

4-1-2020

Meaning of life among elderly individuals with chronic diseases living with family: A qualitative study

Bahtiar Bahtiar

Department of Community Health Nursing, Faculty of Nursing, Universitas Hasanuddin, Makassar 90245, Indonesia, bahtiar.nursing@gmail.com

Junaiti Sahar

Department of Community Health Nursing, Faculty of Nursing, Universitas Indonesia, Depok 16424, Indonesia

Wiwin Wiarsih

Department of Community Health Nursing, Faculty of Nursing, Universitas Indonesia, Depok 16424, Indonesia

Follow this and additional works at: <https://scholarhub.ui.ac.id/mjhr>



Part of the [Epidemiology Commons](#), and the [Public Health Education and Promotion Commons](#)

Recommended Citation

Bahtiar B, Sahar J, Wiarsih W. Meaning of life among elderly individuals with chronic diseases living with family: A qualitative study. *Makara J Health Res.*2020;24:35-40.

Meaning of life among elderly individuals with chronic diseases living with family: A qualitative study

Bahtiar Bahtiar^{1*}, Junaiti Sahar², Wiwin Wiarsih²

1. Department of Community Health Nursing, Faculty of Nursing, Universitas Hasanuddin, Makassar 90245, Indonesia
2. Department of Community Health Nursing, Faculty of Nursing, Universitas Indonesia, Depok 16424, Indonesia

*E-mail: bahtiar.nursing@gmail.com

Abstract

Background: Many elderly individuals receive lifelong treatment caused by chronic diseases with symptoms that affecting them physically, psychologically, socially, and spiritually. Spirituality plays an essential role in health conditions and social relationships given that it provides meaning to the elderly individuals life by allowing them to see the wisdom of life events experienced. This research aimed to explore the meaning of life among elderly individuals with chronic diseases. **Methods:** This research applied descriptive phenomenology using Colaizzi's method of thematic analysis among 13 elderly patients with chronic diseases. **Results:** Elderly individuals with chronic diseases found meaning through the following items: (1) surrender to God, (2) divine destiny, (3) care until death, (4) guarantee for health finance, (5) role replacement, and (6) observing the development of children and grandchildren. **Conclusion:** Elderly individuals with chronic diseases can obtained positive meaning in life through family support. Families are thus expected to facilitate the development of meaning in the lives of elderly individuals with chronic diseases to help them fulfill their spiritual needs.

Keywords: chronic disease, elderly, spirituality

Introduction

The population of elderly individuals has continued to increase every year. Moreover, 2015 data from the United Nations revealed 901 million individuals aged 60 years and over, with estimates showing a 1.4 billion or 56% increase in the elderly population by 2030.¹ Similar elderly population growth has been observed in Indonesia where older adults aged 65 years and over have increased from 5.0% to 10.6%. Based on the 2014 SUSENAS data, Indonesia has over 20.24 million older adults comprising 8.03% of its population, as well as 16.08 million elderly households comprising 24.50% of all households in Indonesia.² Considering that many older adults need lifelong treatment due to chronic diseases, social support is imperative.

Social support, especially from family, is essential for helping elderly individuals with chronic diseases achieve wellness. Positive support from persons closest them, such as a spouse, can reduce depression among elderly individuals with chronic conditions.³ Several other studies have also shown the importance of social support among elderly individuals with chronic diseases.^{4,5} Hence, despite increasing the burden on family members, most older adults with chronic diseases need assistance from a family caregiver.

Previous studies have shown that family caregivers are considerably burdened to the extent that it affects family interaction.^{6,7} Another study showed that half of the caregivers of elderly individuals with chronic diseases in China have felt burdened,⁸ which could consequently influence their well-being.⁹ In conclusion, the need for spirituality is crucial among family caregivers and elderly individuals suffering from chronic diseases.

