The unmet needs of palliative care among patients with non-malignant chronic illness in Indonesia: A phenomenology study

Rona Cahyantari Merduaty[1]*, Tuti Nuraini[1], Sihwastuti Sihwastuti[2]

[1] Basic and Fundamental Nursing Department, Faculty of Nursing, Universitas Indonesia, Indonesia
[2] Palliative Care Team, Cipto Mangunkusomo National Center Hospital, Indonesia

Jurnal Keperawatan Padjadjaran (JKP)

Volume 12(3), 299-307

http://dx.doi.org/10.24198/jkp.v12i3.2397

Article Info

Received : October 21, 2023
Revised : August 24, 2024
Accepted : December 11, 2024
Published : December 25, 2024

Corresponding author

Rona Cahyantari Merduaty*
Basic and Fundamental Nursing Department, Faculty of Nursing, Universitas Indonesia, Depok, West Java, Indonesia; Address: Jl. Prof. DR. Sudjono D. Pusponegoro, Pondok Cina, Kecamatan Beji, Kota Depok, Jawa Barat, 16424, Indonesia; Phone: +6287782918809, E-mail: ronacahyantari@ui.ac.id

Citation

Merduaty, R.C., Nuraini, T., & Sihwastuti, S. (2024). The unmet needs of palliative care among patients with non-malignant chronic illness in Indonesia: A phenomenology study. *Jurnal Keperawatan Padjadjaran, 12*(3), 299-307. http://dx.doi.org/10.24198/jkp.v12i3.2397

Website

http://jkp.fkep.unpad.ac.id/index.php/jkp

E-ISSN: 2442-7276
P-ISSN: 2338-5324

Abstract

Background: People with chronic illness tend to report multiple and complex symptoms that decrease their ability to meet their needs and quality of life (QoL). As an approach to address people with chronic illness, palliative care (PC) in Indonesia is still primarily focused on people with chronic malignancies. This results in that paradigm meaning the spectrum of palliative care is interpreted narrowly only for cancer or end-of-life (EOL) patients.

Purpose: This study explores the experience and needs of patients diagnosed with non-malignant chronic illness toward their illness to identify the need for palliative care.

Methods: Semi-structured interviews were conducted on seven patients with non-malignant chronic illness. An ECOG adaptation palliative patient score developed by Dr. Cipto Mangunkusomo National General Hospital (RSCM) was used to screen the participants. Only participants with a palliative score of four or higher (≥4) were interviewed. All data were recorded, transcribed, and analyzed using Colaizzi's method.

Results: There are six major interrelated themes with one sub-theme emerging from this qualitative study that uniquely match with the illness trajectory of non-malignant chronic patients. The themes are: (1) negative feelings that cannot be described at the time of diagnosis; (2) ignorance of the disease process (sub-theme: late realization that illness cannot be cured); (3) helplessness during the medication/treatment process; (4) shame of being a burden to family and surroundings; (5) limited access and support ; and (6) family and God as motivation and hope reinforcement to recover at the end of illness stage.

Conclusion: People with non-malignant chronic illnesses complain of several challenges, which are not much different from those with cancer. Therefore, patients with non-malignant chronic illness also have a similar need for palliative care. A deeper and broader assessment of palliative care should also be implemented in patients with non-malignant chronic illness after the early diagnostic process.

Keywords: chronic illness; emotions; humans; noncancer; palliative care

Introduction

Along with world development in various aspects, it was reported that life expectancy increased to 73.6 years in 2022 and continues to increase; therefore, it is predicted that the individual age will reach 78.2 years in 2050 (Schumacher et al., 2024). The increase of life expectancy is believed to be a trigger for the surge of non-communicable and chronic illnesses incidences in various parts of the world, such as ischemic heart disease, which is projected to remain the leading global cause of death until 2050, followed by stroke, COPD, Alzheimer's disease, chronic kidney disease, hypertensive heart disease, and colorectal cancer (Schumacher et al., 2024). Deaths caused by chronic illness indicate that the demographic trend that affects most adults imposes a burden of its own in many sectors. It is undeniable that disabilities often accompany the condition of individuals with chronic illnesses in carrying out their daily activities (National Center on Birth Defects and Developmental Disabilities & Centers for Disease Control and Prevention, 2020).

