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ORIGINAL ARTICLES

"Not able to live anymore": Reaction of the grieving process of the elderly dealing with chronic disease: A qualitative study

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Abstract

Psychological issue has negative effects on health status among elderly with chronic diseases. The study aimed to identify responses of the elderly dealing with chronic diseases. This study conducted using a descriptive phenomenology method. Thirteen older adults aged were involved in this study based on the inclusion criteria to explore experiences of living with chronically diseases. The results confirmed that most of elderly who had been living with chronic diseases for several years responses the series of grieving processes. The psychological reactions are often due to suffering experienced on symptoms and complain chronically illness as well as prolonged treatment period, including denial, anger, bargaining, despair, and resignation. Further studies need to address the grieving issues, which involves all aspects of physical, social and spiritual among elderly in order to obtain the valuable information and to design sensitive nursing intervention for elderly with chronic diseases.

Keyword: grieving, chronic illness, elderly, family

1. Introduction

The growth of the elderly group is progressively moving almost throughout the world so that every year would increase. Data from the United Nations in 2015 shows that there are 901 million people aged 60 years and over. This number increased compared to 2000 as many as 607 million older adults or an increase of 48 per cent. The estimation growth of the elderly population will increase by 56 per cent to 1.4 billion population in 2030 (1). Indonesia tends to increase the same number of older adults. Older adults with aged 65 years and over increased from 5.0 per cent to 10.6 per cent (2). Based on 2014 Susenas data, the number of elderly households is 16.08 million households or 24.50 per cent of all households in Indonesia. The number of older adults in Indonesia reaches 20.24 million people, equivalent to 8.03 per cent of the entire Indonesian population in 2014 (3).

The elderly national commission (2010) defines the elderly population, who are 60 years of age or older. The other definitions of elderly are individuals who have reached the age of 60 years and over (4). Older adult categorised by The United Nations at the age of 60 years and over. The other elderly classifications are Oldest old (usually 80 years and over) and centenarians (aged 100 years and over) and super-centenarians (aged 110 years and over) (5). Elderly is one of the sub-populations included in the vulnerable category. Older adult are a vulnerable group because they tend to have higher mortality rates, less access to health services (gaps in service quality), lack of insurance, lower life expectancy and reduced overall quality of life (Shi & Stevens, 2004) in (6).

Chronic or non-communicable diseases are diseases that occur not by being transmitted from individual to another individual characterised by the characteristics of the disease suffered in the long term and the progress of the slow progress of the disease (7). Chronic conditions according to Curtin and Lubkin (1995) are conditions of diseases that are irreversible, latent and lead to interference that covers all aspects of human life. This condition requires supportive service, self-care and bodily functions, and prevents conditions that cause disability (8). Chronic disease is a health problem that costs a lot and can be prevented, for example, heart disease, stroke, type 2 diabetes mellitus, obesity and arthritis (9). Chronic diseases tend to be negative and lead to stereotypes (6). Definition of U.S. National Center for Health Statistics states that the duration of time to be classified of chronic diseases where individuals suffer for three months or more ((10). In the elderly with chronic disease, low levels of spirituality accompanied by symptoms of depression that significantly associated in the second year of chronic disease experience (11).

Psychological problems have an impact on the elderly with chronic diseases. Psychological problems experienced will affect health status. Loneliness experienced by the elderly can increase the severity of chronic diseases and affect social support (12), (13). Loneliness in the elderly has an impact on physical health (14). Older women with chronic diseases have low motivation for self-management behaviour (15). Depression experienced by Korean elderly is associated with chronic illness (16). The risk of suicide related to arthritis and kidney failure experienced by the elderly (17).

The results show that depression and time spent on daily physical activities have a healthy relationship (18). Also, low emotional support, frequent visits to doctors, difficulties accessing health services and cultural orientation are the risk factor of depression on elderly (19). The physical environment will affect health status. The research concludes that adverse events and living in poor urban areas increase the risk of depression in the elderly (20). Also, low socioeconomic status in childhood is associated with the incidence of depression in the elderly (21) and chronic illness suffered by the elderly increases health and care expenses (22). It can assume that psychological problems become one of the obstacles in the process of treatment and treatment of older adults with the disease.

The phenomenon that occurs in the elderly is that some older adults are not able to overcome health problems so that it affects the psychological aspects. Problems get more burdensome when the old experience chronic disease. Some older adults are not able to adapt to the conditions of chronic diseases. Many older adults complain about pain and suffering due to symptoms of chronic disease. Long-term suffering causes the elderly to become

desperate, indifferent, feeling helpless so that it leads to stress. Therefore, we need information and in-depth understanding of the psychological perspective of the elderly during the face of chronic disease.

