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Self-Care Experience and Expectation: Exploring the Values and Cultural Influences Among Patients Living with Chronic Diseases

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Abstract

The incidence of readmission among patients with chronic diseases is often influenced by. values and cultural factors that are sometimes contradictory to medical treatment. This study aimed to explore the experiences and expectations of patients with chronic diseases in self-care based on their values and culture. A qualitative assessment of participants with Betawi culture, in Indonesia was conducted through Focus Group Discussions (FGDs) and an in-depth interview. A total of 46 participants were interviewed consisting of 14 traditional leaders, nine family members, and 23 participants with chronic disease. Thematic content analysis was employed to analyze the interview data. Four themes found from this study regarding the participants' cultural practices, and expectations are (1) Spurt by the traditional healer as health practice is done by participants before medical treatment; (2) Prevention actions are done with herbal consumption, maintaining the environment and improving nutrition; (3) Participant needs family and peer support for their health behavior; (4) Participants expect that the health services become more simple and easier by using technology application. The findings highlight that participants with chronic diseases are eager to do self-care with influenced by families and peers, as well as communities' values and culture. Comprehensive nursing care encourages active patient engagement in self-care practices with family support that in turn will improve their quality of life.

Keywords: *Chronic Disease; Self-Care; Culture, Families'Support.*

Introduction

Noncommunicable diseases (NCDs) also known as chronic diseases, have become a predominant cause of global mortality. NCDs were the leading cause of death globally with 60.8% in 2000 and increased to 73.6% in 2019 (WHO, 2022). The most chronic diseases are cardiovascular diseases, cancers, chronic respiratory diseases, and diabetes (GBD, 2019). Furthermore, patients with chronic diseases encounter a 10.6% risk of readmission (Brunner- La Rocca et al., 2020; Samuel et al., 2022).

A critical determinant of readmission among chronic disease patients lies in incorrect behaviorsand lack of active participation in self-care (Hoffman, 2022; Osokpo & Riegel, 2021; Pugh et al., 2021; Riegel et al., 2019). People will behave and seek care to achieve optimal health basedon the cultural values they adhere to (McFarland & Wehbe-Alamah, 2019; X. Xu et al., 2022).Indonesia has many ethnic groups

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with correspondingly unique cultures (Ipa et al., 2016; Silvana Tumansery, 2018). Among these, the Betawi culture is followed by the traditional people of Jakarta. While Jakarta has grown and become the capital city of Indonesia has attracted a diverse population. Historically, the Betawi culture was influenced by foreign ethnicities such as Dutch, Chinese, Arabs, Indians, and Portuguese and local ethnicities such as Sumatran, Javanese, and Sundanese (Irwan et al., 2020). The influences of many cultures onthe original Betawi culture will in turn create a modified Betawi culture. Despite the cultural changes that take place, the Betawi community members continue to practice and uphold the culture's values in their daily lives, particularly the principles of conquering health issues (Abdul Chaer, 2017). This situation needs to be explored more deeply to gain a better

understanding of their current culture and values with respect to health care and how they maintain their own health (X. Xu et al., 2022).

The self-care capabilities of chronic disease patients are influenced by their beliefs and culturalexperience, ultimately shaping their expectations of recovery (Lin et al., 2019; Saepudin et al.,2018, Befecadu et al., 2022). AIHW, (2020); Befecadu et al., (2022), and Laranjeira et al., 2020) described that to be able to guide people in their self-care ability, nurses have to understand deeply their cultural experience and wellness expectations.

Therefore, nurses must possess an in-depth understanding of their patients' values and social contexts to meet their multifaceted needs (McFarland & Wehbe-Alamah, 2019; Soriano et al.,2019). Aydin et al., (2022) and Cowling, (2018) also stated nurses can enhance patient outcomes while enriching their own professional perspectives. This study aimed to explore theexperiences and expectations of chronic disease patients in self-care behaviors based on Betawivalues and culture.

