



## ORIGINALES

### Caregiving people with dementia: positive responses experienced by spouses

Cuidado de personas con demencia: respuestas positivas experimentadas por los cónyuges

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#### ABSTRACT:

**Primary Goal:** The purpose of this study was to determine the positive response experienced by spouse caregiving their partner with dementia. The role of the spouse as a caregiver for people with dementia is known to have significant effects than the role of other family members. Spouse's acceptance as caregivers for people with dementia can affect the quality of services provided.

**Methods:** This research using a qualitative study with a phenomenological approach to 10 participants obtained using a purposive sampling technique.

**Results:** The results showed that the positive response of the caregivers while caring for a spouse with dementia was seen through feelings of gratitude for the blessings received, acceptance to the conditions experienced, and the feeling of closeness as partner.

**Conclusions:** Positive responses that appear in spouses who are caregivers can be an entry point for health workers to improve the welfare of spouses as caregivers.

**Keywords:** Caregivers, Dementia, Older adults, Positive response, Spouses.

#### RESUMEN:

**Objetivo:** El propósito de este estudio fue determinar la respuesta positiva experimentada por los cónyuges que cuidan a su pareja con demencia. Se sabe que el papel del cónyuge como cuidador de personas con demencia tiene efectos más significativos que el papel de otros miembros de la familia. La aceptación del cónyuge como cuidador de personas con demencia puede afectar la calidad de los servicios prestados.

**Métodos:** Esta investigación utilizó un estudio cualitativo con enfoque fenomenológico a 10 participantes obtenidos mediante una técnica de muestreo intencional.

**Resultados:** Los resultados mostraron que la respuesta positiva de los cuidadores en el cuidado de un cónyuge con demencia se vio a través de sentimientos de gratitud por las bendiciones recibidas, aceptación de las condiciones vividas y el sentimiento de cercanía como pareja.

**Conclusiones:** Las respuestas positivas que aparecen en los cónyuges que son cuidadores pueden ser un punto de entrada para que los trabajadores de la salud mejoren el bienestar de los cónyuges como cuidadores.

**Palabras clave:** Cuidadores, Demencia, Adultos mayores, Respuesta positiva, Cónyuges.

## INTRODUCTION

Aging is a normal process, cannot be prevented and is not a health problem that occurs in humans. While the aging process is progressive, it lasts a lifetime, and can be observed or not<sup>(1)</sup>. The process of aging is a cause of the decline in bodily functions that occurs in the elderly as a consequence of increasing life expectancy in a society. This condition will have an impact on increasing morbidity, especially various degenerative diseases that can accompany it. Degenerative diseases are one of the main inhibiting factors that can cause the elderly to become unproductive and independent, including dementia.

Dementia is a condition that is still considered normal in the elderly by the general public. Dementia is a collection of symptoms that causes irreversible brain damage that occurs over a relatively long period of time (not immediately) and causes the elderly to become unproductive and fully dependent on their family in their daily lives<sup>(2)</sup>. Dementia can be characterized by an inability to remember people around and the time, deterioration in the client's spatial abilities, and the behavior of shutting out or fear of meeting other people<sup>(3)</sup>.

Dementia is a negative consequence of aging changes in the central nervous system and accompanying risk factors that have implications including the inability to carry out daily activities and the need for full supervision by the caregiver. Functional consequence theory states that there are observable effects of aging which are combinations of behavior, risk factors, and age-related changes that can affect the well-being of the elderly<sup>(4)</sup>. The increase in the incidence of dementia that occurs as a result of the negative consequences that arise can cause the elderly's dependence on other people to increase.

Dementia clients have complex needs that may be a burden to those who care for them. Most of the dementia clients are treated at home by family members due to financial constraints and supportive health services. Dementia clients need emotional ties and full support in bio-psychosocial-cultural-spiritual-material from all family members. The full dependence needed by dementia clients can sometimes be a triggering factor for physical and emotional exhaustion from family members of the carer. Behavioral problems and psychological symptoms that occur in dementia clients, as well as sociodemographic and psychological factors from the family of the carer, are the 3 main factors that pose a challenge in providing care by the family<sup>(5)</sup>.

The role of the spouse as a carer for dementia clients is known to have more effects than the role of other family members<sup>(6)</sup>. Research conducted by Rigby, Johnson, & Galvin in 2018 also found that there were differences in the burden on the spouses and children who were carers. The differences that occur when a spouse and child are carers for the elderly with dementia and the risks that may occur in the caregiver can affect the quality of services provided due to the incoming burden<sup>(7)</sup>.