Unfortunately, patients with non-malignant chronic illness are often being left untended by the health system due to the unclear illness trajectory (Bostwick et al., 2017). Meanwhile, a similar burden is reported as to those living with cancer (Dalkin et al., 2016). Several previous studies have shown that patients with chronic illness (other than cancer) who receive palliative care, either in the form of intervention alone or treated specifically in the palliative unit, survive longer than those who do not (Rocker et al., 2016). However, the palliative paradigm is still narrowed to only end-of-life cases and cancer patients (Quinn et al., 2021). Consequently, it impedes the better prognosis of people living with non-malignant chronic illness. Therefore, this study aimed to see what patients with non-malignant chronic illness actually experience and need in response to their disease trajectory. Hopefully, it can capture how palliative care should be initiated and implemented in the future.

Materials and Methods

Design

This study used a qualitative method with a phenomenological approach. Searching the meaning is the characteristic of this approach, and can be an effective method to study the meaning of experience in a particular group of people (Grossoehme, 2014). Understanding a complex phenomenon involved in behavior and communication of patients with non-malignant chronic illness is expected to be broadened by phenomenological approach (Neubauer et al., 2019).

Participants and Setting

Participants in this study were selected using a purposive sampling technique with the criteria established by researchers: (1) patient with non-malignant chronic illness diagnosis (validated by medical record); (2) has been screened and recommended to receive palliative care services; (3) patient is conscious and does not have neurological deficit. Patients with communication barrier were excluded. Sihwastuti (ST) and primary nurses in internal medicine and neurology inpatient wards assisted RCM in identifying patients with those criteria and screened them with the adaptation of the Easter Cooperative Oncology Group (ECOG) palliative patient screening score developed by the Dr. Cipto Mangunkusumo National General Hospital (RSCM). Only participants with a palliative score of four or higher (≥4) were interviewed. Saturation was achieved after six participants were interviewed. One more participant was added to enrich participants' heterogeneity.

Ethical Consideration

Ethical issues in this study have been anticipated by obtaining consent before collecting data through interviews. The research team explained the information about the study after screening eligible participants. Confidentiality of participant data and transcribed interview recordings were kept in a limited access cloud folder. This study was approved by the Faculty of Nursing Research Ethics Board (no.263/UN.F12.D/HKP.02.04/2018 on 26th June, 2018) and RSCM-Faculty of Medicine at the Universitas Indonesia (no. 0693/UN2.F1/ETIK/2018 on 16th July 2018).

Data Collection

RCM was responsible for conducting semi-structured interviews. To complete RCM's responsibility, she was assisted by ST as a research team member and also team leader of palliative care nurses in RSCM. RCM has completed her bachelor's degree in nursing and took qualitative research method and bioethic training to improve her capacity in conducting this research. RCM used her experience as a primary nurse during her internship in the internal medicine ward for learning the characteristics of participant. The length of the interview varied between 25 and 45 minutes, depending on the participants' circumstances at the time. The interviewer, RCM, made sure to ask and explore all the questions with the participants, though there were some participants who could not provide answers for extended periods. Interviews were recorded using the researcher's mobile phone recorder for later transcription. During the interview, RCM was also accompanied by ST as a palliative care team leader to anticipate any physical discomfort which might emerge due to palliative condition.

In conducting the interviews, RCM approached patients who fitted the criteria, explained the objectives of study, and asked patient's consent to participate in this study. After consent was obtained, participants were asked seven questions about their feeling and experience after being diagnosed with non-malignant chronic illnesses. RCM asked participants to tell their story when first time diagnosed, their feelings after being diagnosed, their understanding about the illness, life changes in their life after diagnosis, their expectations for when the illness worsens, their fear during illness, and how much their family know about their expectations and fears.

Data Analysis

The recorded data from the interviews that had been transcribed verbatim were then analyzed using the Colaizzi method, beginning with the familiarization phase and ending with verification. Transcriptions were read several times until RCM and TN were fully immersed with the experience of the participant. This aligns with Grossoehme's (2014) explanation, which describes the importance of re-reading