Method

Study Design

The research design is a descriptive qualitative study using interviews and Focus Group Discussions. The study design adhered to the guidelines outlined in the Consolidated Criteria for Reporting Qualitative Research (COREQ)(Allison Tong et al., 2007). The interview protocol encompassed a series of questions were asked and these were followed by guidelines questions: (1) Background information including age, gender, duration of chronic diseases, and specific diagnose of the diseases, (2) Diagnose and Treatment Experience including patients' reflections on their experience of diagnosis and treatment, highlighting impactful events and self-care (3) Perception and experiences of successful and unsuccessful procedures during the medical and traditional treatment, (4) Experiences in following values and cultural traditions in their treatment and self-care, (5) Expectations of the health services in order to improve their health status.

Population and Procedure

Purposive sampling was used to select the population of 46 participants, which included 14 traditional leaders, nine family members, and 23 people with chronic illnesses. People of Betawi descent suffering chronic illnesses and their families, as well as traditional leaders in the community, were necessary for the inclusion requirements. The selection process of research participants was assisted by community leaders. No relationship between the interviewer and the participants before the study began.

The data collection was conducted between June and August 2022. Eligible participants were contacted to determine their willingness to participate in this study. Willing participants were then given an explanation of the purpose, signed informed concern after the explanation, and confidentiality of the

study and informed that they could withdraw at any point. Data collectioninvolved one-on-one interviews with participants who accompanied their families or caregivers. This approach was taken due to the participants' diverse physical conditions, including instances of hearing disorders. It took another 40 to 60 minutes to conduct the interview. For the traditional leaders, data were collected by FGD. The discussion is over whenthere are no more new topics to be discussed according to the research purpose (Benjamin Saunders et al., 2018). FGD extended for a duration of 60 minutes.

Extensive field notes were taken during and after each interview and discussion describing the circumstances in which the interviews were conducted and immediate impressions of the interactions and the overall dynamics between the interviewer and participants. The interviewguidelines were utilized to explore participants' as well as families' experiences with chronic diseases and the opinions of traditional leaders. These guidelines were strategically structured,drawing insights from a predefined framework centered around the domains of perception,

experience, and expectations. These domains were optimal for investigating the influence of values and cultural factors among patients living with chronic disease through self-care.

The wording and questions changed based on the interview dynamics to maintain continuity and flow and to encourage the interviewees to speak openly. Data saturation was discussed with the research team after each transcription and translation was completed. The interviews and discussions were anonymized and transferred to specialized software for qualitative data organization and management (the ATLAS.tiv8 software).

The analysis was conducted by the researcher (AA, SS), using the content analysis method byGraneheim and Lundman (Graneheim & Lundman, 2004). This strategy consisted of listening,transcribing of each interview and discussion, and identifying keywords. The traditional leader,family, and participants with chronic disease were separately analyzed. Once the keywords were identified and organized, a constant dialogic comparison analysis was conducted to identify similarities and differences between patients, families, and traditional leaders.

The following analytic stage was conducted by all the authors by identifying categories of related keywords and followed by formulating the themes from the appropriate categories related to the values and culture of self-care with chronic disease.

The trustworthiness and credibility of results were enhanced through a member-checking process, the completion of an audit trail, and an investigator triangulation strategy (Nancy Carter et al., 2014). The member-checking process involved an in-person group meeting discussion to confirm the results and interpretations generated during the first analytic stage with some of the study participants. All our analytic decisions can be tracked back through an audit trail, composed of a series of Word, Excel, and PowerPoint documents. Finally, the second stage of the analytic strategy involved perspectives from different researchers, in an effort to ensure the convergence of the final interpretations. This study was approved by The

Nursing Ethics Committee of The Faculty of Nursing Universitas Indonesia (KET-179/UN2.F12. D1.2.1/PPM.00.02/2022).

