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ORIGINAL RESEARCH

Determinants of Physical and Mental Healthrelated Quality of Life among Patients with Breast Cancer During COVID-19 Pandemic



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Abstract

Background: The concern surrounding the physical and mental health-related quality of life (HRQoL) among patients with breast cancer emerged during COVID-19. However, there is a lack of sufficient studies that have specifically addressed this issue. It is crucial to emphasize the evaluation of this aspect as it significantly impacts the enhancement of future physical and mental HRQoL for these patients. **Purpose:** This study investigated the determinants of physical and mental HRQoL among patients with breast cancer during COVID-19.

Methods: In a cross-sectional study conducted between September and October 2022, participation involved 260 patients diagnosed with breast cancer, selected through convenience sampling. Our observation focused on assessing the outcomes of physical and mental HRQoL using the Short Form (SF-12) questionnaire for data collection. Additionally, the data underwent analysis via binary logistic regression. **Results:** Respondents aged <50 years (p=0.010; aOR=2.08; 95% CI=1.18-3.67), unemployed (p=0.022; aOR=2.29; 95% CI=1.16-4.53), and had high depression (p=0.026; aOR=2.41; 95% CI=1.13-5.12) have a more likelihood to have low physical HRQoL. In addition, unemployed respondents (p=<0.001; aOR=4.15; 95% CI=2.14-8.04) and had high anxiety (p=0.004; aOR=2.71; 95% CI=1.38-5.33) have more likelihood to have low mental HRQoL.

Conclusion: In this study, it was found that anxiety, depression, and unemployed respondents were associated with a higher likelihood of experiencing lower physical and mental HRQoL. Nurses and healthcare workers should prioritize addressing psychological issues such as anxiety and depression among breast cancer patients, emphasizing the necessity for interventions aimed at alleviating these concerns.

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1. Introduction

Acute respiratory distress syndrome is an outbreak of Coronavirus disease (COVID-19). The outbreak of the COVID-19 epidemic that began in December 2019 had a moderately severe impact and became the most critical and widespread pandemic of this century (Huang et al., 2020). COVID-19 spreads rapidly in the larger community, including patients with a clinical presentation of acute respiratory distress syndrome, and causes high morbidity and mortality (Hasan et al., 2020). The condition of COVID-19 leads to fear and anxiety that impact physical and mental health-related quality of life (HRQoL) (Shafran et al., 2021). Physical and mental health are integral components of an individual's overall quality of life. Physical health encompasses the state of the body, including aspects such as fitness, freedom from illness, mobility, and the ability to perform daily tasks without hindrance. On the other hand, mental health encompasses emotional, psychological, and cognitive well-being, influencing factors like emotional stability, coping mechanisms, interpersonal relationships, and adaptability to life's challenges. Both physical and mental health play pivotal roles in determining an individual's well-being and ability to lead a fulfilling and satisfying life (Folsom et al., 2009).

Breast cancer patients experience immunosuppression caused by cancer treatments, such as chemotherapy and other therapies. Decreased immunity puts them in a group that is more at risk of contracting the virus and suffering from complications of COVID-19 compared to the general population (Al-Quteimat & Amer, 2020; Al-Shamsi et al., 2020). During the COVID-19 pandemic, patients with breast cancer experienced severe mental disorders such as fear of being infected with COVID-19 during the chemotherapy process and even death (Erdoğan et al., 2022; Hikmat et al., 2022; Stanizzo et al., 2022). This condition also has an impact on physical condition and causes weakness (Yang et al., 2021). With conditions that continue to decline, this can have an impact on the quality of life of patients with breast cancer.

Patients with malignancy experience high levels of psychological distress. Fear of COVID-19 combined with interference with some treatment programs can affect the psychological health of cancer patients (Momenimovahed & Salehiniya, 2021). The COVID-19 pandemic has had an emotional impact, and previous research has shown that breast cancer survivors also feel emotional distress, such as exaggerated anxiety and depression related to a higher level of ruminative response and chronic worry (Choobin et al., 2021). The most commonly reported stressor was a higher level of concern regarding the experienced anxiety and depressive symptoms and a higher fear of cancer recurrence (Massicotte et al., 2021). The previous review studies have only evaluated the quality of life in general, not specific to physical and mental HRQoL, and not during the COVID-19 pandemic (Heidary et al., 2023; Mokhtari-Hessari & Montazeri, 2020; Yan et al., 2016). Thus, this original study aimed to investigate the determinants and analyze their correlation to physical and mental HRQoL among patients with breast cancer during the COVID-19 pandemic.

2. Methods

2.1 Research design

A cross-sectional study was designed to investigate the correlation between independent and dependent variables (Arifin et al., 2022). The study's reporting followed the guidelines outlined in the Strengthening the Reporting of Observational Studies (STROBE) framework for cross-sectional studies (Von Elm et al., 2007).

2.2 Setting and samples

The study was conducted from September to October 2022 at a government hospital and a university hospital in Padang, Indonesia. Both study locations were elected as a referral hospitals for cancer treatment in Padang. A total of 260 respondents were recruited using convenience sampling. The sample size is measured by G*Power analysis statistical app with α =0.05, β =0.20, and effect size of 0.26 (medium effect size). Finally, the minimum sample size was 190-260 participants obtained based on the analysis (Cohen, 2013; Hohls et al., 2021). During the study process, no dropout respondents were found. All of the respondents met the criteria of 1) being female aged 18-60 years, 2) being diagnosed with breast cancer for at least six months, 3) having been during or undergoing chemotherapy and radiology, 4) communicating in the local language (Padang) and Indonesia language, 5) and having the commitment to participate in this study. In addition, respondents with cognitive impairment or psychiatric disorders (e.g., schizophrenia, psychosis, and depression) before the breast cancer diagnosis, were excluded from this study.

2.3 Measurement and data collection

The independent variables in this study included demographical data (age, marital status, educational level, and employment status), disease characteristics (cancer stages, cancer treatment, and disease duration), anxiety, and depression. Moreover, the dependent variables were physical and mental HRQoL. The general information sheet was designed to gather data on demographic and disease characteristics, encompassing details such as age, marital status, education level, number of children, employment status, cancer stages, cancer treatment, and disease duration.

Anxiety and depression were measured using the Hospital Anxiety and Depression Scale (HADS), consisting of seven items for depression and seven for anxiety (Zigmond & Snaith, 1983). Each item is rated on a four-point Likert scale (o = not at all, to 3 = most of the time). The total score ranged from 0 to 21, indicating low anxiety and depression (0-7) and high anxiety and depression (8-21) (Zigmond & Snaith, 1983). The HADS-Indonesian version scale showed

acceptable internal reliability with a Cronbach's alpha of 0.85 for anxiety and 0.80 for depression, with the Kaiser-Meyer-Olkin statistics of 0.89 and Bartlett's test of sphericity (χ 2 (91, N=200) of 1052.38, p<0.001 (Tiksnadi et al., 2023).