Table 1. Characteristic of Participant

Characteristics	Number (n)	Percentage (%)
Age		
18-25 years old (y.o.)	4	57.1
26-35 (y.o.)		
36-55 (y.o.)	1	14.3
55-65 (y.o.)	1	14.3
>65 (y.o.)	1	14.3
Sex		
Woman	3	42.9
Man	4	57.1
Medical Diagnose		
Heart Failure	1	14.3
Renal Failure	1	14.3
Chronic Obstructive Pulmonal Disease		
Stroke or Neurological Disorder	1	14.3
Diabetes Mellitus	1	14.3
Liver Cirrhosis		
Others (HIV/AIDS, SLE, TBC, hematological disorders)	3	42.9
Years (living with diagnosis)		
< 5 years	3	42.9
5-10 years	3	42.9
>10 years	1	14.3
Rehospitalization History (in last 1 year)		
More than once	5	71.5
None	2	28.6

the transcribed interview to get a sense of the whole data. RCM continued identifying significant statements from all participants. Bracketing was applied to formulate meaning in every identified statement, until themes were developed. RCM and TN had brainstorming to write full a description of theme-related phenomenon, then condensed it into a concise narrative to be verified by participants. Applying the Colaizzi method to analyze the data of phenomenology research facilitates the researcher to have a clear and logical process in creating the fundamental structure of explored experience (Wirihana et al., 2018). It also ensures the dependable findings of phenomenology research (Northall et al., 2020).

Trustworthiness

To ensure trustworthiness of this study, RCM performed data triangulation to the research throughout the data analysis process. During data analysis, RCM and TN together re-read and recoded the transcription. Triangulation was also conducted after themes and narrative description of each theme were developed. RCM involved three participants in reading the study results and asking whether the results aligned to the perceptions and experiences conveyed during the interview. Previously, RCM, TN, and ST as investigators in this study performed researcher triangulation to obtain similar perceptions regarding the themes and its description.

Results

In this study, researchers managed to obtain heterogeneity in participants regarding age distribution and chronic illness diagnoses. Unfortunately, prospective participants who obtained a score of at least 4 of ECOG palliative screening tool adaptation and met criteria were most in the young adult range. Those with a higher score of ECOG palliative screening tool adaptation, afforded more potential patients but these were in an impossible condition to be interviewed because of their illness. Selected participants had a score of four or more with a chronic illness diagnosis other than cancer (Table 1).

Based on the qualitative data analysis carried out, eighty-six significant statements were found and coded into 129 keywords, until six interrelated main themes and one subtheme were identified inductively. In addition, the relevance of these themes was identified based on the illness trajectory of chronic illness experienced by the participants.

Only one theme emerges from analysis during this first stage of illness trajectory-time of diagnosis. Most participants report their feeling and emotion after knowing their diagnosis for the first time. Some of them might know their diagnosis after experiencing several symptoms a long time ago, while others just reported their health decline in a short time.

Theme 1: Negative Feelings That Cannot Be Described

Shocked, sad, anxious, and disappointed are some negative feelings that emerged, and were admittedly difficult for the participants to describe the first time they were diagnosed with a chronic illness. One participant said that *"Well, I feel sad, anxious, and so on because we have never heard of dialysis like that"* (Participant 3), and another one said, *"Yes, I'm disappointed. How on earth, I'm surprised to get a disease like this. Someone said SLE was a lifelong disease, there was no cure yet. So, I am shocked"* (Participant 7).

The second stage of illness trajectory is when participants try to be adaptive to all the symptoms, medication, and treatment related to their diseases. Negative and positive themes represent participants' responses to their illness.

Theme 2: Ignorance of the Disease Process

Not surprisingly, in the early days of treatment, almost all participants said they knew nothing about the disease process and its treatment. One of the statements was *"I don't know, I searched it myself, I don't understand. Still don't understand"* (Participant 6).

Another statement was, *"Well, I didn't understand anything before, then I was like this when I was like junior high school. I got sick like this. What do I do? Just be thankful… I didn't know before the effect of this disease, how did it affect me. I didn't know before, so I used to, just like taking regular medication"* (Participant 2).

Subtheme: Late realization that illness cannot be cured

The longer participants were living with their illness, a new realization emerged that the illness cannot be fully recovered. Not many know that the definition of chronic illness is a condition that generally affects individuals for three months or more, which may worsen over time, and cannot be cured but can be controlled (Bernell & Howard, 2016). However, the chronic illnesses suffered differed from the understanding of the disease or the participants' previous knowledge. Treatment carried out by the participants regularly over a long period also failed to cure their disease.

"Finally, I decided to go to Harapan Kita Heart Hospital to be checked, and now I can have surgery. Basically, I also get treatment every month, but over time there is also a feeling of pain in the heart and a heavy chest. It turns out that it is the result of the kidneys too. The kidneys are also treated with no inheritance. The only thing is, they have to be operated on so that the kidneys are washed with blood. Yesterday it was immediately dialysis. Then the heart is the only thing that has to be operated on" (Participant 5).