Spiritual awareness among elderly individuals with chronic diseases has a significant correlation with their health status. Older adults with breast cancer who follow transcendental meditation techniques have been able to improve their quality of life.¹⁰ Other studies have shown that older adults used spirituality as a self-coping mechanism. Accordingly, they believed that their illness could not sever their connection with the almighty God, that God regulates disease, and that prayer activities act as a mediator in dealing with chronic diseases.^{11,12} Therefore, the role of spirituality in helping elderly individuals interpret life during a state of suffering is related to their awareness that God mediates the healing process, through which elderly individuals can achieve hope for a useful, meaningful, and valuable life.

One previous study had shown that elderly individuals with multiple chronic diseases seek to stay healthy and

need caregiving, financial support, and healthcare services to overcome their illness.¹³ Moreover, another study found that family caregivers and healthcare providers engaged in the management of elderly individuals with chronic illnesses, who have to deal with personal problems, a complicated healthcare system, and lack of social support.¹⁴

Previous research has determined how spirituality improves the health status and condition of elderly individuals. Spirituality plays an essential role in helping elderly individuals with chronic disease interpret the meaning of life. Nevertheless, some elderly individuals are unable to find meaning in their life and are thus unable to adapt to the conditions brought by chronic diseases. Chronic suffering causes elderly individuals to feel discouraged, indifferent, and helpless, which lead to stress and burden on the family given that most older adults in Indonesia live with their families. Given the lack of research on how elderly individuals with chronic diseases living with families in Indonesia interpret their lives, information regarding the same has been considered imperative. Therefore, better understanding on the meaning of life among elderly individuals with chronic diseases who live with their families is needed.

Methods

This research utilizes a descriptive phenomenological method.

Population and sample. Our study population comprised 13 elderly individuals with chronic diseases aging between 60 and 78 years old and living with family in Makassar City. The inclusion criteria were as follows: (1) chronic disease for at least two years; (2) able to express about life experiences; and (3) able to speak in Indonesian. The exclusion criteria were as follows: (1) hearing and speech disorders and; (2) mental disorders preventing cooperative communication during interviews.

Recruitment. The research was conducted from January to July 2018. Examinations were performed at home or in community settings. Purposive sampling was used to recruit participants. The researchers obtained a list of elderly individuals with chronic diseases who live in the Rappokalling sub-district of Tallo District, Makassar City from local health volunteers. However, given that such data did not provide the duration of the chronic illness, the researchers utilizes snowball sampling, a technique that uses chain referral from one participant to another based on the inclusion and exclusion criteria. Researchers visited the participant's house before interviewing to make sure the participant satisfied the inclusion criteria. Moreover, the researcher conducted an initial assessment, provided an initial explanation of the study, and established a schedule during the first visit. On the second visit, the participant

obtained informed consent and participated in an in-depth interview using a semi-structured technique.

Ethical consideration. Ethical approval had been obtained from Universitas Indonesia (76/UN2.F12.D/HKP.02.04/2018).

Data analysis. The technique used during data analysis was based on the thematic analysis established by Colaizzi, which included transcribing data from interviews, reading all participant, descriptions formulating statements into codes or labels, forming categories and themes, describing the basic structure of phenomena, and validating research results.¹⁵

Validity and reliability. To determine validity, the researchers conducted a trial interview on six older adults in Tanjung Priok, North Jakarta and Rappokalling district of Makassar city. Recordings and verbatim interviews had been discussed with the observer and experts, after which input and suggestions, which comprised changing interview guidelines, focusing questions submitted to participants on the study objectives, improving probing (the process of enhancing the questions), and improving bracketing during interviews, were obtained. Trial testing of the voice recorder involved adjusting the position and distance between the microphone and the mouth to between 20 and 30 cm in order to improve the recorded sound. The reliability of research was used to confirm dependability. The researchers and external reviewers reviewed the data to ensure no glaring mistakes, discussed inquiry audits, performed English transcription, and analyzed the data for coding, categorization, and thematic analysis.

Results

Demographic data of the participants. Table 1 outlines the demographic characteristics of the 13 older adults who participated in the current study.

The current study identified six themes outlined in the following subsections.