Physical and mental HRQoL was measured using the short form (SF-12) with 12-items and calculated following the scoring algorithm developed by Ware et al. (1996). SF-12 measures consist of two concepts, including Physical Component Summary (PCS-12) and Mental Component Summary (MCS-12). SF-12 consists of two components; first, the PCS-12 score is represented by six items: 1) general health with response categories excellent/very good/good/ fair, 2) moderate activities, 3) climb several flights of stairs with response category limited a lot/ limited/not limited at all, 4) accomplish less (physical), 5) limited in kind of work with response category all of the time/most of the time/a little of the time/none of the time, and 6) pain interference with response category not at all/a little bit/moderate/quite a bit/extremely. Second, MCS-12 is represented by six items: accomplish less (emotional), did work less carefully, calm and peaceful, energy or vitality, downhearted and blue, and social limitations. All items MCS-12 with response: all of the time/most of the time/a little of the time/none of the time. The PCS-12 and MCS-12 scores were computed and normalized for SF-12v2 according to published algorithms (Ware et al., 1996). Scores range from 0 to 100, with a higher score indicating better physical and mental health functioning. A score of 50 or less on the PCS-12 could be considered low physical functioning, while a score of 42 or less on the MCS-12 may be indicative of low mental health functioning (Soh et al., 2021; Ware et al., 1995). The SF-12 version 2 showed good internal reliability for PCS-12 with Cronbach's alpha of 0.83 for anxiety and 0.81 for MCS-12 (Soh et al., 2021).

The data collection process commenced after obtaining permission from the concerned hospitals, adhering to ethical guidelines. The primary method employed for data acquisition involved the administration of a structured questionnaire. To facilitate this process, the researcher, with the aid of a research assistant, conducted the data collection. The researcher and the assistant worked collaboratively, accompanying respondents throughout the questionnaire completion. This approach ensured a supportive environment, enabling respondents to address any queries or concerns they encountered while filling out the questionnaire. By maintaining a supportive presence, the researcher aimed to enhance respondent comfort and accuracy in providing necessary information for the study.

2.4 Data analysis

The data analysis was performed using IBM SPSS 22.0 software. Descriptive statistics comprised frequencies and percentages for categorical variables and mean and standard deviation (SD) for continuous variables. A Chi-squared test was used to examine the correlations between demographic characteristics and disease characteristics, anxiety, depression, and physical and mental HRQoL. The variables with a p-value of \leq 0.20 in the Chi-squared test were further entered into the univariate logistic regression analysis to examine the association of these influential factors with physical and mental HRQoL (Mickey & Greenland, 1989). A multivariate logistic regression model was used to identify the significant predictors of the quality of life of breast cancer survivors after adjusting for confounding variables in the univariate logistic regression model (p<0.05). All tests were two-tailed, with p-values less than 0.05 were considered statistically significant.

2.5 Ethical considerations

This study has been deemed ethically appropriate by the Health Research Ethics Committee of Dr. M. Djamil Hospital Padang, Indonesia (No. L.B.02.02/5.7/410/2022), in accordance with seven WHO 2011 standards. All study participants received a consent form describing the study's aim and providing adequate information for them to make an informed decision about their participation. Those participants willing to participate had to sign the form before completing the questionnaire, and participation was voluntary without any coercion.

3. Results

3.1 Demographics and disease characteristics of the respondents

In total, 260 eligible breast cancer survivors participated in this study. More than half of respondents (62.7%) were younger, with a mean age of 47.14 years (range, 18-60 years). Most

respondents were married (81.2%) and had a high education level (80.8%). Regarding the number of children, more than half (67.3%) of participants had ≤ 3 children and were unemployed (54.0%). According to the cancer characteristics, more than half of the participants were diagnosed in III or IV stages, and the majority received 2-3 treatments. Overall, the mean of the disease duration is 34.26 months. Furthermore, more than 50% had high anxiety, and less than 70% had low depression. From this study, more than half of respondents had low physical and mental health functioning related to quality of life (Table 1).

Table 1. Characteristics of respondents (n=260)

Variables	M(SD)	n	%
Age (years)	47.14(7.37)		
Younger (≤50 years old)		163	62.7
Older (>50 years old)		97	37.3
Marital status			
Married		211	81.2
Widowed/Others		49	18.8
Education level			
Low		50	19.2
High		210	80.8
Number of children			
≤ 3		175	67.3
> 3		85	32.7
Employment status			
Employed		105	40.4
Unemployed		155	59.6
Cancer stages			
I and II		118	45.4
III and IV		142	54.6
Cancer treatment			
1 treatment [†]		37	14.3
2-3 treatment [*]		222	85.7
Disease duration (months)	34.26(26.91)		
≤24 months		145	55.8
>24months		115	44.2
Anxiety	7.48(4.22)		
Low anxiety		123	47.3
High anxiety		137	52.7
Depression	5.67(3.80)		
Low depression		192	73.8
High depression		68	26.2
Physical health functioning	42.88(7.34)		
Low		139	53.5
High		121	46.5
Mental health functioning	42.53(10.93)		
Low		134	51.5
High		126	48.5

Notes:

3.2 The correlation of demographic and disease characteristics, anxiety, and depression with physical and mental HRQoL

Table 2 shows the bivariate analysis of physical and mental HRQoL. In the physical HRQoL, age, number of children, employment status, cancer stages, anxiety, and depression showed a significant relationship with physical HRQoL (p<0.05). Moreover, number of children, employment status, anxiety and depression had a significant correlation with mental HRQoL (p<0.05). Furthermore, the variables with p<0.20 were included in the multivariate analysis.

[†] Surgery, chemotherapy, radiotherapy; †Surgery and, or chemotherapy and radiotherapy and others M: Mean; SD: standard deviation

Table 2. The correlations of demography, disease characteristics, anxiety, depression, physical, with mental health-related quality of life (n=260)

	Phys	sical			Me	ntal		
Variables	High f (%)	Low f (%)	X^2	p	High f (%)	Low f (%)	X^2	p
Age (years)								
Younger (≤50)	69 (39.3)	99 (60.7)	9.29	0.002	76 (46.6)	87 (41.9)	0.59	0.443
Older (>50)	57 (58.8)	40 (41.2)			50 (51.5)	47 (48.5)		
Marital status								
Married	98 (46.3)	113 (53.6)	0.00	0.950	99 (46.9)	112 (53.1)	1.06	0.302
Widowed/Others	23 (46.9)	26 (53.1)			27 (55.1)	22 (44.9)		
Education level								
High	103 (49.0)	107 (51.0)	2.76	0.096	105 (50.0)	105 (50.0)	1.035	0.309
Low	18 (36.0)	32 (64.0)		-	21 (42.0)	29 (58.0)		
Number of children								
≤3	70 (40.0)	105 (60.0)	9.19	0.002	67 (38.3)	108 (61.7)	22.19	< 0.001
>3	51 (60.0)	34 (40.0)			59 (69.4)	26 (30.6)		
Employment status								
Employed	70 (66.7)	35 (33.3)	28.68	< 0.001	80 (76.2)	25 (23.8)	54.22	< 0.001
Unemployed	51 (32.9)	104 (67.1)			46 (29.7)	109 (70.3)		
Cancer stages						, .,		
I and II	65 (55.1)	53 (44.9)	6.43	0.012	62 (52.5)	56 (47.5)	1.44	0.230
III and IV	56 (39.4)	86 (60.6)			64 (45.1)	78 (54.9)		
Cancer treatment								
1 treatment [†]	18 (48.6)	19 (51.4)	0.93	0.760	16 (43.2)	21 (56.8)	0.43	0.509
2-3 treatment*	102 (45.9)	120 (54.1)			109 (49.1)	113 (50.9)		
Disease duration								
(months)								
≤24 months	66 (45.5)	79 (54.5)	0.13	0.711	67 (46.2)	78 (53.8)	0.66	0.414
>24months	55 (47.8)	60 (52.2)		,	59 (51.3)	56 (48.7)		• •
Anxiety						, .		
Low anxiety	78 (63.4)	45 (36.6)	26.72	< 0.001	84 (68.3)	39 (31.7)	36.75	< 0.001
High anxiety	43 (31.4)	94 (68.6)	•		42 (30.7)	95 (69.3)		
Depression	.5 .5 .7				, ,	, , , , ,		
Low depression	107 55.7)	85 (44.3)	24.92	< 0.001	104 (54.2)	88 (45.8)	9.56	0.002
High depression	14 (20.6)	54 (79.4)	. ,		22 (32.4)	46 (67.6)	, ,	