"Well, the mouth ulcers have been given an ointment, vitamin C, but it still doesn't heal, right? I gave the abothyl, it did not recover. The mouth ulcer has not healed for almost three months. It kept getting better, until 10 days there, I could go home. But before going home, the doctor said, 'You have to continue to seek treatment,' he also said, 'you have to take medication regularly.' I asked, 'until when?' the doctor replied 'for a lifetime'" (Participant 1).

Theme 4: Helplessness During the Medication/Treatment Process

Based on the definitions that have been described previously, chronic illness suffered by participants cannot be cured and may worsen at any time. Therefore, participants often undergo regular check-ups or repeated treatment for their non-malignant chronic illness symptoms.

"I dropped because I was tired from 2011 to 2013, I'm bored with taking medication. So, I wasted the medicine. Yes, bored, depression. It's bored to take medicine, I just wasted it" (Participant 1).

"And what I feel now is the worst moment during illness because I can't walk now, so it's helpless" (Participant 7).

"So all the diseases are there so that I am suffering terribly, but still I will go on for surgery. These are all serious kidney and heart diseases. I am not just tired but suffering too. Just waiting in line at the ER for 10 hours. For Harapan Kita, thank God it's good, even if to get a room you have to fight. Sometimes it's sad, but instead of not having a place it is better to be placed anywhere" (Participant 5).

"Tired of being treated constantly, want to be healthy. Tired because the body continues to receive injections, and continues to take medication. The injections continue to cause pain. My mom really knows that I'm afraid of being injected" (Participant 6)

Theme 5: Shame of Being a Burden to Family and Surroundings

Most of the chronic illnesses suffered by the participants resulted in the persistence of certain physical symptoms that interfere with daily activities. This condition is recognized to make participants feel different from those around them. The inability of participants to carry out normal activities as usual also made participants fully dependent on their families to fulfil their daily needs. Therefore, participants expressed feelings of fear and embarrassment during their diagnosis of chronic illness, it became a burden for their family and surroundings.

"There are a lot of fear. Feeling different from my *friends, such as posture for example. When I was in junior high school, I could play soccer, exercise, wake up in the morning, run, but now my activities are just around the house and helping my parents. You can't be tired, you have to take care of your body"* (Participant 2).

"Gradually I didn't want to work, I didn't want anything. My stomach is fat. The first year I was not fat, but 2 years later my stomach was fat like a 9 months pregnant belly. I am embarrassed, even in the office I am embarrassed. Not feeling energetic. Initially the power was reduced until now it is not powerful at all" (Participant 3).

"I used to be able to work, earn money. Now I can't work anymore, have to rest at home, can't be tired. I will immediately drop if I am feeling tired. I have to rest at home" (Participant 7).

Theme 6: Limited Access and Social Support

Participants in this study said that often limited access is one of the things that became a separate factor in undergoing treatment with chronic illness. Inequality in health service units, the amount of funding, and less optimal information from health workers were among things patients acknowledged they often found. One participant said *"The explanation should be accurate. What is the pain, what is the cause, take the medicine that really matches the disease, don't give too much medicine"* (Participant 1). In addition, another said, *"I live in Depok, so in a nearby hospital not so far from my house to hospital. So that my transfusion is closer"* (Participant 2). Another participant said *"We do not need to pay for dialysis but the medicine needs to be paid"* (Participant 3).

Therefore, it can be concluded that the lack of information and health facilities burdens the participants undergoing long-term care related to their chronic illness.

Theme 7: Family and God as Motivation and Hope Reinforcement to Recover

In the end, all participants in this qualitative study always rely upon God Almighty. This belief facilitates every effort to improve their health, even though the participants know their illness will not be completely cured.

"I wish I wanted to take the effort to recover but I believe that if the disease is what God loves, health is also made by God, yes, but still Allah" (Participant 4).

"Yes, if you have this disease, you have to be sincere, just lillahi ta'ala (because of God). In the future, if it is, it will definitely be cured, just pray. Yes, keep up the spirit. Yes, even though there is no cure, you must keep on going. There are still many friends who get SLE too, right. There is still mother who encouraged me" (Participant 6).

"What makes me survive is because I wanted to do that, want to do activities, want to take a walk, want to meet friends again. Since this illness, I am alone at home, I have no friends, I just watched TV. Yes, want to play again" (Participant 7).

