods for COVID-19 will possibly affect the interaction between dementia patients and their caregivers.

This case series is meant to picture the challenges faced by patients with dementia and their caregivers during the COVID-19 pandemic, particularly in confinement, and to review some recommendations for mental health workers to address the issues.

Case One

Mrs. A, 80 years old, a lecturer at a university in Jakarta, arrived on April 20, 2020, accompanied by her daughter. Three days ago, the patient felt she did not live in her own house, did not remember that her mother had died, and always asked to see her. The patient also asked the same questions many times and was confused when at home, asked where she was and had trouble sleeping.

The patient's daughter explained that 6 months ago, the patient began to look gloomy. This change occurred because the patient was no longer able to guide students. According to the patient, this was because the higher education leaders did not want to use older lecturers. After all, there were many younger lecturers, so the patient chose to resign. Besides being gloomy, the patient also began to forget often since the incident.

The patient's daughter noticed this a week ago because she felt that the patient's behavior had become increasingly unusual. Patients often ask to go home, even though they currently live in their own homes. The patient feels locked at home by her daughter, who explains that the patient is being kept at home because of the COVID-19 pandemic.

The patient had never experienced something similar before and was never diagnosed with a mental disorder. The patient did not have a history of hypertension, diabetes mellitus, stroke, head injury, epilepsy, or other chronic diseases. The only medicines the patient has been taking have been ginkgo biloba, vitamin D3 and Omega 3.

Examination found the patient was compos mentis. The patient was disorientated with time, place, and person. The patient looked clean and tidy and looked appropriate for his age. The patient's attitude was quite cooperative. The patient was willing to answer all questions even though they always asked for validation of information from her daughter. The patient speaks spontaneously and fluently and sometimes answers in English. The quality and quantity of talk are sufficient. The mood was euthymic, the affect was quite broad, and there was a correlation between mood and affect. The thought process is coherent. The patient has a thought content disorder, namely the belief that his deceased mother came and invited him to take a walk. The patient was always suspicious of the aides and often accused the helper when the patient's belongings were missing. There is impaired immediate and short-term memory, while the patient's long-term memory is still good. The patient's concentration and attention are sufficient. Patient impulse control is good.

When the patient was asked to do the Clock Drawing Test, the patient did not do it because of being lazy. When asked about the time, the patient answered that it was August 1995. The patient was given donepezil 1 × 5 mg and estazolam 1 × 0.5

mg at night. The patient's daughter is given the education to let the patient do everything she can do on her own. The daughter always forbade patients from doing the daily activities that patients usually do, such as washing dishes, cleaning the room, and watering plants. The family prohibits the patient from doing activities because the patient tends to make a mess and worries that the patient will be tired, eventually making the patient angry. This often leads to arguments between patients and families. Families are taught that the patient's ability to accept and remember the explanations given by the family is minimal.

Currently, the family is confused about how to explain the COVID-19 pandemic to patients.

The patient always asked to leave the house, and wearing a mask and washing their hands was challenging. In the educational session, the patient was invited to wash their hands by giving examples to the therapist. The therapist asked the patient to chat and listen to the patient's conversations during education. This made the patient more cooperative in following the example of how to wash hands. Families were taught that patients would be more cooperative if the activities of wearing masks and washing hands were done in a fun way, so family creativity was needed to make patients comfortable following them.