3.3 Determinants of physical and mental HRQoL

Based on the multivariate analysis using binary logistic regression, respondents with younger age had 2.08 times more likely to have low physical health compared to older age (*p*-value: 0.010; aOR:2.08; 95% CI:1.18-3.67). Based on work status, respondents who did not work (unemployed) had 2.29 times greater to have low physical health rather than employed (*p*-value: 0.022; aOR: 2.29; 95% CI: 1.16-4.53). In addition, respondents with high depression had 2.41 times greater to have low physical health compared to low depression (*p*-value: 0.026; aOR: 2.41; 95% CI: 1.13-5.12). According to mental HRQoL, unemployed respondents had 4.15 times more likely to have low mental health compared to employed respondents (*p*-value: <0.001; aOR: 4.15; 95% CI: 2.14-8.04). Furthermore, respondents with high anxiety had 2.71 times greater to have low mental health compared to respondents with low anxiety (*p*-value: 0.004; aOR: 2.71; 95% CI: 1.38-5.33) (Table 3).

4. Discussion

Physical and mental health-related quality of life (HRQoL) becomes a critical concern for patients with breast cancer. This study explored the determinants affecting physical and mental HRQoL from the perspectives of demographics and physiological symptoms such as anxiety and depression. The correlation between age, employment status, and depression is discussed concerning physical HRQoL. Additionally, work status and anxiety are examined in relation to mental HRQoL.

Table 3. Multivariate analysis of physical and mental health-related quality of life

77		Physical health			Mental health		
Variables	aOR	(95% CI)	p-value	aOR	(95% CI)	p-value	
Age							
Older (>50 years old)	Ref.			NA			
Younger (≤50 years old)	2.08**	(1.18 - 3.67)	0.010	NA	NA	NA	
Level of education							
High	Ref.			NA			
Low	1.03	(0.26 - 4.00)	0.966	NA	NA	NA	
Number of children							
>3	Ref.			Ref.			
≤3	1.16	(0.61 - 1.18)	0.750	1.87*	(0.98 - 3.57)	0.057	
Work status							
Employed	Ref.			Ref.			
Unemployed	2.29**	(1.16 - 4.53)	0.022	4.15***	(2.14 - 8.04)	< 0.001	
Cancer stages							
I and II	Ref.			NA			
III and IV	1.65	(0.94 - 2.89)	0.083	NA	NA	NA	
Anxiety							
Low	Ref.			Ref.			
High	1.73	(0.89 - 3.33)	0.096	2.71***	(1.38 - 5.33)	0.004	
Depression							
Low	Ref.			Ref.			
High	2.41**	(1.13 - 5.12)	0.026	0.79	(0.37 - 1.65)	0.533	

Notes:

4.1 Physical HRQoL

In this study, respondents aged < 50 years were more likely to have low physical HRQoL. Physical activity is a crucial for better quality of life and ageing in the long-term care. This finding is contradicted with a previous study which stated that people aged < 50 years had better physical HRQoL (Jang et al., 2019). Studies stated that engaging in regular physical exercise significantly enhances individuals' physical HRQoL (Gill et al., 2013; Marquez et al., 2020; Wei et al., 2022). Low physical HRQoL at aged < 50 years can be influenced by disease and other risk behaviors, such as smoking and drinking that make it unable to carry out physical activities properly (Megari, 2013; Nari et al., 2021; Tran et al., 2022). However, this study is still limited to several variables, such as lifestyle, which might be associated with the low physical HRQoL in population aged < 50 years. Therefore, the addition of variables to the future studies is highly recommended.

In addition, respondents who were unemployed had more likely to have low physical HRQoL. Unemployment in cancer patients is correlated with increased financial burden, increased costs of living, and ongoing treatment (Mols et al., 2020). In addition, people who are working will have more physical activity, so they can increase their physical strength, and vice versa for people who are unemployed (Schutgens et al., 2009). However, a significant aspect during the COVID-19 pandemic is the situation where parents must manage both childcare and homeschooling (Vogelbacher); this situation can potentially impact physical HRQoL (Galanti et al., 2021; Tavares, 2017). In addition, with these conditions, it is widely reported that people experience increased stress, malnutrition characterized by increased body weight, and decreased physical HRQoL (Alshahrani et al., 2022; Majumdar et al., 2020; Muñoz-Corona et al., 2022).

Furthermore, this study also showed that respondents with high depression had more likely to have low physical HRQoL. This finding is similar with the previous studies (Cho et al., 2019; Fernandes et al., 2021; Hohls et al., 2021). The condition of the COVID-19 pandemic is an added burden that can induce depression among breast cancer patients. Moreover, this circumstance is compounded by uncertainties regarding recovery and the necessity for regular treatments like chemotherapy and/or radiation therapy (de Souza et al., 2014). Also, depressive conditions can exacerbate the severity of symptoms for people dealing with breast cancer (Wondimagegnehu et al., 2019). This has an impact on the immune system and physical conditions that can get weaker

^{*}p<0.1; **p<0.05; ***p<0.01

(Wang et al., 2020). For this reason, it is very important to treat depression in patients with breast cancer, especially during the COVID-19 pandemic.

4.2 Mental HRQoL

Regarding the mental HRQoL, unemployed respondents were more likely to have low mental HRQoL. Patients with breast cancer who have no activity or low social relationships can cause a decrease in low mental health (Yang et al., 2022). Previous studies indicated that breast cancer patients experiencing stable physical health and engaged in work tend to exhibit higher mental HRQoL (Carreira et al., 2018; Jin, 2022). This correlation might be attributed to the supportive environment fostered by colleagues and the potential diversion of the patient's focus away from their illness (Finck et al., 2018). Consequently, it is suggested that breast cancer patients in favorable physical health conditions can actively engage in physical activities, maintain productivity, and cultivate strong social relationships, which can contribute positively to both their physical and mental quality of life. This recommendation emphasizes the potential benefits derived from staying physically active and socially engaged despite the challenges posed by the illness.