Discussion

This study aims to explore experience and needs of patients diagnosed with non-malignant chronic illness toward their illness, which will be a foundation to identify palliative care needs in that group. Since most study in palliative care is conducted in patients with cancer, experience of patients with a non-cancer chronic illness will be a new perspective in developing palliative care for non-cancer chronic area, especially in Indonesia. Non-cancer chronic illnesses, such as cardiovascular illness, stroke, and renal failure, are reported as catastrophic diseases in Indonesia, which burdens health budget and annually increases the disability-adjusting population. Knowing their experience, expectation, and fear when diagnosed and living with the illness is essential to identify their needs of care. Despite different illness trajectories between cancer and non-cancer patients, both suffered from their illness and complain of similar complex needs. Six themes describe the actual needs of patients with non-malignant chronic illness, including physical, psychological, social, economy, and even spiritual domain. This aligns with the palliative care domain developed by National Consensus of Palliative Care.

The challenge of people living with non-malignant chronic illness begins once diagnosis is delivered by the healthcare provider or even long before a diagnosis known. Unclear physical complaints might be felt by patients with non-malignant illness before the diagnosis is known whether in a short or long timeframe. The more intense the physical complaints, thee more daily life was affected, and it pushes them to know what actual health problems they have. Some patients with a non-malignant illness might need to undergo varied diagnostic tests to finally know the diagnosis, and it proves a greater burden on the physical, psychological, and even economic aspects of a patient's life. As illness diagnosis is revealed, patients who might already have suffered lengthy physical symptoms and diagnostic procedures might feel indescribable negative emotions, such as fear, and being anxious, disappointed, and sad. These negative emotions emerge because the participants are in a healthy, prime, and productive condition in their daily lives when they are diagnosed with a non-malignant chronic illness, so this moment becomes a frightening specter for their lives (Brzoza et al., 2022). In terms of disappointment, this emotion perhaps arises due to premature termination (Sommerfeld, 2022). Lack of discussion between patients, family, and healthcare professionals (HCP) and their experience of such critical times may lead to disappointment during diagnosis.

Participants start living with the disease by entering the next non-malignant chronic illness course stage. The sudden diagnosis process and the incomplete explanation from the HCP gave the participants an incomplete understanding of the chronic illness process they suffered. The participants' ignorance continued over time for treatment because of factors such as loss of productivity due to the symptoms (Van Wilder et al., 2021) and recurrent consultation with the physician. Ignorance manifests boredom during the complex treatment, and symptoms might be faced by patients with non-malignant chronic illness and trigger people's negative reaction to incompliance with all health procedures (Van Wilder et al., 2021). Meanwhile, ignorance could be influenced by the level of knowledge regarding their chronic illness. Patients with non-malignant chronic illness with lower knowledge of their disease would have a lower quality of life (Casariego et al., 2019), including ignorance as a negative emotion. It can be implied that most of this study's participants tend to ignore their condition because they have to deal with complex treatments and symptoms without sufficient information regarding the disease.

After being diagnosed with a chronic illness, participants were still shaken by various negative feelings, and tried to adapt to their physical condition by following a series of treatments. After more symptoms were experienced during non-malignant chronic illness, participants realized or became aware that their disease is incurable. Awareness of patient's chronic illness was formed due to their experience facing all symptoms (Hocking et al, 2013). Meanwhile, those with no symptoms tend to be unaware of their condition. Realization or awareness of the status of living with incurable disease brings several benefits for patients, such as reducing futile treatment, facilitating advance care planning, and improving illness acceptance (Ozdemir et al., 2022, 2023). It is expected that, by accepting their illness, participants will show a better attitude toward understanding the chronicity of the disease and involve more in health-promotion behavior (Brzoza et al., 2022).

Stress, depression, resignation, and fatigue are some forms of expression of participant helplessness during repeated treatment in the hospital. Greater pain or unmanageable physical symptoms of patients with a non-malignant chronic illness would lead to poorer functional status and manifest in powerlessness and helplessness. The existence of cognitive bias of participants regarding their chronic illness may also lead to helplessness. Therefore, clear communication between HCP and patients during the treatment should be improved. However, helplessness due to poorer functional status may affect their dependency on family or others in managing their condition (Van Wilder et al.,2021). Patients with a non-malignant chronic illness tend to be different physically and fail to meet society's expectations, making them feel guilty and burdened to others. Congruently, feeling of helplessness and being burdensome is the root of the feeling of shame experienced by these patients. Shame among people living with chronic illness is an energetic failure of the body (Stage, 2022). Unfortunately, shame makes them always feel inferior and turn to isolate themselves rather than reaching for help (Trindade et al., 2020).