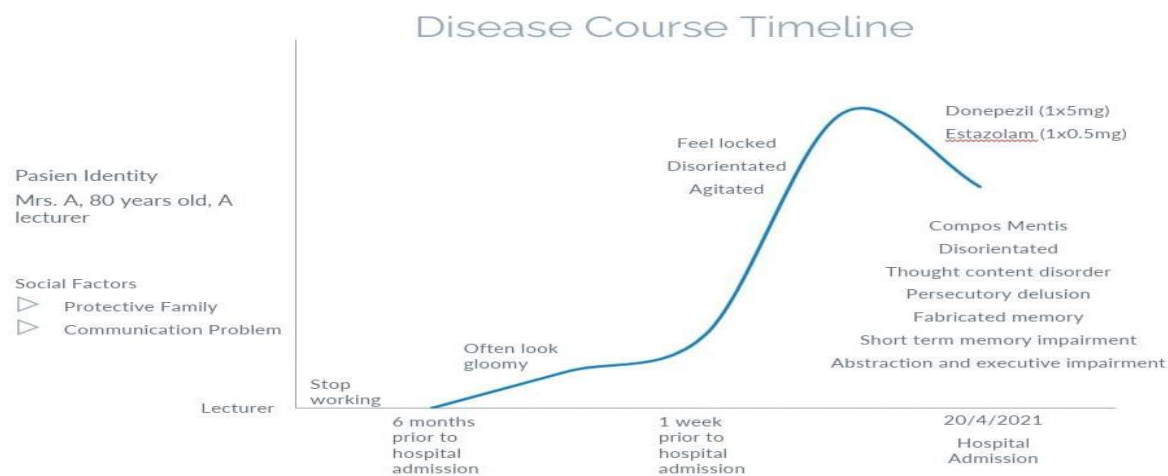


FIG 1. Disease course timeline of case one

Case Two

Mr. AS, a 78-year-old man, has routinely visited the hospital's psychiatric polyclinic since January 2020. The patient previously underwent treatment from a psychiatrist at another hospital in 2018 with a diagnosis of dementia but had not been treated for the past 1 year due to cost problems. Since the end of 2017, the patient has experienced progressive memory loss accompanied by changes in behavior.

When he first came to the hospital polyclinic in January 2020, the patient was in a condition of decreased cognitive function with an MMSE score of 12/30 and disorder in each examination domain; orientation, memory registration, language, abstraction, and executive, attention, and calculation, and recalling. The patient does not know exactly where he is and does not remember his daughter's name. There are often aggressive behaviors at home, such as hitting, motor restlessness, pacing around the house, and loss of basic abilities such as bathing, eating and wearing clothes and footwear properly. Patients also show mood problems, often appear to cry and express suicidal thoughts, are suspicious of householders if they forget where to put them, and forget when they have done certain activities such as eating or bathing.

The patient was given donepezil 1 × 5 mg, aripiprazole 1 × 2.5 mg, risperidone 2 × 0.5 mg, and zolpidem 1 × 5 mg. The patient's behavior showed significant changes after that. The patient becomes calmer, shows no aggressive hitting behavior, no longer screams, has no visual hallucinations, has less motor anxiety, and sleeps better. The drug was maintained until the patient's last control in May 2020.

Before experiencing changes in memory, function, and behavior, the patient is a pastor who is still actively providing services. Patients also have a habit of reading books and doing household chores.

Currently, the patient lives with his daughter, son-in-law, and two teenage grandchildren. The patient's daughter is the patient's primary caregiver.

Since experiencing cognitive decline, the patient's daughter has established a routine for the patient in the form of sunbathing and walking around the housing complex every morning, going to the hospital once per week, followed by going to a shopping center, traveling around the city by car every few days, and going to traditional markets on weekends with family. The patient's daughter can accompany the patient every day because of her job as a housewife.

In April 2020, in response to the increasing number of cases and deaths due to Covid-19, the Indonesian government implemented the confinement program in Jakarta, where patients live. The confinement led to the temporary closure of communal places where large numbers of people usually gathered, such as markets, shopping centers, places of worship, restaurants, salons, etc. The confinement was also followed by limiting the activities of the mode of transportation in Jakarta.

The confinement has an impact on a patient's routine. The patient can no longer go to the hospital because of his age, which makes him susceptible to infection with the SARS-Cov-2 virus, so the patient's daughter took the drug for him. Patients are no longer able to go to shopping centers and markets. Patients are still invited to go around the complex and sunbathe every morning, but only on the street in front of the patient's house. During the confinement, there was no change in the medication consumed by the patient.

Since confinement and the change in routine, the patient has experienced motoric anxiety again, pacing back and forth in the house, getting angry, screaming, only wanting to eat and take medicine when coaxed, crying a lot, and saying that he wanted to die. Patients often say that all they see is a wall, making them think it is better to die. According to the daughter, there has been no change in the situation at home and the environment at home recently.