Patients with breast cancer experienced anxiety related to cancer treatments, fear of cancer recurrence and fear about uncertainties surrounding life and death (Bagutayan, 2012; Tiedtke et al., 2012). In addition, cancer patients also have anxiety regarding postponed appointments, delayed treatments, and limited access to medical facilities due to COVID-19 pandemic (Rucinska & Nawrocki, 2022). Furthermore, cancer patients are vulnerable to COVID-19 infecttion and had 60% increased risk of positive COVID-19 test compard with individual without cancer (Lee et al., 2021). These collective stressor may contributes to anxiety among patients with breast cancer, impacting their mental HRQoL. Therefore, it can make the healing process of the disease take longer (Carreira et al., 2018). Prior investigations have demonstrated a notable increase in anxiety levels among breast cancer patients amid the COVID-19 pandemic (Bartmann et al., 2021; Shah et al.; Stanizzo et al., 2022; Yasin et al., 2021). This surge in anxiety can be attributed to the fear associated with potential COVID-19 infection, intensifying concerns about the worsening of their existing medical condition and the heightened risk of mortality. Consequently, this finding places an augmented responsibility on nurses. Beyond addressing the complexities of cancer treatment, nurses are now compelled to provide interventions aimed at alleviating anxiety among breast cancer patients. Effective mental health management becomes crucial, encompassing strategies to regulate stress, depression, and anxiety levels. These interventions are essential to mitigate the amplified psychological distress experienced by breast cancer patients, thereby enhancing their overall well-being and coping mechanisms during this challenging period characterized by the pandemic.

5. Implications and limitations

In the context of the COVID-19 pandemic, understanding the nuances HRQoL among breast cancer patients has never been more critical. Our research underscores the profound role healthcare professionals play in shaping the QOL of these patients. During global crises, such as pandemics, external factors might exacerbate the mental and physical health challenges faced by breast cancer patients. Nurses should recognize the heightened challenges faced by breast cancer patients during crises like the COVID-19 pandemic and offer personalized care and interventions that address both physical and mental health concerns. This brings to the fore the crucial importance of tailored clinical interventions. Furthermore, our findings illuminate the necessity for systemic changes. Policymakers, armed with this knowledge, can champion reforms that embrace specialized care models during such crises.

This study offers empirical evidence to identify the determinants of physical and mental HRQoL among patients with breast cancer during the COVID-19 pandemic. However, several limitations should be considered. Firstly, the confirmation of causal relationships between risk factors and physical and mental health-related quality of life was hindered by the cross-sectional study design. Secondly, the limited generalizability of their findings arose from recruiting all participants solely from two hospitals within one province of Indonesia. Thirdly, the exclusion of other risk factors such as chronic diseases, health behaviors, and lifestyle factors from the study should be noted.

6. Conclusion

Physical and mental HRQoL aspects among breast cancer patients shows a substantial correlation with various demographic and psychological factors, including age and employment status, as well as anxiety and depression levels. This study revealed a clear association indicating that higher levels of anxiety and depression significantly increase the likelihood of experiencing lower physical and mental HRQoL. This underscores the critical need for targeted interventions aimed at reducing anxiety and depression specifically tailored for breast cancer patients. Initiating such interventions becomes pivotal in addressing the challenges posed by these psychological factors, thereby potentially enhancing the overall quality of life experienced by individuals grappling with breast cancer. Recognizing the impact of anxiety and depression on the QoL of breast cancer patients and implementing targeted strategies such as psychological intervention to mitigate these psychological challenges stands as a vital step in improving the well-being and coping mechanisms of these individuals.

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Conflict of interest

None

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ORIGINAL RESEARCH

Family Coping Strategies and Quality of Life of Patients with Type-2 Diabetes Mellitus in Primary Health Care in Indonesia



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quality of life

Abstract

Background: The intricate caregiving responsibilities undertaken by family caregivers in the care of patients with chronic diseases induce stress, potentially reducing the family's ability to provide effective care. In instances where family caregivers of patients with type-2 diabetes mellitus (T2DM) are unable to employ effective coping mechanisms, there exists the potential for an adverse impact on the patient's quality of life.

Purpose: This study aimed to analyze the relationship between family coping strategies and the quality of life of patients with T2DM undergoing treatment in primary health care in Malang, Indonesia. Additionally, it sought to investigate the influence of demographic factors on both family coping strategies and the quality of life of these patients.

Methods: The study employed an observational analytic design with a cross-sectional approach. The participants included 327 individuals with T2DM and 327 family caregivers, selected from 16 primary healthcare centers using cluster random sampling techniques. Data were collected using the COPE Brief questionnaire to assess coping strategies and the DQOL (Diabetes Quality of Life) questionnaire to measure the quality of life. Statistical analysis was conducted using the Spearman rank test and multivariable logistic regression.

Results: The findings of the study revealed that a majority of family caregivers employed adaptive coping strategies (93.9%), while a significant proportion of individuals with T2DM reported having a good quality of life (84.1%). The analysis demonstrated a positive relationship between family coping strategies and the quality of life among T2DM patients. Specifically, better family coping strategy was associated with higher quality of life in T2DM patients (p=0.000; r=0.447; r=0.05). Also, a comprehensive demographic analysis revealed that education significantly influences both the variables of family coping strategies and patient quality of life, with odds ratios of 1.284 and 1.561, respectively.

Conclusion: The research findings emphasize the mutual influence between family coping strategies and quality of life of T2DM patients. Nurses should prioritize attention to demographic factors such as education, age, gender, and duration of diabetes to enhance family coping strategies and improve the patients' quality of life.

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1. Introduction

Diabetes mellitus remains a global health issue with a persistently high incidence. According to the International Diabetes Federation, approximately 425 million adults aged 20 to 79 have diabetes mellitus, and it is estimated that this number will reach 629 million by 2045 (International Diabetes Federation [IDF], 2021). In 2015, the death toll due to diabetes mellitus in Indonesia was 185 thousand people, making it the seventh country worldwide with the largest population affected by diabetes mellitus (Cho et al., 2018). Data from the Basic Health Research reveals that in East Java province, patients with type-2 diabetes mellitus (T2DM) rank among the top 10 in Indonesia, with a prevalence of 6.8% (Basic Health Research of East Java, 2018). Malang has a notably higher mortality rate among T2DM patients compared to other cities in East Java, standing at 2.3%; this rate is attributed to low consumption of fruits and vegetables, coupled with insufficient physical activity (Ministry of Health of the Republic of Indonesia [MoHRI], 2018). A

preliminary study conducted from January to July 2019 gathered data indicating that 1,787 individuals in Malang are diagnosed with T2DM every month (Department of Health of East Java, 2023).

The high incidence of T2DM has resulted in various adverse impacts, both physical and psychological, for sufferers and their families. Physically, T2DM sufferers experience macro and microangiopathy (Brunner & Suddarth, 2010). Psychologically, they endure anxiety, anger, grief, shame, guilt, hopelessness, and depression (Bhat et al., 2020). Anxiety arises due to sufferers feeling helpless or unable to overcome the problem (Bhat et al., 2020). Long-term dependence on T2DM treatment alters lifestyles, interaction patterns, and family habits, leading to boredom and stress among caregiving families (Kalra et al., 2018). The illness experienced by family members becomes an unexpected situational stressor, leading to health problems within the family, often referred to as family illness (Mahler et al., 2022). Families can overcome these challenges if they have effective coping mechanisms.