Results

Demographics and Characteristics of Participants

The findings were extracted from the analysis of 32 in-depth individual interviews and FGD with traditional leaders. The obtained data, as illustrated in Table 1, provides a comprehensive of the participants' demographic and clinical profiles. The age range from 37 to 79 years, reflecting the diversity

in age distribution. The gender encompassed both males and females, offering almost balanced representation (13 male and 10 female). The duration of illness variedacross the participants, which are diagnosed from 2 to 12 years. The chronic diseases were diverse, with diabetes mellitus and tuberculosis being the most chronic diseases.

Table 1: The Participants' Characteristics.

Code	Age	Gender	Length ofDisease (Years)	Diagnosis Disease
P1	61	Male	2	Renal failure
P2	49	Female	3	Diabetes Mellitus
P3	55	Female	3	Hypertension
P4	62	Male	2	Stroke
P5	70	Female	2	Diabetes Mellitus
P6	61	Female	6	Hypertension
P7	72	Male	2	Tuberculosis
P8	70	Female	3	Hypertension
P9	53	Female	10	Heart Disorders
P10	60	Male	2	Tuberculosis
P11	60	Male	3	Tuberculosis
P12	73	Male	3	Tuberculosis
P13	56	Female	2	Diabetes Mellitus
P14	60	Female	2	Tuberculosis
P15	59	Male	4	Tuberculosis
P16	62	Male	5	Diabetes Mellitus
P17	79	Male	8	Diabetes mellitus
P18	71	Male	5	Renal failure
P19	50	Male	9	Stroke
P20	60	Male	8	Renal failure
P21	71	Female	5	Cardiovascular Disease
Code	Age	Gender	Length of Disease(Years)	Diagnosis Disease
P22	37	Female	12	Cardiovascular Disease
P23	75	Male	5	Disease Diabetes mellitus

The characteristics of participant families and community leaders are summarized in Table 2. The participants are delineated by distinct codes: F1 to F9 for family members and TL1 to TL14 for community leaders.

Table 2: Participant Families' and Community Leaders' Characteristics.

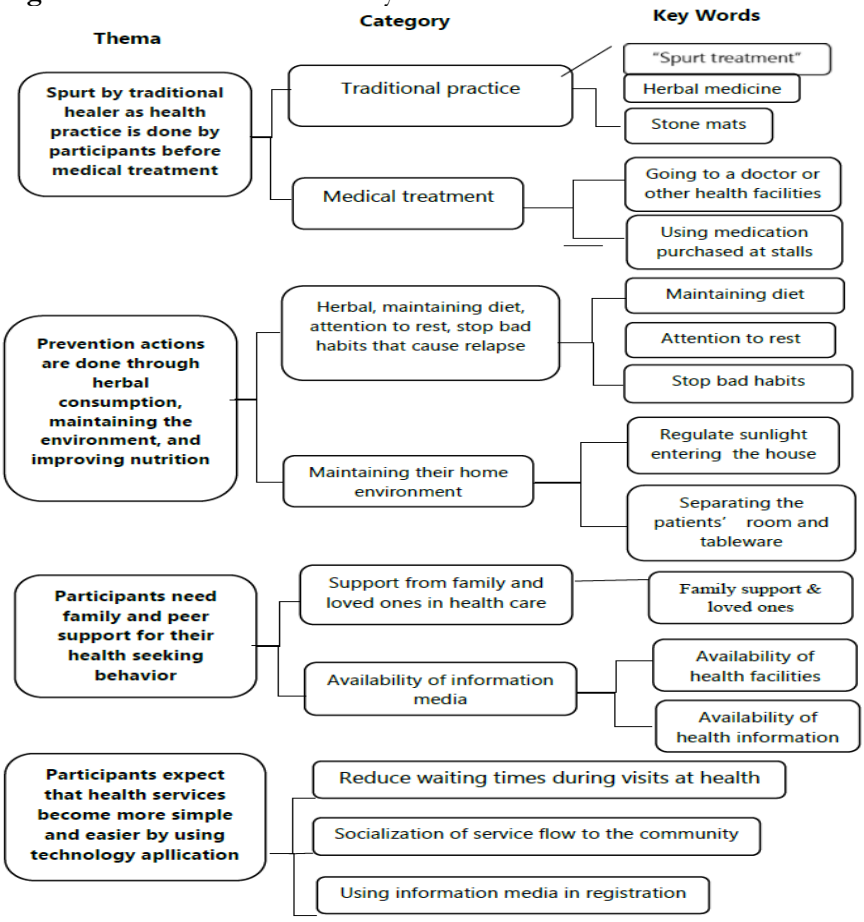
No	Code	Age (Years)	Gender
1	F1	40	Male
2	F2	60	Female
3	F3	34	Female
4	F4	52	Male
5	F5	30	Female
6	F6	54	Female
7	F7	42	Female
8	F8	44	Female
9	F9	40	Female
10	TL1	43	Female
11	TL2	41	Female
12	TL3	28	Female
13	TL4	80	Female
14	TL5	39	Female
15	TL6	41	Female
16	TL7	66	Female
17	TL8	47	Female
18	TL9	49	Female
19	TL10	48	Male
20	TL11	49	Male
21	TL12	48	Male
22	TL13	50	Male
23	TL14	50	Male

