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## Older people living with chronic illness

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## ABSTRACT

This study aimed to gain a better understanding of what it is like for older people to live with chronic illness. A Phenomenological method was used. A purposive sampling strategy was used to recruit older people with chronic illness from one community in Nakhonratchasima province, Thailand. Semi-structured interview guides were used to explore the participants' experiences and perceptions. Data saturation was reached after 30 interviews were completed. The data was analyzed using thematic analysis. Four themes emerged from the data: 1) living a restricted life, 2) feeling overwhelmed, 3) understanding and accepting loss, and 4) being kind to oneself and learning to live with the disease. The findings may increase understanding about what older people with chronic illness experience. Health care providers can use this understanding to relate health care and guidance to their patients by incorporating cultural influences and religious/spiritual beliefs into the standardized care for this population.

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## Introduction

Chronic diseases, also known as non-communicable diseases (NCDs), have become the leading cause of death and disability worldwide. Chronic illnesses are ongoing, generally incurable, illnesses or conditions that require ongoing medical attention and affect a person's daily life.<sup>1,2</sup> It reported that 80–92% of older adults have at least one chronic illness and 50–77% have two or more.<sup>3</sup> Cardiovascular disease, arthritis, and diabetes are among the most common chronic illness in older adults. Heart disease and cancer together account for nearly 46% of all deaths.<sup>4</sup> Arthritis is the most common cause of disability. Older people with arthritis reported that they have trouble with their normal activities and vision difficulties.<sup>5,6</sup> Diabetes is the leading cause of kidney failure, lower-limb amputation not due to injury, and new cases of blindness among adults.<sup>7</sup> Moreover, it has also been reported that approximately 63% of all deaths in the world are attributed to NCDs, and this causes great socioeconomic harm to all countries, particularly developing countries.<sup>8</sup>

The number of older persons (defined as age 60 and over) in Thailand has grown rapidly and will continue to do so in future decades. Since 1960 the number of older people in the Thai population has

increased seven-fold, from approximately 1.5 million to 10.7 million in 2015, or 16% of the total population. Future population ageing will occur even more rapidly, with the number of older persons projected to increase to over 20 million by 2035, at which point they will constitute over 30% of the population. Moreover, within the next few years, persons age 60 and older will outnumber children under age 15 for the first time in Thai history.<sup>9</sup>

The reasons for the rapid rise in chronic illnesses are varied. They include the aging population, longer life expectancies due to improvements in medical care for infectious diseases, and advances in diagnostic technology and treatment options for many chronic diseases.<sup>10</sup> Changes in the ways people live, eat, work, and play also contribute to increased prevalence of chronic conditions like diabetes, high blood pressure, and heart disease, while improved treatments for conditions such as cancer and congestive heart failure extend life expectancy.

The health consequences of chronic illnesses are extensive. Quantitative studies have shown that chronic illness have a huge adverse effect on individual's quality of life (QOL), both physically and mentally.<sup>11–18</sup> Experiencing a chronic illness has devastating physiological effects on patients and their families.<sup>19</sup> It has also been conclusively established that the consequences of chronic disease include increased health risks, reduced QOL, decreased probability of being employed, and greater financial burdens due to managing the conditions. In addition, findings from qualitative studies have revealed that people with chronic illness experience loss of self because they are living a restricted life, existing in social isolation, living with uncertainty, and having to depend on others and medical

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technology.<sup>20,21</sup> Although patients with chronic illness understand their illness and its cause, they are unaware of the illness's symptoms and have little knowledge of how to manage them. Eventually, there are negative consequences as the illness affects their lives.<sup>22</sup>

A major challenge for our health care system in the 21<sup>st</sup> century is developing better ways of caring for older people with chronic illness. Healthcare providers play a vital role in providing care to older people with chronic illness so they can live long and productive lives and enjoy a good QOL. It is, therefore, imperative for them to understand how older people live their lives. A true understanding of the patients' world would help healthcare providers to support individuals and facilitate providing quality care and holistic practices.