Family coping is defined as an active process when families utilize existing family resources and develop behaviors that will strengthen family units and reduce the impact of stressful life events (Amador-marín & Guerra-martín, 2017). Sanjaya (2023) highlighted that a positive response from the family and its subsystems in addressing diabetes mellitus-related issues involves dietary management. This adaptation not only applies to the sufferers but also necessitates adjustments within families to alleviate the burden on the patients; the better the family coping, the higher the level of adherence to diabetic management. However, families may not always have effective or competent coping mechanisms in dealing with the problems of sick family members. NANDA explains that the declining family coping signifies the inadequacy and ineffectiveness of the family in assisting sufferers to manage and master the adaptive tasks related to health problems (NANDA, 2020). Some related factors include demographic characteristics (Rondhianto et al., 2020), prolonged illness, and deprivation of supportive abilities from the family, lack of information on the family, and inadequate family understanding of the health problems faced by the family. Maladaptive family coping can significantly impact quality of life (QoL) (Bou, 2023).

Quality of life is defined as an individual's perception of their position within the cultural context and value system in which they live, encompassing their relationship with their goals, expectations, standards, and life focus (WHO, 2012). This concept includes several dimensions, such as physical function, psychological function, social function and environment. Quality of life is a predictor in patients with chronic diseases, so that it becomes a major competency in the goals of long-term care interventions, improving patient welfare, and productivity. The decreased QoL of T2DM patients is caused by long-term drug consumption, hospital admissions, disease burden, complications, and early death (Alaof et al., 2022). A study by Teli (2017) showed that T2DM patients experienced declines in all aspects, including physical function, mental function, pain, general health and role changes where all components showed a value of < 80. This indicates a decline in the QoL of T2DM patients. The significance of improving the QoL of T2DM patients is related to their response to therapy and disease progression. Low QoL can worsen complications and can lead to disability or death (Abdul et al., 2020).

Family caregivers in the long term often experience fatigue when accompanying patients (Kang et al., 2020). They may tend to neglect tasks, fall into monotonous routines, ignore or overlook older patients, and experience stress and depression (Sherman, 2019). Moreover, inadequate relationship patterns contribute to suboptimal caregiving roles, impacting the quality of life for the patients (Kalra et al., 2018). This situation is exacerbated by the insufficient intervention and support provided to family caregivers by primary health nurses, resulting in a lack of knowledge and skills. In Indonesia, primary health efforts primarily focus on individuals with T2DM, overlooking the potential involvement of families in community health initiatives. The challenges faced by families with T2DM patients undergoing outpatient care in primary health care settings are getting increasingly complex. The intricate caregiving responsibilities undertaken by family caregivers arise from constrained social support and limited access to information sources aimed at enhancing knowledge and skills. The paucity of literature offering guidance to family caregivers adversely affects their coping mechanisms, ultimately impacting the quality of life of T2DM patients. Therefore, this study was conducted to analyze the relationship between family coping strategies and the quality of life of patients with T2DM undergoing

treatment in primary health care. Additionally, it sought to investigate the influence of demographic factors on both family coping strategies and the quality of life of these patients.

2. Methods

2.1 Research design

This research was an analytic observational study with a cross-sectional approach. This study explored the occurrence and underlying reasons for the health phenomenon by analyzing the dynamics of correlations between different phenomena or between risk factors and outcome factors. Data were collected or approached at a single point in time to understand the relationships and interplay between these factors.

2.2 Setting and samples

This research was conducted from March to June 2020 in the working areas of 16 public health centers (PHCs) in Malang, Indonesia, spanning five districts. The study involved T2DM family caregivers and patients. Inclusion criteria for family caregivers encompassed individuals residing in the same household as a person with T2DM, having familial ties (blood relationship, adoption, or marriage), being over 17 years old, and possessing proficient verbal communication skills. On the other hand, family exclusion criteria comprised families or family caregivers who were unwell or had health issues, whether infectious (e.g., TB) or non-infectious (e.g., diabetes, hypertension, stroke), and elderly caregivers aged over 60. For patients, the inclusion criteria involved enrollment in the *Prolanis* program (an Indonesian initiative educating and supporting individuals with non-communicable diseases like diabetes and hypertension, focusing on nutrition, lifestyle changes, medication adherence, and regular health check-ups for overall health improvement and complication prevention), independence, proficient reading abilities, and possession of health insurance. The exclusion criteria were patients who had not attended the *Prolanis* program in the last two months, those with other physician-diagnosed conditions (such as hypertension, stroke, osteoarthritis, or heart disease), and those living alone at home.

The sample size in this study was determined using the Isaac and Michael formula (Sugiyono, 2013). The research population, derived from the average patient visits during the period of January-December 2019, consisted of 1,787 individuals. A margin of error of 0.05 was applied, resulting in a sample size of 327 for each group, encompassing both T2DM patients and their family caregivers. This study used probability sampling with cluster random sampling technique. The initial data on the number of T2DM patients was sourced from the Malang Health Service. Subsequently, the proportion of the sample size for each public health center was calculated.

2.3 Measurement and data collection

Data collection involved the utilization of the COPE Brief questionnaire for coping strategies, originally developed by Carver and adapted into Indonesian by Latifah (2020). Additionally, the Diabetes Quality of Life (DQoL) questionnaire, initially developed by the Diabetes Control and Complications Trial (DCCT) Research Group and adapted into Indonesian by Wicaksana et al. (2021), was used. Both instruments were tested for validity and reliability by the researchers on 20 patients with T2DM at a primary health care center in Dau, Malang Regency. The Brief-COPE is a 28 item self-report questionnaire designed to measure effective and ineffective ways to cope with stressful life events. This instrument consists of three dimensions: emotion focused coping, problem focused strategies, and dysfunctional strategies with answer choices using a Likert scale of never=1, sometimes=2, often=3, and always=4. The COPE Brief questionnaire underwent validity and reliability testing, yielding the Pearson correlation validity test results ranging from 0.496 to 0.905, all surpassing the threshold of 0.349, and demonstrated reliability assessed using Cronbach's alpha, resulting in a value of 0.755. The coping mechanism scores ranged from a minimum of 28 to a maximum of 112. Coping strategies were categorized into two groups: adaptive and maladaptive. This categorization was made based on the average total score, with coping mechanisms having an average score ≤ 70 categorized as maladaptive, and those with a total score > 70 categorized as adaptive (Sandra et al., 2022).

The DQoL instrument consists of 46 core items, encompassing four indicators: satisfaction with treatment, impact of treatment, concerns about future diabetes impact, and concerns about social and work issues. The scale provides five answer choices: very satisfied=5, moderately satisfied=4, neither=3, moderately dissatisfied=2, and very dissatisfied=1. The DQoL

questionnaire underwent validity and reliability testing, resulting in Pearson correlation validity test values ranging from 0.64 to 0.87, all exceeding 0.349, and demonstrated reliability using Cronbach's alpha with a value of 0.88. Quality of life scores range from a minimum of 46 to a maximum of 276. A total score \leq 184 indicates poor QoL, while a score > 184 indicates good QoL.

The data collection process began with submitting a permit to the Malang City Health Office, followed by coordination with the persons in charge of the *Prolanis* program to obtain data on T2DM sufferers. Patient data were collected during their visits to primary health care services, while data from family caregivers were obtained through home visits conducted with the assistance of community health volunteers. Before completing the questionnaires, respondents received an explanation about the research's aims and objectives and were requested to willingly participate by signing a research consent form.