The challenge of patients with a non-malignant chronic illness worsens due to the limited access to healthcare, social, and financial support. Patients with a non-malignant chronic illness who come from lower socioeconomic status tend to have lower access to financial and social networks that may help them during stressful conditions on their disease trajectory (Van Wilder et al., 2021). Even patients who come from good socioeconomic status might be burdened by their non-malignant chronic illness. Consistent physical and psychological symptoms, regular check-ups, or exacerbation period potentially make their productivity decline. Patients can not earn money because they need to resign from their job. Worse still, family members as caregiver also need to resign to take care of the patient. This unfortunate condition can be somewhat alleviated by national healthcare insurance from Social Security Agency on Health (BPJS). However the referral system is somehow quite stressful for patients with a non-malignant chronic illness, who are burdened with physical discomfort.

Patients with non-malignant chronic illness who feel shame to their family and friends might disturb their connection with society. Sometimes, family also try to confine the illness of their family members to their surroundings. Feeling shame and fear to burden others might be a main reason why patients and family with non-malignant chronic illness become more closed. This condition makes patients and family with non-malignant chronic illnesses reluctant to ask for help when they need transport, health logistics, or financial support when an emergency situation arises. Meanwhile, there might be also situations where society reluctantly welcomes patients and family with non-malignant chronic illnesses. In several remote areas in Indonesia, living with chronic illness, regardless of the causes, can be a curse for the family. Therefore, when situations worsen, no one from the surroundings can provide the support. Amore unfortunate condition is when the neighborhood area does not have proper physical facilities (transportation system) to facilitate patients with a non-malignant chronic illness to get treatment quickly. Furthermore, palliative care, which should be facilitated for these people to improve their quality of life, is still limited. Thus, those conditions may lead to this theme emerging.

Ultimately, faith in religion and God among patients with a non-malignant chronic illness is the resource of their eternal hope to cope with suffering (Klimasiński et al., 2022). Their faith in God is represented by prayer as an expression of spirituality. While praying, patients with non-malignant chronic illnesses can have a moment of serenity and silence. In this moment, they can have a little bit of time to reflect and maintain their sanity amidst life's challenges due to their illness. Prayer among patients with non-malignant chronic illnesses is not only a medium for asking for recovery from their chronic illness (Jors et al., 2015) but also plays a role in positively transforming their experience by expressing gratitude (Hamilton et al., 2019). The spiritual drive is key for patients with non-malignant chronic illnesses to interpret their condition to have a more positive meaning and boost their self-care management and compliance with treatment (Pham et al., 2020).

Reflecting on the exposure to these needs, patients with non-malignant chronic illnesses are not much different from cancer patients. However, the narrow paradigm that has long developed in the healthcare environment is that palliation only applies to cancer patients. From the beginning of chronic illness trajectory, patients with non-malignant chronic illnesses also require palliative care. The disease process tends to be long, and the uncertain trajectory of a chronic illness may be a barrier for HCP to introduce palliative care from the start. Therefore, a deeper and broader assessment related to palliation should also be implemented in patients with non-malignant chronic illnesses.

Limitations

There were difficulties in obtaining appropriate participant characteristics regarding the inclusion criteria set. Determination of palliative status for patients outside of cancer in the hospital is still uncommon. Palliative referral in the hospital for adult patients is often done when the patient's prognosis is very poor (end of life), so it is challenging to find palliative patients with adequate communication skills. This condition made it difficult for this study to find participants, so only seven patients were involved. In general, the proportion of diseases varied. However, there were limitations to finding female participants with a non-malignant diagnosis who were undergoing or being referred to palliative care. In addition, this study has limitations in generalizing the range of chronic illness duration suffered by participants due to the various diagnoses and research methods used. Although individuals with the same chronic illness experience the same stressor, each individual has different adaptation mechanisms depending on their physical and psychosocial factors. This made the researchers unable to divide the participants into duration groups based on their disease trajectories.