Surrender to God. The second, fourth, fifth, tenth, eleventh, twelfth, and thirteenth participant felt that the meaning of life involved their relationship an almighty God. The elderly individuals felt dependent on a source of strength beyond human ability. Moreover, the participants felt that they had a more severe disease compared to others, which made them surrender their illness to God until death. Participants also expressed hope for healing by praying to the almighty God, as stated by the following participant:

“It depends on God how to live... get the most severe disease... I surrender to God... if I will in dealing with the dying process, I wish everybody let me go ... ” (P5)

Table 1. Characteristic of participants

Characteristic	N	Percentage (%)
Age (in years)		
60–70	10	77
71–80	3	23
Education level		
Illiterate	4	30
Elementary School	5	40
Primary School	0	0
Senior High School	4	30
Job		
Housewife	9	70
Domestic Worker	1	7.5
Driver	1	7.5
Farmer	1	7.5
Civil servant pensionary	1	7.5
Religion		
Islam	13	100
Other	0	0
Duration of illness (in years)		
2–10	10	77
11–20	2	15
21–30	1	8

“Just given the gift of God... resigned to God and prayed for healing of my illness” (P11)

Divine destiny. Divine destiny, a form of self-transcendence experienced by elderly individuals, had been experience by the second, fifth, eleventh, and twelfth participant. The participants believed that their condition was their destiny and the will of God that must be faced and that they must remain grateful for such destiny. The meaning of living among elderly individuals with chronic disease was self-transcendence expressed by surrendering to God and believing that the illness experienced was divine destiny. Self-transcendence provided not only meaning to life but also hope for cure during illness, as supported by the following statements:

“. just be grateful if you are sick, I can’t do anything beside just trying to live, this my fate from God” (P2)

“. because of the destiny of God... besides, I seek treatment too, All of these because of God... I feel grateful to God because I am still alive” (P12)

Care until death. The third and eighth participant expressed that survival guarantee comprised their meaning in the life. The participants expressed hope of receiving treatment until death and desired to be cared for by their children during illness, as described by the following statements:

“I said there were many of my children, the most important thing, i could be treated by my children until I am die” (P3)

“The desire that I expected (in sick condition), Just my child as hoping” (P8)

Guarantee for health finance. The tenth participant disclosed that he had been financed for his chronic illness. Children pay for the living and treatment expenses of elderly individuals given that they are no longer able to work, as supported by the following participant statement:

“My children funded me for my illness condition, I can’t handle it because I am jobless now because of the disease” (P10).

Role replacement. The fourth and tenth participant expressed expectations regarding role replacement. Accordingly, the fourth participant revealed that he was unable to carry out social duties and roles and therefore transferred such roles to his child. Moreover, the tenth participant stated that he could no longer participate in a wedding due to feelings of shame related to his condition as highlighted by the following statements:

“I told to my son to replace me for ceremonial family, I felt guilty but at the same time I was grateful for substitute me” (P4)

“I am embarrassed to go to the bride because of my illness, It was okay if my child goes to agenda of family... it just same if my child substitutes me” (P10)

Observing the development of children and grandchildren. The fifth and tenth participant expressed hope that they could observe the development of their children and grandchildren. Participants revealed that their children and grandchildren were their source of strength, reason for life, and supporting factor when dealing with chronic diseases.

“I have been sick for more than 30 years, I had Cancer surgery and it made me but if I see my grandchildren coming together, I am happy... I hope I can see my grandchildren go to school... I can still see my children” (P5)

“Fortunately, it was my great pity for my child because of I got sick like this. I don’t know the future of my children, I am so scare if I die because no one of them is married” (P10)

Discussion

Surrender to God. Elderly individuals with chronic illness included herein believed that surrendering to

God was their meaning in life given their assumption that surrender to God was a way of dealing with their illness and that diseases came from God and should be accepted. Moreover, participants expressed feelings of resignation to their condition, self-acceptance of their illnesses, patience in dealing with their illness, and decreased fear of death. Self-acceptance among older adults with chronic diseases indicate that they have reached transcendence.