2.4 Data analysis

The data were analyzed using SPSS (Version 22.0. IBM Corp, Armonk, NY, USA). Descriptive analyses were conducted for the family caregiver and patients sociodemographic data. Bivariate analysis to examine the relationship between family coping and patient quality of life was performed using the non-parametric Spearman rank test. For the analysis of demographic factors affecting both variables, multivariate analysis was employed. This involved utilizing multiple logistic regression with a corrected confidence level (CI) set at 95%.

2.5 Ethical considerations

This study obtained ethical approval from the Health Research Ethics Committee, Faculty of Medicine, Universitas Brawijaya, under ethical clearance number o6/EC/KEPK/01/2020. Prior to their participation, participants provided their consent by signing an informed consent form.

3. Results

3.1 Demographics characteristics

Table 1 shows the characteristics of family caregivers, indicating that the majority were <45 years of age, amounting to 158 (48.3%) respondents. Among them, 317 (96.9%) were Muslims, 168 (51.4%) were male, 159 (48.6%) had completed senior high school education, and 188 (57.5%) were entrepreneurs. Table 1 also shows the characteristics of T2DM patients, highlighting that the majority were aged between 45 and 65 years, totaling 207 respondents (63.3%). Among these patients, 317 (96.9%) were Muslims, 263 (80.4%) were female, 169 (51.7%) had an elementary school education level, 225 (68.8%) were unemployed, 195 (59.6%) had a diabetes duration of less than five years, and 189 (57.8%) had blood sugar levels ranging from 100 to 200 mg/dl.

Table 1. Demographic characteristics of family caregivers and patients with T2DM

Demographic characteristics	Family o	aregivers	Patients		
Demographic characteristics	f	%	f	%	
Age (years)					
<45	158	48.3	7	2.1	
45-65	123	37.6	207	63.3	
>65	46	14.1	113	34.6	
Religion					
Islam	317	96.9	317	96.9	
Christian	7	2.1	7	2.1	
Catholic	3	0.9	3	0.9	
Gender					
Male	168	51.4	64	19.6	
Female	159	48.6	263	80.4	
Education					
No School	1	0.3	2	0.6	
Elementary School	71	21.7	169	51.7	
Junior High School	54	16.5	76	23.2	
Senior High School	159	48.6	65	19.9	
College	42	12.8	15	4.6	

Table 1. Continued

Demographic Characteristics	Family (Caregiver	Patients	
Demographic Characteristics	f	%	f	%
Employment				
Unemployed	120	36.7	225	68.8
Laborer	9	2.8	3	0.9
Farmers	1	0,3		
Government employees	9	2.7	4	1.2
Entrepreneur	188	57.5	95	29.1
Diabetes Duration				
<5 years			195	59.6
>5 years			132	40.4
Blood Sugar Results				
<100 mg/dl			8	2.4
100-200 mg/dl			189	57.8
>200 mg/dl			130	39.8

3.2 Distribution of family coping strategies and quality of life patients

Table 2 indicates that the majority of families employed adaptive coping mechanisms, totaling 307 respondents (93.9%), while 20 respondents (6.1%) utilized maladaptive coping strategies. These outcomes were based on the respondents' responses in the coping strategy questionnaire. Furthermore, the table reveals that 275 T2DM patients (84.1%) had a good quality of life (QoL), while 52 patients (15.9%) had a poor QoL.

Table 2. Distribution of family coping strategies and quality of life of T2DM patients

Variables	f	%
Family Coping Strategies		
Adaptive	307	93.9
Maldaptive	20	6.1
Quality of Life Good	275	84.1
Poor	52	15.9

3.3 Analysis of the relationship of coping strategies and quality of life

Table 3 shows that among the 275 respondents with good QoL, 271 (98.5%) used adaptive coping strategies, and only 4 (1.5%) respondents used maladaptive coping methods. The research findings also indicated that 69.2% exhibited adaptive family coping strategies, despite their reported poor QoL. Additionally, the table shows the correlation between family coping strategies and the QoL of T2DM patients, indicating a significant positive association: the better the family coping, the higher the QoL of T2DM patients (p=0.000; r=0.447; α =0.05).

Table 3. Analysis of the relationship of coping strategies and quality of life

			Qualit	Correlation	<i>p</i> -value			
Coping Strategies	Good Not Good Total		Coefficient					
	f	%	f	%	f	%	-	
Adaptive	271	98.5	36	69.2	307	93.9	0.447	0.000
Maladaptive	4	1.5	16	30.8	20	6.1	0.447	0.000

3.4 Demographic factors affecting family coping strategies and patient OoL

Based on Table 4, it is evident that demographic factors such as age, gender, and education significantly influenced family coping strategies (p<0.05). Similarly, age, gender, education, and diabetes duration were identified as demographic factors influencing the patient QoL (p<0.05).

A detailed demographic analysis indicates that education plays a dominant role in the family coping strategy variables and patient QoL (OR: 1.284 and 1.561).

Variables	В	SE	OR	95%CI	p
Family Coping					
Age	2.754	0.936	1.025	0.231;1.657	0.03^{*}
Religion	0.753	1.875	0.491	0.167;1.235	0.31
Gender	3.050	0.836	1.142	0.371;1.631	0.01^{*}
Education	3.671	0.625	1.284	0.873;1.762	0.00^{*}
Employment	0.835	1.736	0.081	0.218;1.716	0.25
Constant	5.41 2	1.976			
Quality of Life					
Age	2.614	0.946	1.075	0.314;1.572	0.04*
Religion	0.437	2.651	0.573	0.131;1.325	0.71
Gender	2.937	0.637	1.351	0.172;1.732	0.02^{*}
Education	3.736	0.621	1.561	0.758;1.835	0.00^{*}
Employment	0.536	2.472	0.024	0.182;1.372	0.61
Diabetes Duration	2.853	0.635	1.181	0.371;1.691	0.02^{*}
Blood Sugar	0.518	2.4528	0.093	0.142;1.182	0.67
Constant	5.64 2	1.872			

^{*}The study reveals a relationship between demographic characteristics and research variables

4. Discussion

This study investigated the relationship between family coping strategies and QoL of patients with T2DM, alongside exploring demographic influences. The findings revealed a positive link between effective family coping strategies and higher QoL in T2DM patients. Additionally, our analysis highlighted education as a key factor significantly impacting both family coping strategies and patient QoL.

4.1 Family coping strategy

The results of this study indicate that almost all family caregivers employed adaptive coping strategies in providing care for family members with T2DM. Adaptive coping refers to individual efforts to deal with stressors in a positive, rational, and constructive manner (Hapunda, 2022). Theis finding aligns with a study conducted by Mustamu et al. (2020), which stated that 82.9% of family coping falls under the "positive" category while caring for family members with T2DM. Another study showed that more than half (61.4%) of families caring for children with chronic diseases have adaptive coping strategies (Setyoadi et al., 2023). The process of adaptive family coping in dealing with chronic illnesses involves a series of steps and strategies undertaken by the family to address the physical, emotional, and social challenges that arise in relation to the family member's chronic health condition.

Based on the analysis in this study, family coping strategies can be influenced by factors such as age, gender, and education. The study results show that 85% of family caregivers fall into the adult age category. Mature caregivers are expected to have emotional maturity, good planning and decision-making skills, and the ability to provide positive support in caring for sick family members. These factors contribute to adaptive coping strategies within the family (Mogueo & Defo, 2022). Family coping strategies are also influenced by the gender of the family caregivers. The study results show that more than half (51.4%) of family caregivers are males. Men and women have different responses when faced with problems. Men generally enjoy challenges and even think that problems can provide positive motivation. Women have a negative awareness of the presence of problems; for women, problems can trigger negative hormones that cause stress, anxiety, and fear. Family coping strategies tend to be adaptive when the caregiver is male, as men can think positively when faced with problems (Rico-Blázquez et al., 2022).