Themes and sub-themes from the qualitative data analysis by thematic content which the keywords were generated from FGD and one to one interview and forming the 13 sub-themes.These sub-themes were effectively grouped into four main themes including (1) Spurt by the traditional healer as health practice is done by participants before medical treatment; (2)

Prevention actions are done with herbal consumption, maintaining the environment andimproving nutrition; (3) Participant needs family and peer support for their health behavior; (4)Participants expect that the health services become more simple and easier by using technologyapplication.

A comprehensive illustration of these themes and sub-themes is presented in Figure 1 for reference. This categorization provides a coherent framework for comprehending the multifaceted facets of self-care experiences and expectations within Values and Cultural Influences Among Patients Living with Chronic Diseases. The following figure shows the analysis process:

Figure 1: Thematic Content Analysis.



Theme one: Spurt by Traditional Healer as Health Practice is Done by Participants Before Medical Treatment.

Participants expressed their engagement in their self-care activities entailing a blend of medicaland traditional ritual treatments. Before visiting a doctor or using other health services, the majority of

individuals with chronic conditions first tried traditional medicines.

“Yes, my parents frequently inform me that when they feel sick, they treat it at homewith traditional medicine first, and only if that doesn't work do they visit a doctor.” (P7).

“I most frequently take over-the-counter medications that I bought in shops. I visit adoctor if I don't feel better.” (P14).

Similar statements were expressed by both patients and their families, as well as by traditionalleaders. Various traditional treatments are carried out, some are done by coming to trusted people, and “spurt treatments” are administered by traditional leaders.

“The treatment of a sick person with a brief wisdom-like spurt has long been an accepted procedure. If they are feeling unwell right now, a lot of individuals nevertheless invite a wise person to their house "(TL8).

This traditional health practice behavior was also mentioned by seven out of 12 traditional leaders, who stated:

“Many patients seek out traditional healers for spurt treatments, and in reality, these treatments cure and heal the patients.” (TL 1).

Other traditional remedies are carried out such as the use of herbs and stone mats. The statement is as follows:

“We frequently use herbs as a treatment for health problems like fever and cough”(TL3).

“I use stone mats if I'm having back problems “(TL13).

Seven of 23 participants also revealed that they practiced traditional medicine, especially herbalmedicine. The statement below elucidates this.

" When we are ill, we follow grandma's advice and ingest herbal medicine. comparableto moringa and saga leaves. It has been that way ever since” (P3, P15, P20).

Participants also carried out traditional treatments with stone mats, this is believed to improvehealth. The following expressions reveal this:

“I've tried using a stone to massage myself, and I'll do anything to get better.” (P7,P15, P23).

Families and traditional leaders of the participants all agreed on these points of view. They saidsome traditional medicines are more effective in curing certain chronic diseases.