The patient's daughter asked the therapist what causes the patient to regress and how to deal with it. The therapist hypothesized that the deterioration of the patient's condition is due to a change in the routine that has been the foundation of the patient's regular life and prevents him from experiencing daily confusion. The patient's current anxiety may occur due to disorientation due to daily changes in the activities and environment he sees and

experiences. The patient's daughter was advised to maximize routines that can be carried out outside the home, such as taking the patient around the city by car without stopping somewhere. The patient's daughter was also advised to often bring the patient around the complex that is not crowded, use masks and carry a sanitizer for hands, and maximize activities in the home by gradually introducing new routines that can be done at home to patients. Patients' children are also given education and examples of how to reorient time and place to patients.

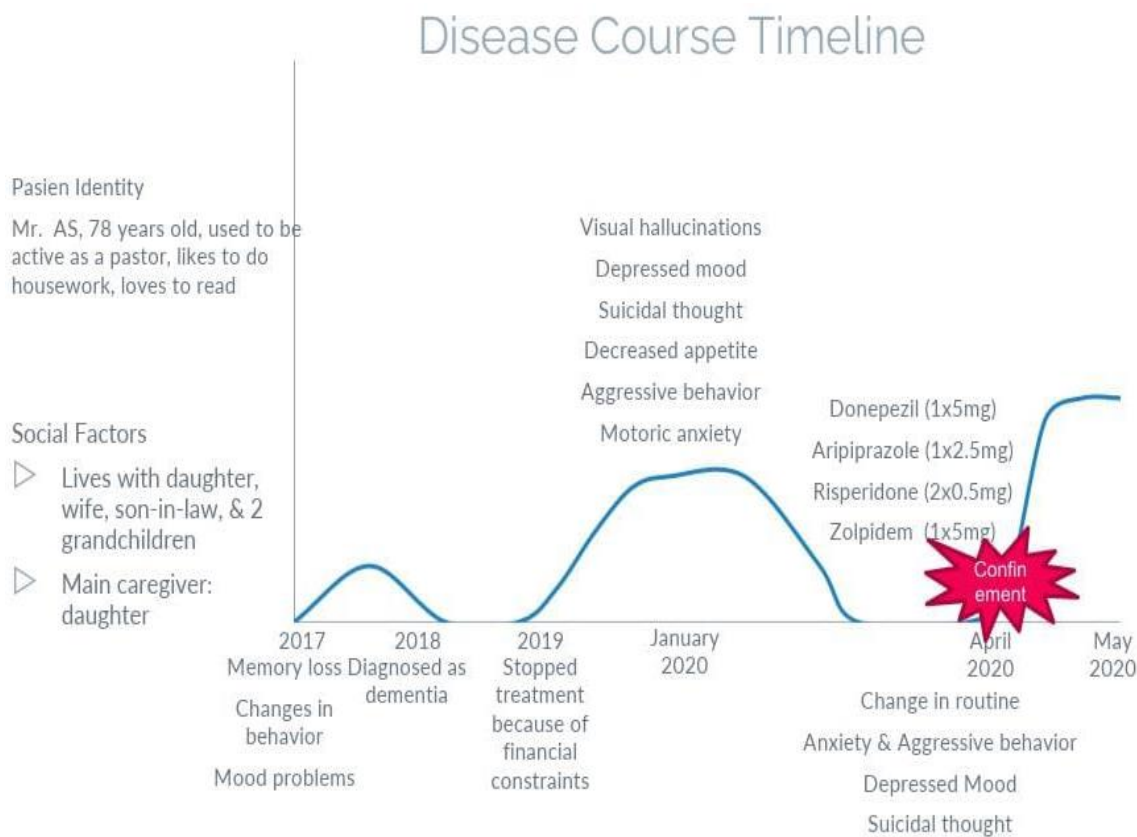


FIG 2. Disease course timeline of case one

DISCUSSION

Dementia is a progressive decline in cognitive function, including memory, language, and thinking abilities. Dementia is commonly found in the elderly, causing dependence on family, caregivers, and the community.³ Symptoms of decreased cognitive function are complicated by behavioral and psychological symptoms of dementia that inhibit activity. In addition, the environment around the patient is also a factor that influences the onset of dementia symptoms.⁵