The demographic factor of education has the greatest contribution to family coping strategies, as the research results showed that more than half (60.4%) of family caregivers have a high school and college education levels. Education can influence a person to have planning and decision-

making skills in life. The higher the level of education, the more positive mindset is formed, resulting in better control over stressors, as individuals become more responsive to information and have more knowledge to implement adaptive family coping strategies (Bekele et al., 2022).

Family coping in caring for patients with T2DM involves a dynamic process in which family members collectively respond to the challenges and demands associated with managing diabetes within the household (Luthfa & Ardian, 2019). It is important to remember that each family has different needs and challenges in dealing with T2DM. The support and assistance required may vary depending on the health condition, social support, and available resources. It is essential for family caregivers to seek appropriate support and resources to help them overcome the challenges that arise throughout the journey of T2DM. Findings of this study also highlight the importance of considering diabetes knowledge, family support, the role of nurses, coping skills, and family empowerment in enhancing family coping.

The results of this study also suggest that although coping strategies can be adaptive for families, the quality of life for individuals with T2DM may not always be good. Several factors can affect the quality of life of T2DM patients, including complications, stress, and psychological well-being (Alaof et al., 2022). Complications associated with T2DM can significantly impact the quality of life (Teli, 2017). Additionally, stress and anxiety related to managing the condition and daily life can also affect the overall well-being of people with T2DM (Kalra et al., 2018). It is important to note that the quality of life of T2DM patients can vary among individuals and is influenced by various factors such as the severity of the condition, access to health services, social support, and individual coping mechanisms. Therefore, it is critical to provide comprehensive support and interventions to address the specific needs and challenges faced by individuals with T2DM.

4.2 Quality of life of patients with T2DM

The research results indicate that patients with T2DM have a "good" quality of life. This finding is reinforced by the study of Abualhommos et al. (2022), which stated that 73.8% of T2DM patients have a good quality of life. Improving the quality of life is considered the ultimate goal of chronic disease care programs (Ritter & Bonsaksen, 2019). The quality of life of patients with T2DM encompasses various dimensions, reflecting the impact of the disease on the daily lives of patients. Several demographic factors influencing the quality of life of T2DM patients include age, gender, education, and duration of illness. The results of this study show that almost all T2DM patients are classified as pre-elderly and elderly. Elderly individuals with T2DM may experience a decline in physical function (Amin et al., 2022). According to the study conducted by Wylie et al. (2022), aging is associated with a decrease in physical strength due to muscle weakening, impacting activities related to physical fitness and contributing to a decline in the quality of life for T2DM patients.

This study reveals that gender demographic factor also affected the quality of life of T2DM patients. In this study, the majority (80.4%) of patients are female. T2DM is more prevalent in women than in men, attributed to the decline in estrogen hormones due to menopause. Changes in hormone levels after menopause can lead to fluctuations in blood sugar levels. The higher percentage of fat accumulation in women than in men can reduce insulin sensitivity in muscles and the liver. Also, the difference in physical function between men and women influences the quality of life of T2DM patients (Ciarambino et al., 2022).

The finding of this study also showed that education level has a dominant contribution to the quality of life of T2DM patients. Abualhommos et al. (2022) suggest that education level is not related to the occurrence of T2DM but has an influence on the quality of life of T2DM patients. Previous research results highlight the significance of the education level as a crucial variable, indicating that respondents with higher education generally experience a better quality of life compared to those with lower education (Alshayban & Joseph, 2020). Disease duration is also found to be a contributing factor to the quality of life among T2DM patients. Specifically, results show that a disease duration of less than five years is associated with a better quality of life. However, the quality of life for T2DM patients with a disease duration of less than five years can vary, depending on individual factors and the management of the disease (Alaof et al., 2022).

However, it is important to remember that the experience of quality of life can differ among individuals. Nevertheless, there are other factors that can influence the quality of life of T2DM patients with an illness duration of less than five years. These factors may include blood sugar

control level, complications related to T2DM, and the level of adherence to the recommended treatment and lifestyle changes (Sari et al., 2018). Therefore, it is crucial to maintain good disease management, including following the treatment plan recommended by the doctor, maintaining a healthy diet, engaging in regular exercise, and managing stress. With proper management and adequate support, T2DM patients with an illness duration of less than five years can achieve a good quality of life.

4.3 Family coping strategies and quality of life

The results of this study indicate a positive correlation between effective family coping strategies and the improvement of the quality of life (QoL) in patients with T2DM. This finding aligns with a study conducted by Dewi et al. (2020), which revealed a significant correlation between coping mechanisms and QoL with a p-value of 0.003 (α >0.05). The coping mechanisms employed by family caregivers play a crucial role in influencing the quality of life of T2DM patients. The support and coping mechanisms provided by family caregivers can have a significant impact on the patients' quality of life.

Several studies have shown a significant correlation between the coping mechanisms of family caregivers and the quality of life of T2DM patients (Cyran-Grzebyk et al., 2023; Dewi et al., 2020; Freeman-Hildreth et al., 2019). Well-applied coping strategies align with the family's desires in caring for T2DM patients, thereby enhancing the quality of life through comprehensive family support. Maintaining close contact with healthcare providers, where families receive information about diabetes care, enables the family to be a solution to every problem faced by patients (Powers et al., 2020). Furthermore, the coping mechanisms applied by family caregivers can significantly influence the quality of life of T2DM patients. Effective coping strategies, such as emotional support, collaborative problem-solving, and active involvement in patient care, can enhance the quality of life of T2DM patients. Grover et al. (2016) showed that coping strategies can impact the quality of life of children and adolescents with type-1 diabetes caregivers, indicating that coping strategies can also significantly affect the quality of life of T2DM patients. Therefore, it is essential to pay attention to the coping mechanisms applied by family caregivers in efforts to improve the quality of life of T2DM patients.

Coping mechanisms can influence an individual's quality of life. In this context, coping refers to the strategies an individual uses to deal with stress, challenges, or problems in daily life (Hapunda, 2022). When someone employs effective coping mechanisms, they tend to have a better quality of life. Some studies indicate that positive coping mechanisms, such as social support, problem-solving, and adaptation, can improve an individual's quality of life (Dewi et al., 2022; Hapunda, 2022; Mojahed et al., 2019). Social support from families, friends, or the community can provide crucial emotional and practical support in facing life's challenges. Effective problem-solving helps an individual address problems constructively, while good adaptation allows an individual to adjust to changes and face difficult situations.

In the context of T2DM, effective coping mechanisms can help patients face challenges related to disease management, such as maintaining a healthy diet, exercising, and managing stress (Adu et al., 2019). Support from family and the medical team can also play a crucial role in improving the patient's quality of life (Pamungkas et al., 2017). However, it is important to remember that each individual has different coping mechanisms, and what works for one person may not be the same for another. It is also crucial to note that every family has unique needs and dynamics. Therefore, an effective approach to improving adaptive family coping may vary. In this regard, consulting with healthcare professionals, such as doctors or nurses, can assist in designing strategies that suit the family's needs and situation (Hood et al., 2018). Additionally, the quality of life is influenced by other factors such as health conditions, social environment, and genetic factors (Dendup et al., 2018). Improving adaptive family coping can positively impact the quality of life of patients with T2DM.