Theme two: Prevention Actions Are Done with Herbal Consumption, Maintaining the Environment, and Improving Nutrition

The sub-themes of this section include continuing to consume herbal remedies, getting enoughsleep, stopping the bad habits, and avoiding situations that could lead to relapse. The majorityof participants said that paying attention to eating habits was the main step in preventing diseaserelapses. 12 out of 23 participants expressed this.

" Please refrain from consuming coconut milk in order to prevent having your heartpierced as we want to ensure that it doesn't occur once more " (F6).

Some participants said they were focusing more on rest habits. This was revealed by 10 out of23 participants. One such statement was as follows:

" People frequently encourage me to pay attention to my sleep patterns, refrain from staying up too late, and get enough sleep " (P14, P17, P21).

Maintaining their home environment was revealed by seven out of 23 participants. Controllingthe quantity of sunlight entering the house, partitioning the patient's room, and separating the

crockery can prevent the recurrence of the illness and the spread of the disease to others. Thiswas expressed by the participants, especially to prevent the spreading of Tuberculosis.

All traditional leaders agreed that patients with Tuberculosis have to prevent actively the spreading of the disease, as they stated:

" We were told to do so since he has lung disease and needs to sunbathe every day to maintain his body's health because bacteria die off when sunlight is exposed" (TL 1, TL 3 TL 9).

Other participants revealed that disease prevention can be enhanced by stopping habits and activities that trigger relapse. Fourteen out of 23 participants stated that the prevention was improved through stopping smoking and controlling food intake including 'prohibited foods'.Habits that must be stopped were dominated by quitting smoking, and avoiding sweet foods, spicy foods, and nuts. As the statement of one participant described:

"I monitor my diet, already refrain from consuming sweets, and have never been ill"(P 9, P15, P17).

Other habits that must be stopped such as long walks were mentioned by three out of 23 participants, they said that it can cause shortness of breath, as the statement below:

"Last time, I used to stroll around, but my shortness of breath prevented me from doingso" (P7, P9, P4).

This theme resonates with participants' commitment to proactive measures for disease prevention across different aspects of their lives.

Theme Three: Participants Need Family and Peer Support for Their Health Seeking Behavior

Additional sub-themes that accompany this subject include Obtaining health information frommedia, accompanied by family and peers to the health facilities, and availability of health facilities. All participants expressed that support from family and close ones will greatly influence the healing process. However, four out of nine family participants revealed.

difficulties in making patients comply when taking medication or avoiding prohibited foods. As they stated:

"He (the patient) refused to take the prescription since he finds it boring to take thetablets every day, even though we had to prepare it for swallowing" (F3, F7, F10, F11).

Traditional leaders (10 out of 14) revealed that the support of family and loved ones is neededbecause it will affect the treatment process that must be undergone. For example, they said:

"If the patient's family has prepared the medication, they will typically take it. (TL3) "One individual, who has no family, chose not to take her medication, and we feel bad for her" (TL 13, Tl7).

All participants expressed their willingness to be supported by their family, as the statement of participants:

"Normally, I only take the medication if my wife has already made it." (P15)."If my wife doesn't supply the medication, I won't take it." (P7, P17).

"I'm depressed because I have to wait till my son gets home before he can help metake my medication and I'm alone." (P20)

The participants felt support in self-care is also due to the availability of health service facilities(14 out of 23) and information media. As they stated:

"Everything is simpler in Jakarta. All I have to do to get better if I become sick is goto the doctor and

get some medicine, and we can just choose the correct one." (P19)

Among the participants, 10 out of 23 participants had difficulty accessing health facilities dueto their location and required more money for transportation.

They Stated as Follows

"I frequently reserve health visits for when I have money because the clinic is faraway and I have to pay for transportation" (P1, P7, P13).

Seven out of 23 participants did not seek information from information media (mobile phones)because they did not know how to use mobile phones. The participants received information through TV media or information from other people. They stated this as follows:

"The average person in this country can learn about health issues from television or other media, but they virtually ever do so using an android mobile phone because so few people own them and they are usually unable to utilize them." (P6, P9, P12).

Theme Four: Participants Expect that the Health Services Become Simpler and Easier by Using Technology Application.