Transcendence is an essential predictor of mental health and well-being that results in healing and hope.¹⁶ Previous studies have shown a significant direct relationship between self-transcendence, spiritual well-being, and the total effect of self-transcendence on spiritual well-being.^{17,18} This is similar to psychological acceptance of chronic diseases from a spirituality perspective. Inward and outward reflection and finding meaning and purpose in life are sub-processes of transcendence, while re-evaluating expectations about the disease could likely be a sub-process of positive self-assessment.¹⁹ One study showed that faith helps disease acceptance and improves coping strategies; seeking medical care does not conflict with beliefs about destiny; and spirituality increases inner strength, fosters hope and acceptance of self-responsibility, and helps find meaning and purpose in life.²⁰

Our results show that experiences among elderly individuals with chronic diseases are generally relatively similar, where different ways of interpreting life depend on life experiences and spiritual strength. The results of our research and participant experiences are in line with the self-transcendence theory that an increase in vulnerability increases self-transcendence and leads to well-being.²¹ One study describes self-transcendence as life satisfaction, positive self-concept, positive life expectancy, and finding meaning in life.²²

Divine destiny. Elderly individuals with chronic diseases believe that what they are currently experiencing comes from God and cannot be changed, consequently accepting their illnesses as part of their destiny. The participants' experiences suggest that their meaning in life is derived from self-transcendence by surrendering to God and viewing their condition as divine destiny. Moreover, the process of self-transcendence that occurs within the participants provides them with a positive assessment of the condition through which they can derive meaning in life from attitudinal values. Opinions from participants suggested attitudinal values, such as absence of a need to cure the illness and awareness of death, which indicated that participants implemented attitudinal values that trigger self-acceptance of the illness with patience, fortitude, and sincerity.

Different studies have shown that stressors among elderly individuals, such as chronic illness and spouse's death, have various physical and mental health consequences—which trigger elderly individuals to overcome pain and suffering and adapt to the health problem. Moreover, elderly individuals have been preparing for the battle with chronic disease,^{4,14,23} and have been found to become depressed because of the symptoms of the illness, pain, disability, and loneliness during chronic illness.²⁴ Hence, research shows that depression among the elderly population is closely related to the presence of chronic diseases.²⁵ Other studies have indicated that the existence of chronic diseases, such as arthritis and kidney failure, is closely related to a high risk for suicidal thoughts and attempted suicide.²⁶ Our participants' experiences show the need for positive self-assessment in order to avoid negative feelings associated with the chronic illness experienced. Suffering, perceived as the process of disease development, allows participants to develop a broad view of their chronic condition through which they can interpret their suffering and obtain wisdom.

Care until death. Elderly individuals with chronic diseases expressed hope that family caregivers would provide care until death and perceive the family as an essential element in care and treatment. Indeed, studies have shown that family caregivers have an impact on longevity and improving health status.²⁷ Moreover, families help elderly individuals develop resilience toward chronic diseases. On the other hand, chronic diseases among elderly individuals significantly affect family members, especially those responsible for care.²⁸ Furthermore, one study showed that family caregiver's involvement has a psychological effect on individuals with medical illness.⁶

Elderly individuals at home are in constant and desperate need of help, especially during illness. Chronic diseases are conditions that require careful management for an extended period, which necessitates an exceptional family caregiver. Older adults therefore hope that family members guarantee the care and financing of their chronic diseases and that family assist them in achieving a satisfying life arrangement while adjusting to reduced income.

Guarantee for health finance. Given that elderly individuals remain dependent on their children and families for economic support, they hope to continue to receive funding, especially for their medication and care. This guarantee for the care and financing of chronic diseases is centered on religion. Elderly individuals want to be treated and cared for as taught by Islam, where children and not social welfare institutions bear the burden of caring for their parents. Elderly individuals expect to be treated like a baby that requires care and individual attention with full affection in accordance

with the teachings of Islam. However, the result shows that providing care for the elderly with chronic diseases negatively affects the welfare of the caregiver.²⁸ Moreover, older adults with chronic diseases who do not have children and relatives are at high risk of being admitted to a social care institution.