Conclusions

Non-malignant chronic illness does not only have an impact on physical changes. There is a more complex dimension to the needs of such patients. Negative feelings, such as anxiety, fear, and disappointment, are the first problems that arise when the diagnosis is communicated. The lack of information and openness from health workers regarding chronic illness conditions that turn out to be incurable led to the realization that patients came late and it often made patients depressed, tired, and helpless. The inability of patients with non-malignant chronic illnesses to carry out normal daily activities also often makes them embarrassed and afraid to burden their surroundings. This is exacerbated by the lack of access, facilities, and high care costs, making it difficult for them to undergo treatment. Therefore, patients often raise unrealistic hopes for recovery by making God and their families a source of strength to undergo a long care and healing process. Reflecting on the exposure to these needs, patients with a non-malignant chronic illness are not much different from cancer patients. However, the narrow paradigm that has long developed in the healthcare environment is that palliation only applies to cancer patients. Therefore, a deeper and broader assessment related to palliative care should also be implemented in patients with non-malignant chronic illness.

Declaration of Interest

I confirm that there are no known conflicts of interest associated with this publication and there has been no significant financial support for this work that could have influenced its outcome.

Acknowledgment

I thank to Faculty of Nursing Universitas Indonesia as a sponsor of this research through Grant of Young Scholar 2018.

Funding

Funding for this research was provided by Faculty of Nursing Universitas Indonesia.

Data Availability

All data are available as part of the article and no additional source data are required

References

Bernell, S., & Howard, S. W. (2016). Use your words carefully: What is a chronic disease? *Frontiers in Public Health, 4.* https://doi.org/10.3389/FPUBH.2016.00159

Bostwick, D., Wolf, S., Samsa, G., Bull, J., Taylor, D. H., Johnson, K. S., & Kamal, A. H. (2017). Comparing the palliative care needs of those with cancer to those with common non-cancer serious illness. *Journal of Pain and Symptom Management, 53*(6), 1079-1084.e1. https://doi.org/10.1016/J.JPAINSYMMAN.2017.02.014

Brzoza, K. B., Główczyński, P., Piegza, M., Błachut, M., Sedlaczek, K., Nabrdalik, K., Gumprecht, J., & Gorczyca, P. (2022). Acceptance of the disease and quality of life in patients with type 1 and type 2 diabetes. *European Journal of Psychiatry, 36*(2), 114–119. https://doi.org/10.1016/J.EJPSY.2021.12.001

Casariego, E., Cebrián-Cuenca, A. M., Llisterri, J. L., Micó-Pérez, R. M., Orozco-Beltran, D., Otero-Cacabelos, M., Román-Sánchez, P., & Sáez, F. J. (2019). Knowledge and experiences of Spanish patients and carers about chronic disease. *International Journal of Environmental Research and Public Health, 16*(1). https://doi.org/10.3390/IJERPH16010039

Dalkin, S. M., Lhussier, M., Philipson, P., Jones, D., & Cunningham, W. (2016). Reducing inequalities in care for patients with non-malignant diseases: Insights from a realist evaluation of an integrated palliative care pathway. *Palliative Medicine, 30*(7), 690–697. https://doi.org/10.1177/0269216315626352

Grossoehme, D. H. (2014). Overview of qualitative research. *Journal of Health Care Chaplaincy, 20*(3), 109. https://doi.org/10.1080/08854726.2014.925660

Hamilton, J. B., Kweon, · Leslie, La-Urshalar, ·, Brock, B., & Moore, A. D. (2019). The use of prayer during life-threatening illness: A connectedness to God, inner-self, and others and difficulty sleeping. *Sandberg. Journal of Religion and Health.* https://doi.org/10.1007/s10943-019-00809-7

Hocking, A., Laurence, C., & Lorimer, M. (2013). Patients' knowledge of their chronic disease-the influence of socio-demographic characteristics research. *Australian Family Physician, 42*, 411–416.

Jors, K., Büssing, A., Hvidt, N. C., & Baumann, K. (2015). Personal prayer in patients dealing with chronic Illness: A review of the research literature. *Evidence-Based Complementary and Alternative Medicine, 2015*. https://doi.org/10.1155/2015/927973

Klimasiński, M., Baum, E., Praczyk, J., Ziemkiewicz, M., Springer, D., Cofta, S., & Wieczorowska-Tobis, K. (2022). Spiritual distress and spiritual needs of chronically ill patients in Poland: A cross-sectional study. *International Journal of Environmental Research and Public Health, 19*(9). https://doi.org/10.3390/IJERPH19095512

National Center on Birth Defects and Developmental Disabilities, & Centers for Disease Control and Prevention. (2020, September 16). Disability and health related conditions. https://www.cdc.gov/ncbddd/disabilityandhealth/relatedconditions.html