This theme is supported by the following sub-themes: Reducing waiting times during visits tohealth care, disseminating service flow information to the community, and using information media for registration procedures. The participants' biggest hope was to reduce waiting times during visits to healthcare providers (18 out of 23 participants). However, some participants (five out of 23) stated that currently acknowledged that their existing waiting time was already relatively brief, attributed to the use of information media (specifically WhatsApp) for hospitalregistrations. This phenomenon was particularly prevalent among participants. They expressedthis as follows:

" I can now easily register for hospitals because I am a member of a WhatsApp group."(P15, P17, P18).

The traditional leaders (four out of seven participants) hoped that all hospitals would use an online registration system (WhatsApp) to reduce waiting times in hospitals. They stated that:

"Since our patients previously received accurate information from the service, we areoptimistic that the information system will progress." (TL 9, TL12, TL14).

"In order to reduce waiting times, we believe that all hospitals will eventually employonline registration systems" (TL12, TL14).

This theme embodies participants' collective yearning for enhanced accessibility, streamlined procedures, and reduced waiting times within the healthcare ecosystem, substantiating the profound impact of technology on healthcare service expectations.

Discussion

This qualitative study was conducted to explore the experiences and expectations of chronic disease patients in self-care behaviors who live in the Betawi community, based on their values and culture. Our findings, underscore the profound influence of values and community cultures on family support, patients' perceptions, experiences, and health-seeking behaviors ultimately enhancing the patient's ability and willingness to engage in self-care and prevention actions. This study shows that participants perform self-care with a combination of medical and traditional ritual treatments. Self-care might have another meaning to patients with chronic diseases, since living optimally with chronic diseases often requires a set of behaviors to control their disease process, decrease of burden from the symptoms, and improve survival (Riegel et al., 2019).

Self-care is essential in the long-term management of chronic diseases, it can be seen as an overarching construct built from the three key concepts of self-maintenance, self-care monitoring, and self-care management. Our findings are in line with the dimensions of self- care highlighted by Dingwall & Cairney, (2011) and Sevilla-Cazes et al., (2018). They stated that self-care maintenance through adherence to self-care behaviors such as regular exercise and taking medication is prescribed. The second key point in the concept of chronic patient self-care is self-care monitoring through regular measurement of physiological changes and routine control (Cioffi, 1991). This concept was not elaborated on by participants. This happened because participants thought that as long as there were no symptoms, the body was in good health (Cioffi, 1991; Whitaker et al., 2015). The third key point in self-care theory is

self-care management, for example, changing diet or medication dose based on the detection and interpretation of symptoms. Participants were encouraged to change their diet when there were changes in signs or symptoms in the body. This finding aligns with the results from (E R Lenz et al., 1997; J. Xu et al., 2019).

The value and culture among participants led them to engage in some traditional behaviors such as "spurt treatments", the use of herbs, and lying on a stone mattress. This result is in linewith the research by Zewdneh Shewamene et al., (2019). They found that the use of traditionalmedicine and related health beliefs influenced the healthcare-seeking behaviors of African migrant women in Australia.

A traditional healer, according to the WHO definition, is a person who is recognized by the community in which he/she lives as being competent to provide health care by using vegetable,animal, and mineral substances and certain other methods based on the social, cultural and religious background as well as on the knowledge, attitude, and beliefs that are prevalent in thecommunity regarding physical, mental and social well-being and the causation of disease and disability (Sundararajan et al., 2021). The utilization of some of its health services and coverageof some of its activities was low. Many patients presented late to the hospital and were alreadyin the advanced stages of a disease, and many patients had first visited a traditional healer before seeking help at the hospital (Stekelenburg et al., 2005). This condition was also revealedin this study, in which participants sought more traditional health practices first before finally seeking help from more modern medical treatments.