Research has provided us with an initial, although general, understanding of the dimensions of health among patients with chronic illness. Previous studies have shown that there is no clear picture of what their lived experiences are, or how they allow older people to incorporate the illness into their everyday lives. In addition, although there are numerous qualitative studies focusing on chronic illness, the participants' ages in those studies varied, ranging from 40 to 80 years old. The impetus for the current study was directly related to the lack of qualitative studies focusing on how older people with chronic illness learned to live their lives and the belief that in-depth interviews and the systematic analysis of self-reported experiences about living with chronic illness could promote the delivery of supportive and quality care. Therefore, the purpose of this study was to explore the lived experiences of older adults with chronic illness.

## Design and methods

### Design

This study was aimed at gaining a better understanding of what the lived experiences of older persons with chronic illness are. In this study, a descriptive phenomenological design underpinned by Husserl's philosophy, as modified by Giorgi, was used as the guiding framework<sup>23</sup> to discover the first hand experiences of older participants with chronic illness. Descriptive phenomenology methods are designed to capture the true meanings of an experience by delving into the reality of living with chronic illness in depth.<sup>24,25</sup> It is also suggested that descriptive approaches are used to illuminate poorly understood aspects of experiences.<sup>25</sup> This approach attempts to move beyond the clinical model of health and, instead, provides a deeper insight into what older people with chronic illness experience in their life. This method also allows investigators to arrive at a deeper understanding of the older people's experience of living with chronic illnesses. Although each participant has their own personal experience, when multiple participants' experiences are examined together, the interwoven stories create a more complete, meaningful picture that allows people outside the phenomena to understand their reality. The researcher endeavored to identify the essences of these experiences as faithfully as possible.

### Study participants

For a phenomenological study, it is important that all participants experience the phenomenon being studied.<sup>23,26,27</sup> Thus, a purposive sampling strategy was used to recruit participants, specifically, older people with chronic illness from a community in Nakhonratchasima province, Thailand. Inclusion criteria for participants included: 1) having one or more chronic disease; 2) being able to comprehend Thai; and 3) being over 60 years of age. The exclusion criteria were being: 1) diagnosed with major psychiatric

problems, or 2) under 60 years of age. A home care nurse who served the target community assisted with the recruitment. Once participants agreed to take part in the study, the researchers asked each individual to sign a consent form. Recruitment ceased when data saturation was reached.<sup>28</sup>

### Ethical considerations

This study protocol was approved by the Institutional Review Board for Suranaree University of Technology. To build trust between the participants and researchers, the researchers accompanied the home care nurse on home visits prior to recruitment for the study. When potential participants were identified during the home care visits, the home care nurse assisted the researchers in recruiting. The researchers obtained the consent forms from the prospective participants. Each participant was informed about the purpose of the study, potential costs and benefits derived from participating in the study, their right to withdraw from the study at any point and given assurance of protection of participant confidentiality. Moreover, participants were informed that data would be kept safe and confidential and would not go any further and that only authorized persons would have access to the data. To assure the participant's privacy concerns, each individual participant determined the setting for their interview. This allowed them to be more relaxed, perhaps translating into a better, more informative interview. All interviews were conducted at participants' homes. When interviews are conducted within a patient's home, the interviewer is provided a glimpse into the living environment of the participant, permitting a fuller understanding of, or connection with, their lives.

### Data collection

The researchers collected the data between November 2016 and February, 2017. A semi-structured interview guide was used to direct the conversation toward the participants' experiences and perceptions (see Table 1). The face-to-face interviews were in Thai, beginning with an open question about how the patient experienced falling ill and how had they learned to live with the ongoing illness. Follow-up questions (e.g., *tell me more, in what way, and how did you feel or experience it*) were asked to gain deeper insight into the phenomenon. Interview duration varied between 60 and 90 minutes. All interviews were audiotaped and transcribed verbatim for data analysis.

### Data analysis

The researchers reached the point where there was no more additional information related to the studied phenomenon being

**Table 1**  
Semi-structured interview guide.

Interview guide
Greeting... <i>"We are here to talk with you about what it is like to live with chronic illness and how you live your life. Please explain your feelings the best you can. None of your thoughts and/or feelings will be judged. Everything will be safely kept confidential and will not go any further. If you feel uncomfortable to answer any of the questions, you can let us know right away."</i>
1. Tell me what it is like to live with chronic illness.
2. How has your health status been over the years?
3. How has going through this experience changed your life?
4. What helps you understand your illness and your treatment?
5. How do you manage living with a devastating disease?
6. Are there any other things you would like to share with us before we finish?

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