Role replacement. Chronic diseases among elderly individuals serve as a barrier toward social interaction, such as attending family or social events. Moreover, the health status of elderly individuals makes them reliant on their children to replace their role within the family and community. Another guarantee expressed by participants during chronic illness is that their role be replaced. Participants with physical limitations and decreased body function experience changes in social interaction and indicated that they no longer feel able to engage in social activities and feel embarrassed to attend activities, such as weddings, because of their disease condition. Other studies have shown that elderly individuals who have chronic injuries experience a change in their social role²⁹ and that the disease can affect their ability to engage in social activities.³⁰ Elderly individuals who are tired, in pain, or are physically limited may feel isolated. Side effects from treatment can also make it challenging for them to continue normal social activities.

Observing the development of children and grandchildren. Elderly individuals with chronic diseases have concerns about the course of their condition, triggering hopes for observing the development of their children and grandchildren. Hope and assurance have been found to make life more meaningful. We can conclude that observing the development of children and grandchildren, as well as instrumental support through financing and role replacement during illness, provides emotional support. With emotional and instrumental support from family members, elderly individuals can attain a more positive meaning in life, allowing them to feel excited about living. The results of the present study found that observing elderly individuals with chronic diseases found meaning in observing the development of their children/grandchildren.

Some limitations of this study need to be discussed. First, given that all participants embraced the Islamic religion, our results cannot be applied to those from other religions. Moreover, the current study lacked undergraduate participants. Another limitation is that the research team performing the inquiry audit did not reside within the study area, increasing the time needed to confirming dependability.

Conclusions

The study results identified the following items that provided meaning to the life of elderly individuals with

chronic illness: (1) surrender to God, (2) divine destiny, (3) care until death, (4) guarantee for health finance, (5) role replacement, and (6) observing the development of children or grandchildren. Elderly individuals with chronic diseases were able to obtain meaning in life through family support. As such, families are expected to facilitate the development of meaning among the lives of older individuals with chronic diseases in order to support the fulfillment of their needs. Thus, family support needs to be explored to enhance our understanding on the interaction among family caregivers and elderly individuals with chronic diseases. Moreover, the family is expected to provide instrumental and emotional support to elderly individuals with chronic diseases, which can help them find meaning in life and support the fulfillment of their psychological and spiritual needs.

Acknowledgments

We thank all the participants, community health volunteers, and Cita Sehat Foundation for their cooperation and support during the research process.

Funding

We thank the Indonesia Endowment Fund for Education (LPDP) Ministry of Finance for funding this research.

Conflict of Interest Statement

The authors declare no conflicts of interest.

Received: October 16th, 2019 Accepted: January 29th, 2019

References

1. United Nations. Department of Economic and Social Affairs, Population Division (2015). World Population Ageing, 2015.
2. BPS. *Statistik Penduduk Lanjut Usia 2014: Hasil Survei Sosial Ekonomi Nasional [Statistic of Elderly Population in 2014: Results of the National Socio-Economic Survey]*. Jakarta: Badan Pusat Statistik; 2015.
3. Ahn S, Kim S, Zhang H. Changes in Depressive Symptoms among Older Adults with Multiple Chronic Conditions: Role of Positive and Negative Social Support. *Int J Environ Res Public Health*. 2016;14:16.
4. Karantzas GC, Gillath O. Stress and wellbeing during chronic illness and partner death in later-life: The role of social support. *Curr Opin Psychol*. 2017;13:75–80.
5. Kang M, Kim J, Bae S-S, Choi Y-J, Shin D-S. Older Adults' Perception of Chronic Illness Management in South Korea. *J Prev Med Public*