Social-economic factors were also mentioned by the participants as reasons for not going to modern healthcare facilities first to get medical treatment and services. Participants have to spend money for transportation and in some cases, they did not have enough money for both medical treatment and transportation. The participants who live in the rural areas outside Jakarta are not able to easily access health services institutions, while if they use the traditional

practices, they do not pay a lot. This result was different from the results obtained by Stekelenburg et al., (2005). They found in their study that two-thirds of all respondents said that they had to pay for an animal, which means a cow in most cases. Most traditional healersuse a 'no cure, no pay' system, which could attract people to accept the higher costs of treatment.

The prevention actions of participants were mostly influenced by families and peers, also basedon their experiences. Maintaining a diet, observing adequate rest hours, and Stopping habits and activities triggering relapse are the prevention actions that they know can prevent disease relapse. However not all participants acted that way and this mostly included the elderly participants, since their diet was still influenced by traditional foods and eating habits.

This result is in line with the result of a study by Jiang et al., (2013). They found that the dietaryrestrictions among elderly patients with poor health and diabetes were heavily influenced by their cultural eating habits and understanding of nutrition. That in turn will lead to re-hospitalization.

The self-care behaviors of the participants in this study were very much influenced by many factors including family support, their knowledge and experiences of health-related diseases, and mostly by values and their community's culture. This was also mentioned in the systematic review result from (Lukmanm N.A., Leibing, A., and Merry, L., (2020). They found that the factors that influenced the self-care experience of adults with chronic diseases in Indonesia are religion, knowledge, health literacy, cultural expectations, family and peer support, health professionals, and community support. All participants expected that the health services may be needed to be improved especially to make it easier to be accessed by patients by using appropriate social media as well as information systems that are culturally acceptable. Finally, the health care providers must take into consideration the values and cultural sensitivities in their care implementation. Their study found that it is very important for health providers to

have an understanding of cultural or religious perspectives that patients hold including values in taking complementary or traditional therapies.

Modern health services require a different type of nurse who understands very well the integral and holistic perspectives in order to improve the quality of care that in turn will improve the patient's quality of life. (Gripshi, 2021) described that holistic nursing is the most complete way to fulfill the client's needs that help heal the whole person (by taking into account the relationship among mind, body, emotion, spirit, society, culture, and environment). This is very useful when implemented in the care of chronically ill patients. By utilizing a holistic care approach, nurses are able to really take enough time with patients and will recognize and intervene with each individual differently based on their bio-psycho-social, spiritual, and cultural understanding (American Holistic Nurses' Association, 2015). In this light, health providers, particularly nurses, play a pivotal role in bridging the gaps between modern medical practices and culture, thereby enhancing patient outcomes and enriching the quality of care in chronic disease management.

Several limitations should be acknowledged in this study. Firstly, the sample size, while diverse in participant backgrounds, might not fully encompass the entirety of values and practices within the Betawi culture. Secondly, reliance on self-reported data introduces the potential forrecall bias and social desirability bias, as participants might present their behaviors and valuesin a manner deemed more socially acceptable. Furthermore, the inclusion of traditional leadersand family members could introduce bias in responses due to potential hierarchical or family dynamics. Lastly, the study's cross-sectional design precludes establishing causal relationshipsbetween values, practices, and health outcomes. Despite these limitations, the study offers valuable insights into the intricate interplay between cultural values and self-care behaviors among patients with chronic diseases, thereby contributing to the existing body of knowledgein this field.

Conclusion

The study highlights the significant influence of family and peer support, as well as deeply influence of values and community culture on the perspectives, experiences, and health-seekingbehaviors of patients living with chronic diseases. The findings reveal that the participant's self-care preference for traditional treatment initially, followed by modern medical interventions in cases of disease relapse. Nevertheless, the participants have taken account of the prevention actions to prevent the recurrence of the disease. The study also highlights expectations articulated by participants, families, and traditional leaders to enhance healthcare services. As healthcare professionals, nurses are required to understand the importance of a holistic care approach and they should be able to implement it in order to improve the quality of care that in turn will improve the quality of life of chronically ill patients.

Conflict of Interest Disclosure

There is no potential for conflict in the article created.

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