2. Objective

The purpose of this study was to identify the response of the elderly in dealing with chronic diseases.

3. Methods

This study uses descriptive phenomenology method. This descriptive phenomenology approach aims to explore the broad perception of a phenomenon or experience of one's life. The populations in this study were elderly who lived In Makassar City and had a chronic disease. Inclusion criteria for participants in this study were: (1) suffering from the chronic disease for at least two years; (2) able to express experience by telling about life experiences; (3) able to speak in Indonesian.

This study describes the experience of 13 older adults aged 60-78 years who experience chronic disease. Types of chronic diseases that are felt by the elderly include cataracts, high cholesterol, rheumatism, lymph disorders, hypotension, hypertension, pain in joints, heart disease, ovarian cancer, diabetes mellitus, gastritis, and chronic wounds in a range that varies between 2-29 years. The education level of the elderly is a primary school, up to senior high school and the elderly are not in school. Research participants embraced Islam. Purposive sampling technique used in this study.

4. Results

The response felt by the elderly with chronic diseases experienced over the years is a series of grieving processes. The grieving process felt by the elderly is a psychological reaction from the suffering experienced due to symptoms and complaints of chronic illness. The series of grieving process reactions that are displayed are denial, anger, bargaining, despair, and resignation.

Denying is the process of rejection or uncertainty of the elderly over the occurrence of chronic diseases experienced at least two years. Disclaimer responses or feelings of uncertainty are experienced by the third, sixth and tenth elderly.

"I think of this, why am I this ... I was hit by another disease (lymph and hypotensive disorder) like this?" (P3)

"Why do I keep on doing this, my condition continues, my path, my feelings" (P6)

The fifth elderly expressed the response accompanied by crying because he felt tortured by God. This older adult has two chronic diseases that have not healed, namely heart disease 29 years ago and ovarian cancer 20 years ago.

"I said why did you torture me (me) O Allah ... when did you pick me up (cry)" (P5)

Bargaining as a response reaction to chronic diseases is felt by the first, third, fourth, sixth, and seventh elderly. The elderly think that they will soon face death when complaints related to the disease come.

"Hopefully I do not vomit my blood, then I die, that is what I think" (P3)

"I want to die; then I feel weak my life ... who knows if I want to die ... I want to die" (P4)

The desperate response to chronic illness was revealed by the first, third, fifth, sixth, seventh, eleventh, and thirteenth elderly. Elderly feel unable to live life with the illness and complaints that do not heal. The older experience shows that older adults who have had a chronic illness for a long time feel a decrease in the spirit of facing illness and living their lives.

"There is no longer a feeling of life ... now it seems that I cannot afford it" (P5)

"A headache that has never healed ... how it does not die, it does not heal too, a lot of my mind does not die, it does not stop working" (P7)

Elderly as the first participant in this study felt resigned to the conditions due to the ageing process that occurred so that it felt that corrective action in treatment was no longer possible.

"Want to seek treatment again is difficult because it is old. Do not want to be operated on because the age is advanced "(P1)

An experience of mourning process due to chronic illness in the form of denial, anger, bargaining, despair and resignation. Not all participant felt mourning reactions, depending on the response of each older adult. Also, to experiencing the mourning process reaction, the elderly with chronic diseases experience difficult obstacles presented in the second theme.

5. Discussion

The findings of the study found that three out of thirteen participants experienced grieving process reactions at the stage of denying where participants expressed denial or rejection of chronic disease conditions. Denial is a response of an individual's rejection of the conditions. Denial of chronic conditions felt even though the elderly have experienced a disease for at least two years. This condition is a burden on the mind for participants in dealing with chronic diseases experienced.

The results of the study from (23) state that senior women with osteoporosis feel a denial of themselves because of conditions that conflict with their wishes. Also, denial is significantly related to the experience of older people suffering from type 2 diabetes mellitus because of the need to fight disease rather than allow the disease to control their lives (24). The findings of this study are different from the results of research from (25) that Chinese elderly feel the loss, denial, worry, and loneliness that cannot avoid, but the elderly can achieve welfare and life satisfaction.

The equation obtained from the findings of the study with the results of previous studies is that older adults with chronic disease experience denial during illnesses which is participants three, six and ten expressed similar things about chronic diseases experienced as a

psychological burden. The old experiences are in line with the results of previous studies, denial is reasonable and cannot separate from chronic diseases.