The rapid increase in COVID-19 cases has caused public concern about the spread of infection and uncertainty about the future of the pandemic. This becomes stressful, increasing the likelihood of recurrence in people with a previous history of mental disorders.^{6,7}

Dementia patients already have limited activities and are isolated from their environment. During the COVID-19 pandemic, the social and physical confinement makes the programs and daily routines designed for the patient impossible. This situation can exacerbate disorientation in dementia patients.⁸

We can observe these conditions in the case of Mr. AS. Since the confinement, Mr. AS has shown a behavior change. He became more aggressive and experienced a depressive mood. These behavioral changes are part of 'non-cognitive' neuropsychiatric symptoms known as behavioral and psychological symptoms of dementia (BPSD).^{9,10}

Several risk factors can lead to BPSD, which are divided into three categories; factors related to the patient (neurobiological changes, medical disorders, unmet needs); factors of caregiver (stress, workload, depression, lack of education about the illness, communication problems); and environmental factors (safety problems, excessive stimulation or lack of motivation, lack or absence of

routine).^{11,12}

Environmental factors can cause a decline in the patient's condition, namely, a change in routine which has been the foundation for the regularity of the patient's life and prevents him from experiencing daily confusion. Current patient's anxiety may occur due to disorientation due to changes in activities and environment that he sees and experiences daily.

Patients with dementia also have difficulty remembering and understanding that the surrounding environment is currently affected by the COVID-19 pandemic. In a minority of cases, the word "Coronavirus" can quickly evoke a patient's memory of a pandemic condition, but the memory can be lost again after a few minutes. One of the symptoms of dementia is difficulty remembering recent events compared to past events. In many cases, the patient is confused about the idea of the current condition, ranging from "don't know/don't remember" to "confused interpretation".¹⁴ Due to this condition, the patient has difficulty adhering to health protocols, even raising arguments between the caregiver and the patient.¹⁸ In Mrs. A's case, the patient felt locked at home by his daughter, regardless of her child's explanation.

Difficulty following recommended health protocols during a pandemic, such as washing hands, physical distancing, reporting themselves if they feel symptoms, and doing self-isolation, have made dementia patients susceptible to COVID-19 infection. This adherence problem is due to the patients experiencing memory problems, making them difficult to remember health protocols.^{14,15} Patients with frontotemporal dementia (FTD) are less likely to adhere to health protocols than patients with other dementias. This is caused by several things, such as; FTD patients often develop inappropriate social behavior (disinhibition) and a lack of understanding or indifference to the feelings of others (loss of empathy),¹⁵

FTD patients are very fixated on routine daily activities and are not flexible (stereotyped behavior) making it difficult for them to adapt to new routines such as health protocols.¹⁵ FTD patients are known to have difficulty understanding the abstract meaning of a concrete experience, for example understanding that hand washing is an act of cleaning invisible germs. The inability to understand the reasons behind the health protocol makes FTD patients unable to understand the importance of the health protocol.^{13,15,16}

This condition not only affects dementia patients but also becomes a challenge for their caregivers. One study found that caregivers for dementia patients had higher stress levels than caregivers for other conditions. Dementia patients tend to be more dependent on caregivers because of the difficulty of carrying out basic activities if the patient's symptoms worsen.¹⁷ Factors that aggravate the caregiver's stress can come from the patient's behavior and the caregiver's life conditions. Dementia patients' behaviors, such as disruptive actions, miscommunication, and apathy, can lead to conflict between the caregiver and the patient.^{5,17, 18} The living conditions of the caregiver, such as economic, social, and health factors, also affect stress levels.