- Heal.* 2014;47:236–43.
6. Leung K, Chen C, Lue B, Hsu S. Social support and family functioning on psychological symptoms in elderly Chinese. *2007;44:203–13.*
 7. Joel F. Correlate of burden and coping ability of caregivers of older adults with chronic illness in Nigeria. *Scand J Caring Sci.* 2018;32:1288–96.
 8. Hu X, Peng X, Su Y, Huang W. Caregiver burden among Chinese family caregivers of patients with lung cancer : A cross-sectional survey. *Eur J Oncol Nurs.* 2020;37:74–80.
 9. Or R, Kartal A. Influence of caregiver burden on well-being of family member caregivers of older adults. *Psychogeriatrics.* 2019;19:1–9.
 10. Nidich SI, Fields JZ, Rainforth MV, Pomerantz R, Cella D, Kristeller J, et al. A Randomized controlled trial of the effects of transcendental meditation on quality of life in older breast cancer patients. *Integr Cancer Ther.* 2009;8:228–34.
 11. Shevon Harvey I, Cook L. Exploring the role of spirituality in self-management practices among older african-american and non-Hispanic white women with chronic conditions. *Chronic Illn.* 2010;6:111–24.
 12. Smith-Cavros E, Avotri-Wuaku J, Wuaku A, Bhullar A. “All I Need Is Help to Do Well”: Herbs, medicines, faith, and syncretism in the negotiation of elder health treatment in rural Ghana. *J Relig Health.* 2017;56:2129–43.
 13. Ploeg J, Canesi M, D Fraser K, McAiney C, Kaasalainen S, Markle-Reid M, et al. Experiences of community-dwelling older adults living with multiple chronic conditions: A qualitative study. *BMJ Open.* 2019;(e023345).
 14. Fotokian Z, Shahboulaghi FM, Fallahi-khoshknab M. The empowerment of elderly patients with chronic obstructive pulmonary disease : Managing life with the disease. *Plos one J.* 2017;12:1–16.
 15. Streubert JH, Carpenter RD. *Qualitative research in nursing.* 3rd ed. Philadelphia: Lippincott Williams & Wilkins; 2003.
 16. Young C. *Spirituality, health and healing: An integrative approach.* Ontario: Jones and Bartlett Publishers; 2011.
 17. Haugan G, Rannestad T, Hammervold R, Garasen H, Espnes GA. The relationships between self-transcendence and spiritual well-being in cognitively intact nursing home patients. *Int J Older People Nurs.* 2014:65–78.
 18. Kim S, Reed PG, Hayward RD, Kang Y, Koenig HG. Spirituality and Psychological well-being: Testing a theory of family interdependence among family caregivers and their elders. *Res Nurs Health.* 2011;34:103–15.
 19. Duggleby W, Hicks D, Nekolaichuk C, Holtslander L, Williams A, Eby J. Hope, older adults, and chronic illness: A metasynthesis of qualitative research. *J Adv Nurs.* 2012;1–13.
 20. Nabolsi MM, Carson AM. Spirituality, illness and personal responsibility: The experience of Jordanian Muslim men with coronary artery disease. *Scand J Caring Sci.* 2011;25:716–24.
 21. Reed PG. *The theory of self-transcendence: Middle range theory for nursing.* 2nd ed. New York: Springer Publishing Company; 2008.
 22. Mccarthy VL. The role of transcendence in a holistic view of successful aging. *J Holist Nurs.* 2013;31:84–92.
 23. Hassani P, Izadi-Avanji F-S, Rakhshan M, Majd HA. A phenomenological study on resilience of the elderly suffering from chronic disease : a qualitative study. *Psychol Res Behav Manag.* 2017;10:59–67.
 24. Warner CB, Roberts AR, Jeanblanc AB, Adams KB. Coping resources, loneliness, and depressive symptoms of older women with chronic illness. *J Appl Gerontol.* 2017;073346481668721.
 25. Park J-I, Park TW, Yang J-C, Chung S-K. Factors associated with depression among elderly Koreans: the role of chronic illness, subjective health status, and cognitive impairment. *Psychogeriatrics.* 2016;16:62–9.
 26. Kim SH. Suicidal ideation and suicide attempts in older adults: Influences of chronic illness, functional limitations, and pain. *Geriatr Nurs (Minneap).* 2016;37:9–12.
 27. Allert G, Sponholz G, Baitsch H. Chronic disease and the meaning of old age. *Hastings Cent Rep.* 1994;24:11–13.
 28. Latham K. Chronic illness and families. *Wiley Blackwell Encycl Fam Stud.* 2016.
 29. Goldberg E. The lived experience of diverse elders with chronic wounds. *Heal Manag Publ.* 2010;56:36.
 30. Helgeson VS, Reynolds KA. Social psychological aspect of chronic illness. In: *Computer intervention: illness self-management/quality of life of rural women.* Blackwell Publishers Ltd. 2009;25–46.