Denial is a conscious or unconscious refusal to accept or believe a prognosis that is characterised by a condition of shock and disbelief in the loss (26), (27). The denial stage is the beginning of the mourning reaction process. The loss felt by the elderly such as ageing, disability, movement and deterioration of bodily functions is regular in themselves and usually carried out calmly and able to adapt well (28). Mourning reactions are automatic like reflexes and expressed according to their respective cultures. Grief is experienced emotionally and accompanied by changes in mind, behaviour, social interaction, physical well-being, and the ability to live everyday life (27).

The denial stage that occurred in the participants in this study was a normal reaction when participants were in a condition suffering from chronic disease. The denial is understandable because of the significant changes that are felt in the body of the participant so that it changes the health status. There is a negative stimulus that is felt during dealing with chronic diseases due to the ageing process, disease progression and physical mobility problems. The stimulus will affect the emotional elderly who then also affect the cognitive aspects, behaviour, social interaction, welfare and the ability to live everyday life. The expression of the experience of participants who continue to question the condition of chronic illness suffered so that it assumes that participants still do not believe or do not accept the perceived prognosis of the disease. Also, repeated events (comeback) in participants and accompanied by a poor prognosis with a long illness at least two years adds a sense of conscious or unconscious rejection. The recurrence phase (comeback) is by the chronic illness trajectory model theory (8). The conclution that the denial experienced by the elderly in this study is a normal reaction due to significant changes in the ageing process, disease progression and mobility problems. Physical as well as the incidence of a comeback.

An angry response was revealed by one participant who suffered from heart disease 29 years ago and ovarian cancer 20 years ago. Seeing the history of suffering due to the illness suffered by the participants has long aroused an angry response to his condition and expressed his feelings to God. Participants assume that he is being tortured by Allah SWT so that feelings and desires arise to face death. Other responses are feelings of resentment or anger towards the disease or pain that does not go away even after taking the drug. Research results suggest that Hispanic and non-Hispanic elderly people with chronic disease experience anger towards their chronic disease condition (29). (30) states that when denial as a defence mechanism cannot continue again and the mourning client switches to feelings of anger, rage, jealousy and resentment towards others.

The equation obtained from the findings of the study with the results of previous studies that the elderly with chronic disease experience anger. The anger felt was a result of the condition of chronic illness experienced and then expressed by the five participants with the feeling of being tortured by God. Anger is a strong feeling of hatred or an error that is expressed by anger towards the family, the health care system, God, or other external forces (27). Anger usually occurs in response to perceived threats (31). Anger is healthy when individuals with the condition of feeling unfair, their rights are not fulfilled, or reality is not in line with expectations (26). The theory is anger arises due to the threat of changes in health conditions experienced in long periods of time. The reality experienced was not in line with the expectations of the five participants, causing anger towards the destiny that God gave to the participants by the statement from (27). Anger arises due to changes that are not by the

expectations of the individual so that if the elderly with chronic diseases are at the stage of anger is a normal reaction in the face of disease.

The next response felt by the elderly during chronic illness is bargaining. Fifth participants have entered the bargaining stage in the face of chronic disease. Bargaining occurs when individuals feel they want to fight destiny from God. Bargaining happened to the fifth participants where they felt they wanted to die because of the condition of chronic illness suffered. According to the results of a study by (32), older adults with the Chronic obstructive pulmonary disease (COPD) are unable to stop smoking at the stage of bargaining or contemplation. The results of research by (33) state that the awareness of older adults with chronic disease marked by an understanding of human death and individual understanding of the next hope of death against him.

The equation obtained from the findings of the study with the results of previous studies is that older adult with chronic disease experience a bargaining stage during the face of chronic disease from the expressions of participants one, three, four, six and seven. Bargaining occurs when individuals feel they want to fight destiny from God. The reaction happened to the five participants where they felt they wanted to die because of the condition of chronic illness suffered by the results of research from (33).

According to the grieving theory, bargaining is a stage where individuals try to reach an agreement with God or destiny in return for behavioural changes to perceived loss (26), (27). Participants in the research included in the bargaining stage that tried to reach an agreement with God. The bargaining experience is from the five participants who predicted they would die because of their illness. Awareness of death is healthy for the elderly. According to (34), there is an increasing fear of death in old age which has an impact on the formation of religious attitudes and beliefs in the afterlife. When the elderly are in a weak condition due to chronic diseases suffered, awareness of death is reflected in the participants so that it triggers contemplation of the conditions they face. Bargaining is a normal reaction that will arise when individuals are faced with problems, especially experiencing chronic illness, which raises a sense of trying to reach an agreement until awareness of death arises.