Acceptance of partners as carers for the elderly with dementia can affect the quality of services provided, research conducted by Peacock et al. in 2010 reveals that partners can perceive their role as an opportunity to reciprocate, to find personal strengths, and to become closer with a partner who has dementia<sup>(8)</sup>. The results show that identifying the strengths of caregivers can be an effective strategy to support their role as caregivers. Other research using 11 assessment points of Positive aspects of Caregiving (PAC) found that couples value life more and are able to develop a more positive attitude while caring for the elderly<sup>(9)</sup>.

Positive aspects of a partner in caring for a partner with dementia include four main domains which include: self-satisfaction in providing care, feelings of belonging to a partner, increased closeness and family function, and the ability to focus more on life goals<sup>(10)</sup>. The positive response that appears to a partner while caring for a husband/wife who has dementia can determine the final outcome of the treatment process carried out. The purpose of this paper is to obtain an in-depth interpretation of the positive response and its meaning in the experience of couples living life as dementia caregivers.

## METHODS

This research is a qualitative study with a phenomenological approach. The research is located in Bekasi City. The research was conducted in February-June 2019. The determination of participants was carried out using the purposive sampling technique and obtained 10 participants which can be seen in table 1. Data collection was carried out through interviews and direct observation of the participants. Interviews were conducted to get a clear meaning of the husband or wife's experience in caring for a partner who has dementia. The questions asked during the interview process are semi-structured in the form of open-ended questions, with the aim that during the interview process the information provided is not too broad from the original purpose.

Interviews were conducted by asking open-ended questions and in accordance with the needs of the researcher without leaving the theoretical foundation established in the study. The goal is that researchers get broad information from participants, the information conveyed by participants should be free from the influence of others, this is called the bracketing process or a process in which the researcher does not interfere with his knowledge of the information provided by the participants. In this study, researchers conducted interviews to identify the experiences of a husband or wife in caring for a partner who has dementia and its meaning. The interview process took 45-60 minutes.

The researcher analyzed the data using the data interpretation step based on Colaizzi, including (a) Providing an overview of personal experiences of the phenomenon under study, namely the researcher began by listening to the participant's verbal description, reading and rereading the description. Furthermore, the researcher analyzes specific statements to provide a full picture of his own experience of the phenomenon under study. (b) Make a significant statement, the researcher found statements about how the participants experienced their various experiences which were made in a list. (c) Making a theme based on the statements collected, (d) Making a textural definition, namely a description of what the participants experienced, (e) Making a structural definition, namely the researcher describing how the experiences experienced by the

participants could occur, and (f) Making a digest based on the experiences of participants. The data that the researchers found were then peer-reviewed with other researchers and afterward returned the results of the analysis to the participants to confirm the data.

**Table 1 Characteristics of Participants**

No	Name of participant (age)	Name of demensia patients (age)	Period of marriage	Employment status	Recent education	Beginning of the partner diagnosed with dementia	Experience of getting information about dementia
1.	Mrs. T (64 years old)	Mr. R (73 years old)	42 years	Housewife (IRT)	Diploma (Secretary)	Early 2017	Yes
2.	Mrs. J (65 years old)	Mr. N (69 years old)	40 years	Housewife (IRT)	Elementary School	2012	No
3.	Mrs. E (67 years old)	Mr. A (87 years old)	40 years	Housewife (IRT)	Elementary School	Early 2017	Yes
4.	Mrs. S (78 years old)	Mr. A (76 years old)	60 years	Housewife (IRT)	<i>Sekolah Rakyat</i>	2012	No
5.	Mrs. R (67 years old)	Mr. A (75 years old)	47 years	Entrepreneur	Junior High School	Early 2018	Yes
6.	Mr. R (65 years old)	Mrs. U (63 years old)	45 years	Entrepreneur	<i>Sekolah Rakyat</i>	2003	No
7.	Mrs. C (60 years old)	Mr. M (70 years old)	28 years	Housewife (IRT)	Diploma in Makeup	2012	Yes
8.	Mr. E (68 years old)	Mrs. E (68 years old)	43 years	Private employees	Upper Secondary	Early 2017	Yes
9.	Mrs. I (60 years old)	Mr. O (65 years old)	35 years	Laundry Worker	No School	Early 2018	No
10	Mrs. N (65 years old)	Mr. M (75 years old)	49 years	Housewife (IRT)	No School	2015	No

## RESULTS

The theme of positive responses experienced by carers is a collection of feelings of gratitude for the blessings that are still obtained, acceptance to the conditions experienced, and reasons for caring for a partner.