Management of exacerbation of dementia symptoms caused by psychosocial problems can be done by conducting pharmacological and non-

pharmacological interventions. Studies show that exacerbation conditions in dementia can be treated by administering low doses of antipsychotics.¹³ Non-pharmacological interventions include enrolling dementia patients in social groups, exercise groups, and pet therapy.²⁰ Some non-pharmacological interventions can also be given via telephone or video call.²¹

Another factor that must be considered using masks when interacting with dementia patients. This can interfere with facial recognition ability and interpersonal reassurance. The presence of family and friends is beneficial for the patient to overcome their disorientation.²² In the case of Mrs. A and Mr. AS, reorientation was carried out by conducting reality orientation training, which reduces confusion, disorientation, memory loss, and behavioral problems by providing environmental clues so that patients can find important information such as time, person, and place. This method has shown significant cognitive and behavioral improvements in dementia patients.²³

Besides pharmacological treatment, the caregiver must carry out non-pharmacological intervention training to deal with the anxiety and agitation symptoms of patients with dementia. Because of their cognitive impairment, several things need to be considered in providing education to dementia patients. Some of the following principles need to be considered in educating patients with dementia.²⁴

TABLE 1. Principles of educating dementia patients

1.	Principles of educating dementia patients
2.	Know the severity of the patient's dementia
3.	This will affect how we deliver education, such as word choices and the extent to which the information needs to be conveyed.
4.	Prepare a sufficient amount of time
5.	Providing education to dementia patients should not be rushed.
6.	Avoid noisy places
7.	Choose a quiet and calm room where they can focus on your voice.
8.	Make sure the patient is getting enough rest
9.	Adequate rest will help the patient understand and process the information given.
10.	Divide the information you want to provide into small pieces
11.	Gradually provide chunks of information, starting with what the person needs the most.
12.	Use words that are easy to understand
13.	Dementia makes it difficult for a person to understand idioms or euphemisms.
14.	Pay attention to their reactions and understanding
15.	Sometimes it is necessary to repeat the process of giving the information until the patient fully understands the context.

Anxiety and agitation sometimes occur due to several trigger factors, such as an uncomfortable environment, inability to perform activities, etc. These symptoms need to be adequately handled by

the caregiver to improve the patient's quality of life.²⁵ Education that can be provided to caregivers to manage anxiety and agitation in dementia patients is provided below.

TABLE 2. Education for the caregiver on how to handle the anxiety and agitation of dementia patients

1.	Education for caregivers on how to handle the anxiety and agitation of dementia patients
2.	Find the cause of the anxiety and agitation in the patient
3.	The patient will usually be restless in certain situations, such as moving to a new environment, changing routines, or being unable to perform activities.
4.	Create a comfortable environment for the patient
5.	Avoid anything that can be a stressor to the patient.
6.	Make yourself a good listener
7.	Listen to all the patient's complaints and give a response that can make the patient feel at ease.
8.	Adjust the patient's routine according to the patient's ability
9.	Dementia patients experience cognitive decline, so avoid activities that have complex methods. This is not to restrict the patient from doing exercises.
10.	Give time to the patient's hobbies.
11.	Activities such as gardening, sightseeing, and listening to music can soothe the patient's symptoms.
12.	Monitor patient needs and comfort.
13.	Check the patient's condition, which can trigger symptoms such as hunger, thirst, pain, and itching.
14.	Contact the doctor if the patient's anxiety symptoms persist after a non-pharmacological intervention.

CONCLUSION

This case series identified several difficulties experienced by dementia patients, such as; disorientation, behavior problems, difficulty understanding and obeying the confinement recommendations, hand hygiene recommendations, and wearing masks. Apart from the difficulties for the patient, the difficulties found in the caregivers include; how to educate patients about confinement, hand hygiene, wearing masks, how to deal with behavioral disorders, and difficulty in understanding that changes in patient behavior are symptoms caused by the limitations of dementia patients which are influenced by changes in environmental situations.

This case series demonstrates the importance of the role of mental health professionals in educating caregivers about changes in patient behavior as a symptom of dementia that has regressed due to changes in environmental situations, with the hope of reducing communication friction between caregivers and patients that could potentially worsen patients' symptoms. Mental health workers are also tasked with educating patients in a way that is tailored to the patient's needs. This education is also used to provide examples to caregivers about how to instruct dementia patients. Modifying patient activities that can be done at home or around the house with a regular schedule and reality orientation to prevent disorientation in the patient is also needed.

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