Another response felt by the elderly in dealing with chronic diseases is despair. The majority of participants expressed feelings of hopelessness due to chronic illness. Some participants felt discouraged regarding the treatment process and symptoms of chronic illness that did not heal. At this stage, participants are at high risk towards depression. The results showed that depression and self-efficacy were significant predictors of medication adherence in elderly patients with hypertension. Then, partial self-efficacy is the connecting factor between depression and medication adherence (35). According to (36) need help in delivering elderly medicines to their homes to support optimising treatment.

The equation obtained from the findings of the study with the results of previous studies, namely the elderly with chronic disease experience a desperate response due to the treatment process as felt by participants thirteen, one, six, seven, and eleven. Participants felt that health information were given to participants regarding the treatment of diseases and psychological support in the treatment process. The findings of the study by the results of previous studies stated that medication adherence was related to the psychological condition of the elderly. Also, other studies state that in order to achieve optimal treatment in the elderly it is necessary to take drug delivery to the homes of each older adult.

Desperation is an individual psychological response marked by a sense of surrender. According to (37), despair is common and ordinary happens in response to grieving. So, the

feeling of despair felt by participants is a natural thing to arise in the condition of suffering from chronic disease. Also, some diseases that are owned by participants are diseases that require life-long treatment and care such as hypertension, diabetes mellitus, coronary heart disease and others. The expressions of experience conveyed by participants such as a feeling of being unable to live on and desperate to continue the treatment process of chronic diseases. This fact reflects that many participants are in a desperate stage in the treatment process. Seeing this fact, most likely the elderly will lead to treatment disobedience. It can assume that the elderly can experience despairing reactions due to long-term treatment of chronic diseases.

The last response experienced during the grieving reaction process in this study was resignation. The participant said that it was no longer possible for him to take medication and surgery for cataracts that he suffered so that participants surrendered to the condition of the disease. The results of the study indicate acceptance of the disease can be improved by improving the clinical condition of the patient and providing psychological support (38). The response of sadness of HIV positive women to facilitate their acceptance and better adaptation to disease (39). Older adults with chronic diseases in Thailand found that the elderly feel overwhelmed, understand accepting loss, and be kind to themselves and learn to live with illness (40).

The equation obtained from the findings of the study with the results of previous studies is that older adult with chronic disease experience a phase of resignation or acceptance. The first participant revealed the absence of the possibility to perform medical procedures for chronic diseases experienced. This experience supported from the results of research from (38) clinical conditions influence the acceptance of the disease. Also, resignation to the disease condition by participants was also felt by Thai seniors who received loss and life with chronic diseases (40). The research is consistent with the opinion of (41) that changes in ageing are complicated things that lead to pathological conditions that will affect the physical condition of the elderly. The emergence of resignation is an average effect on the grieving process (27). Resignation that occurs in participants has become an irreversible condition and participants are aware of it. The ageing process that occurs is no longer possible for participants to get further treatment because of the high risk that must be faced. Therefore, older adults with chronic diseases who have reached the stage of resignation have realised that the disease conditions experienced cannot be followed up because ageing that occurs will pose a higher risk.

The results showed that it was normal for the elderly to experience denial, anger, bargaining during chronic illness. Also, the elderly could experience a desperate reaction during a chronic illness due to a long treatment process. Elderly experience resignation is a sign that the elderly are aware of the condition of the disease they are experiencing. If no further action for a psychological problem, it will have an impact on severe psychological disorders. Therefore, nurses can implement nursing interventions related to grieving problems based on the stage of the grieving process.

6. Conclusion

The elderly experience denial, anger, bargaining during chronic illness is usual. Also, the elderly could experience a desperate reaction during chronic illness due to the prolonged treatment process. Besides, resignation reaction was a sign that the elderly were aware of the condition of the disease. Therefore, nursing intervention is needed related to grieving issues that include aspects of self, physical, social and spiritual. Community nurses can apply nursing interventions focusing on the stage grieving issues including verbal, psychological

approaches (opening feelings), physical (physical activity), social (sharing with a peer through self-help groups) and spiritual (praying, dhikr and surrender).

Declaration of conflict of interest

No conflict interests

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