The feelings of gratitude for the blessings that were felt by the participants consisted of 2 categories which included still having other positive aspects and feeling grateful. The category still has other positive aspects said by several participants, including:

“...yes, God is really love me because I still got blessed by my sustenance” (Participant 2)

"...especially on this time, our kids didn't bother us about money because they had their steady income, so that's blessing for us" (Participant 3)

"...yes, Alhamdulillah (our money) is still enough, we are blessed as an older adults..." (Participant 4)

While the category of feeling grateful can be seen from several statements from participants, including:

"...thank God that I have been fostered (by God) long ago until I'm still busy (on my age) now that's what I took as a lesson..." (Participant 5)

"...if you ask me whether I'm sad or not, the answer is no feeling of sadness, I assume everything as a normal as long as I'm in a fit condition. Alhamdulillah..." (Participant 6)

"...Grateful (to God) to be given the opportunity to take care of my wife..." (Participant 8)

Participants showed acceptance to the conditions experienced by the participants in several statements consisting of several categories including accepting the situation, fortitude, sincerity, and not demanding the partner. Acceptance of the conditions made by the participants are as follows:

"But I knows, yes like it or not you have to go through and have to accept that the condition is like that" (Participant 1)

"...it's our responsibility, just accept as our fate" (Participant 4)

"I also don't insist on him...what else do we want to do..." (Participant 5)

The resilience shown by the participants was evident from several statements made, including:

"...The children sometimes get bored too, especially other people. Let me face it" (Participant 2)

"Tawakal (patience), if we are tawakal (patience) there is nothing more to do..." (Participant 4)

"Yes, I surrender (to God) because what else can I do..." (Participant 9)

In addition to the resilience experienced, there were several statements from the participants which also showed sincerity of the conditions they experienced, here are some statements that show the sincerity experienced by the participants:

"...Yes sincerely to Allah, everything as His will..." (Participant 2)

"...So if it (the condition) is the same, let God give him the best..." (Participant 5)

"...the lesson is like this. More accepting, It's our fate..." (Participant 10)

The experience of caring for a partner who has dementia for a certain period of time causes a feeling of not demanding that the partner do certain things, this can be seen from the statement:

"...yes I forced myself to like it. If we argued, we will fight..." (Participant 6)

"...at least it (the caregiving) should be flexible, like that" (Participant 6)

"Now, I never force her to eat again..." (Participant 8)

The third sub-theme in the part of the positive response theme is the reason for caring for a partner which consists of 3 categories, each of which is a sense of reluctance with the partner's condition, feelings of loving the partner, and feeling changes in the partner's behavior.

In the reluctance category, participants showed these emotions through several statements including:

"I don't have the heart to him, I don't have the heart, I'm still strong enough (to caregiving him)..." (Participant 3)

"Yes, the change was, if in the past she used to go home to our hometown by herself, but now I don't have the heart to let her go by herself" (Participant 6)

While togetherness as a couple, participants said several things that support this category, including:

"The reason is, because we both took care of the children since we were young by ourself..." (Participant 4)

"...yes maybe because we are a couple...as a husband and wife, just imagine that we have been living in marriage for 40 years..." (Participant 5)

"...yes, we have to go together like that..." (Participant 6)

"...yes, what do i feel? I feel tied up it's hard to go to anywhere..." (Participant 10)

The third category in this sub-theme is feeling changes in behavior caused by disease conditions, this can be noticed through participant statements:

"If her behavior is very much different. Previously her life was very neat, now all messy" (Participant 6)

"... she's so untidy, if she usually always mop the floor every day, now it's every two day..." (Participant 6)



## DISCUSSION

The positive response experienced by caregivers is a collection of several positive behaviors that appear and are experienced by caregivers while caring for a partner with dementia. Bielsten, Lasrado, Keady, Kullberg, & Hellström in 2018 state that a marital relationship can last if the couple maintains positive feelings, responds positively to the output that appears and is not worried about what is to come<sup>(11)</sup>. Spouses who experience a fracture in their relationship are known to have a burden, a sense of isolation, guilt, and higher levels of intolerance to the problems of everyday life than those who have more intimate relationships. A positive relationship between caregivers and their partners with dementia can reduce negative emotional levels and provide more positive caregiving<sup>(12)</sup>. The theme of positive responses experienced by caregivers is a collection of feelings of gratitude for the blessings obtained, acceptance to the conditions experienced, and responses or a sense of closeness as husband and wife.

The gratitude felt by the caregivers include the fact that they still have their own sustenance and gratitude for being able to take care of their partner and are still healthy until now. This is related to the research of Jang & Yi in 2017 who found 2 themes consisting of empathy for their partners and the days the caregivers lived with feelings of gratitude because they could still be with their partners<sup>(13)</sup>. The caregivers emphasized that one of the positive aspects they had was related to acceptance of their partner's condition with dementia. The results of the study also show that the caregiver burden experienced is also influenced by the knowledge they have, a sense of caring for their partner and how the quality of the relationship between caregivers and their partners<sup>(14)</sup>. The similarities that appear in the research results with the theory related to gratitude experienced can be caused, among other things, because Indonesians have a tendency to assume that a complete and good family is a family that stays together under any conditions. In addition, as a couple, caregivers feel their own pleasure in caring for their partners and have gratitude if they are able to provide optimal care for their partners.