Neubauer, B. E., Witkop, C. T., & Varpio, L. (2019). How phenomenology can help us learn from the experiences of others. *Perspectives on Medical Education, 8*(2), 90–97. https://doi.org/10.1007/S40037-019-0509-2/TABLES/2

Northall, T., Chang, E., Hatcher, D., & Nicholls, D. (2020). The application and tailoring of Colaizzi's phenomenological approach in a hospital setting. *Nurse Researcher, 28*(2), 20–25. https://doi.org/10.7748/NR.2020.E1700

Ozdemir, S., Chaudhry, I., Ng, S., Teo, I., Malhotra, C., & Finkelstein, E. A. (2023). Prognostic awareness and its association with health outcomes in the last year of life. *Cancer Medicine, 12*(4), 4801–4808. https://doi.org/10.1002/CAM4.5286

Ozdemir, S., Lee, J. J., Malhotra, C., Teo, I., Yeo, K. K., Than, A. U. N. G., Sim, K. L. D., & Finkelstein, E. R. I. C. (2022). Associations between prognostic awareness, acceptance of illness, and psychological and spiritual well-being among patients with heart failure. *Journal of Cardiac Failure, 28*(5), 736–743. https://doi.org/10.1016/J.CARDFAIL.2021.08.026

Pham, T. V, Cherry, ·, Beasley, M., Gagliardi, J. P., Koenig, H. G., & Stanifer, J. W. (2020). Spirituality, coping, and resilience among rural residents living with chronic kidney disease. *Journal of Religion and Health, 59,* 2951–2968. https://doi.org/10.1007/s10943-019-00892-w

Quinn, K. L., Wegier, P., Stukel, T. A., Huang, A., Bell, C. M., & Tanuseputro, P. (2021). Comparison of palliative care delivery in the last year of life between adults with terminal noncancer illness or cancer. *JAMA Network Open, 4*(3), 1–13. https://doi.org/10.1001/jamanetworkopen.2021.0677

Rocker, G., Downar, J., & Morrison, R. S. (2016). Palliative care for chronic illness: Driving change. *Canadian Medical Association Journal, 188*(17–18). https://doi.org/10.1503/cmaj.151454

Schumacher, A. E., Kyu, H. H., Aali, A., Abbafati, C., Abbas, J., Abbasgholizadeh, R., Abbasi, M. A., Abbasian, M., Abd ElHafeez, S., Abdelmasseh, M., Abd-Elsalam, S., Abdelwahab, A., Abdollahi, M., Abdoun, M., Abdullahi, A., Abdurehman, A. M., Abebe, M., Abedi, A., Abedi, A., … Murray, C. J. L. (2024). Global age-sex-specific mortality, life expectancy, and population estimates in 204 countries and territories and 811 subnational locations, 1950–2021, and the impact of the COVID-19 pandemic: A comprehensive demographic analysis for the Global Burden of Disease Study 2021. *The Lancet, 403*(10440), 1989–2056. https://doi.org/10.1016/S0140-6736(24)00476-8

Sommerfeld, E. (2022). Patients' response to moments of disappointment with their therapist: The roles of disappointment experience, emotional abilities, and perceived alliance negotiation. *Psychotherapy Research.* https://doi.org/10.1080/10503307.2022.2144526

Stage, C. (2022). Shame, chronic illness and participatory storytelling. *Body & Society, 28*(4), 3–27. https://doi.org/10.1177/1357034X221129752

Trindade, I. A., Ferreira, C., & Pinto-Gouveia, J. (2020). Shame and emotion regulation in inflammatory bowel disease: Effects on psychosocial functioning. *Journal of Health Psychology, 25*(4), 511–521. https://doi.org/10.1177/1359105317718925/FORMAT/

EPUB

Van Wilder, L., Pype, P., Mertens, F., Rammant, E., Clays, E., Devleesschauwer, B., Boeckxstaens, P., & De Smedt, D. (2021). Living with a chronic disease: Insights from patients with a low socioeconomic status. *BMC Family Practice, 22*(1), 233. https://doi.org/10.1186/S12875-021-01578-7

Wirihana, L., Welch, A., Williamson, M., Christensen, M., Bakon, S., & Craft, J. (2018). Using Colaizzi's method of data analysis to explore the experiences of nurse academics teaching on satellite campuses. *Nurse Researcher, 25*(4), 30–34. https://doi.org/10.7748/NR.2018.E1516