The acceptance shown by the caregiver is a response from a sincere and steadfast feeling to the condition of a partner who suffers from dementia, this is supported by research conducted by Wadham, Simpson, Rust, & Murray in 2015 which says that caregivers show a sense of acceptance or resilience in dealing with fear and anxiety due to their partner's dementia condition<sup>(15)</sup>. Other research also shows that caregivers who focus only on the positive aspects of their relationship with their partner who suffers from dementia are known to have higher levels of relationship satisfaction and lower caregiver burden than those who focus on the negative aspects experienced when providing care<sup>(16)</sup>. The acceptance shown by the research participants in accordance with the research results could be because as Indonesians, the interviewees had relatively strong spiritual and religious roots as Indonesians in general. So that caregivers have a high level of acceptance of how the end of the dementia condition experienced by their partner, besides that as a partner, caregivers have a tendency not to yell or scold if their partner who has dementia does not follow what is ordered because it is still influenced by social norms in society.

The closeness response as a spouse is the feeling that the caregiver gets in feeling the changes experienced by the partner and the sense of closeness and intimacy as a

couple who has been married for a long time. Friedman, Bowden, & Jones in 2010 states that in the final stage of family development tasks or older adults family stage, there are at least 6 developmental tasks, including: (a) Maintaining a satisfying life, (b) Adjusting to declining income, (c) Maintaining marital relations, (d) Adjusting to the loss of a partner, (e) Maintaining family ties between generations, (f) Continuing to understand their changes, which if the partner can carry out well, it will produce positive outputs<sup>(17)</sup>. Research conducted by Braun, Mura, Peter-Wight, Hornung, & Scholz in 2010 also shows that caregivers who use more positive communication techniques are known to have lower emotional burdens and levels of depression<sup>(18)</sup>. In addition, depression experienced by caregivers is also directly correlated with the level of communication made to their partners who have dementia.

Merrick, Camic, & Shaughnessy in 2013 show that spouses who are caregivers have several feelings including commitment to being together, a sense of closeness as a partner, acceptance and focus on current conditions and awareness of the partner's condition<sup>(19)</sup>. Meanwhile, research conducted by Conway, Watson, Tatangelo, & McCabe in 2018 shows that efforts to maintain intimacy as a couple are carried out by couples, one of whom has dementia. In addition, the role of support from other parties has an important role in achieving a positive response that is owned by caregivers<sup>(20)</sup>.

Caregiving of people with dementia for a long time is known to have a correlation with high levels of caregiver stress and low quality of relationships with their partners, so the importance of effective support for caregivers is something that must be done so that the provision of care for people with dementia can be more effective<sup>(21)</sup>. The support that caregivers get (both from the government and other NGOs such as the Alzheimer's Society) is known to bring positive benefits to them. The various activities provided, information related to the condition of dementia, as well as support and social networks provided by non-profit organizations to caregivers are considered very valuable for caregivers while providing care to older adults people with dementia<sup>(8)</sup>. Various responses, both negative and positive experienced by caregivers show that being a caregiver for a spouse with dementia is difficult and could lead to disruption of their health. The responses shown by caregivers are influenced by the conditions of social environment, the culture embraced, the education level of caregiver, the economic status of family, and the caregivers' values of life<sup>(22)</sup>.

The importance of the positive response that caregivers have in the process of caring for their partner with dementia proves the need for attention from health workers to ensure that caregivers can maintain a positive level of relationship with their partner<sup>(12)</sup>. Health professionals and policy makers are expected to start considering providing health policies and social support that are more oriented to the positive things owned by the family as an opportunity to improve care delivery rather than just focusing on existing problems<sup>(8,16)</sup>. Effective development of the potential of social capital in the community requires a large amount of money and the effects of massive changes in life in society can be a major challenge faced by policy makers. However, the positive effect created is the emergence of new and more effective social networks that can promote a more meaningful social life, especially in older adults. Social capital is one of the most important factors in strengthening biological and psychological perspectives in relation to the complexities of older adults health<sup>(23)</sup>.



## Research limitations

Limited information on the number of partners, one of whom is a caregiver for a partner suffering from dementia in Bekasi who can be used as participants in the study according to the inclusion criteria. This is because the data owned by the researcher is data from families, especially children who care for parents with dementia. Various things caused, among others, limited information that could be reached by older adults couples and one of the spouses who had passed away so that only the partner who had been a caregiver or who suffered from dementia remained.

## CONCLUSIONS

The positive response of caregiver while caring for their spouse with dementia can be seen through feelings of gratitude for the blessings received, acceptance to the conditions experienced, and the response or feeling of closeness as husband and wife. Positive responses that appear in spouses who are carers can become an entry point for health workers to improve the welfare of caregivers and policy makers to focus more on forming regulations that are more supportive of older adults carers with dementia.

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