5. Implications and limitations

The study results provide several important implications regarding family nursing practice. The families are the main target in community health initiatives because they have the potential to enhance the health of family members with chronic illnesses like T2DM. Managing T2DM necessitates prolonged treatment to maintain blood sugar levels within normal limits, change healthier behavior, and increase adherence to treatment. Long-term care requires good family

coping skills in making the best decisions for sick family members. Within primary health care settings, community nurses play a pivotal role in enhancing the knowledge and abilities of family caregivers in caring for sick family members at home. The knowledge and skills acquired will assist in enhancing family caregiver coping. The promptness and accuracy of the family in making decisions regarding the care needs of family members with T2DM will contribute to improving the patient's quality of life.

This study has limitations. It only focused on families dealing with T2DM in the community, limiting its scope to urban areas and failing to represent rural settings. Consequently, the study's conclusions might not be generalizable to cases other than T2DM. In addition, because this study uses a descriptive cross-sectional design, it cannot infer causality between variables or follow changes over time.

6. Conclusion

Based on the research results, it can be concluded that there is a positive relationship between effective family coping strategies and the improvement of the quality of life of T2DM patients. Demographic factors, including age, gender, and education, play a significant role in influencing family coping strategies. Similarly, demographic elements such as age, gender, education, and diabetes duration have an impact on the patient's quality of life. Among these factors, educational background is identified as having the greatest contribution to influencing both family coping and the patient's quality of life in the context of T2DM. The findings suggest a recommendation for nurses to prioritize attention to demographic factors such as education, age, gender, and duration of diabetes in order to enhance family coping strategies and improve the overall quality of life for patients with T2DM. Additionally, the study proposes further research that focuses on improving the quality of life for individuals with T2DM, emphasizing considerations of the condition's severity, access to health services, social support, and individual coping mechanisms.

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Author contribution

All authors (SS, FE, JH, FR, NDK, YS and DDSLI) contributed substantially to the study design, data collection, analysis, and interpretation of results. All authors drafted and revised the article, approved the published version, and agreed to be accountable for all aspects of the work.

Conflict of interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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ORIGINAL RESEARCH

Barriers and Challenges Against the Utilization of Novel Teaching Methods for Nursing Students: Perspectives of Nursing Instructors



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Abstract

Background: The first step in effectively applying novel teaching methods is identifying barriers and challenges to implementing appropriate interventions. A literature review revealed no studies exploring nursing instructors' viewpoints on the reasons for not using novel teaching methods.

Purpose: The present study aimed to explore the challenges and executive barriers against using novel approaches in instructing nursing students from the perspective of nursing instructors.

Methods: In this descriptive-analytical study, 163 nursing instructors from three nursing schools in Fars Province, Southwest Iran, were selected using convenience sampling. A researcher-developed questionnaire comprising 17 items scored on a five-point Likert scale was utilized to collect data. These items were categorized into three domains: challenges related to students (n=4), instructors (n=8), and structural-managerial aspects (n=5). The questionnaire's reliability coefficient was found to be 0.89 using the test-retest method. The Kolmogorov–Smirnov test was used to test the normality of variables and the independent t-test was employed to examine the relationship between genders and educational degrees across all three domains.

Results: The mean scores for challenges and barriers related to the instructors, students, and structural-managerial aspects were 33.24(7.16), 16.31(3.93), and 22.14(3.64), respectively. A significant relationship between gender and educational degree was observed across all three domains (p<0.001).

Conclusion: The barriers and challenges against using novel teaching methods for nursing students from the perspective of nursing instructors included challenges related to instructors, students, and structural-managerial aspects. The support and encouragement of educational institution managers in executing these methods could help promote the utilization of these techniques and improve the quality of education.

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1. Introduction

Education is a complicated process, particularly in medical sciences, where graduates face clients requiring complex services (Buja et al., 2019). Education in medical sciences should aim at training skillful, ethical, research-oriented, entrepreneurial, and reflexive students ready to encounter challenging and complicated work environments. However, training such students is challenging and requires great infrastructure (Gutierrez et al., 2016). One strategy to enhance the quality of medical student education involves altering teaching techniques (Samarakoon et al., 2013). A successful instructor enhances learning effectiveness by adhering to teaching principles and aligning teaching methods with students' learning styles (Ahmed et al., 2018).

Iurea et al. (2011) showed that if a teacher adapts their teaching style to the student's learning style, the student's scientific performance and educational framework for student participation will increase. Thus, sustainable learning will gradually be achieved. They also discovered that dynamic teaching and learning styles support learner satisfaction and student awareness of their learning styles. The student's learning style adaptation method based on teaching strategies and their application significantly affects learning and satisfaction (Iurea et al., 2011).

The instructor-teaching method is the primary source of adjustment to interaction styles in the classroom and an important factor in motivating students and enhancing their cooperation (González et al., 2017). In this context, awareness of teaching methods, conformity to student learning styles, and variety in utilizing these techniques considerably affect learners' learning and satisfaction. Dynamic teaching and learning styles also support learners' satisfaction. Despite the variety of teaching methods in medical sciences nowadays, many instructors still use the lecture method (Wang & Liu, 2019; Yazici et al., 2016).

As with other majors, many nursing educational programs employ lecturing. In this method, learners' capacities are not properly addressed, the role of learners is not significant, and learning is superficial. To overcome these shortcomings, educators have begun to use participatory and active learning methods (McLaughlin et al., 2014). To that end, Benner and MacKinnon et al. proposed changes in the education system, such as moving away from teaching decontextualized knowledge and better integrating active learning in the classroom. New and innovative instructional strategies must be integrated within nursing education to achieve these goals (Benner et al., 2012; MacKinnon et al., 2017).

Considering the positive effects of novel teaching methods based on problem-solving, the role of self-orientation in learning, and the impact of lifelong learning on medical students, it is necessary to develop and implement student-centered methods based on learning theories in universities and provide opportunities for improvement of learning among nursing students as health care providers (Alghasham et al., 2012). The new teaching method, which we call the modern method, is more activity-based and centers the learner's mind, which involves them entirely in the learning process. In the modern teaching method, curriculum teaching and planning keep the learners as the primary target. The new method focuses more on teaching the students to improve their intellect by using various new and innovative ideas rather than making them recite the syllabus to clear the examination with the same old style (Anderson, 2022).

A previous study has systematically reviewed the effectiveness of new teaching methods in Iran (Karimi Monaghi et al., 2013). They selected and reviewed thirty-two articles in their study and concluded that the new methods of teaching, including problem-based learning (PBL), clinical simulation, self-directed learning, small group sessions, competency-based education, concept maps, and case-based learning (CBL), increase student learning, satisfaction, and participation, and promote deep learning, and creative thinking (Karimi Monaghi et al., 2013). Another study also showed that new student-centered teaching strategies, such as the discussion method, lead to deeper learning and student satisfaction than traditional teaching strategies, such as lecture-based learning (Meng et al., 2019). Sharma (2017) and Al-Hammouria et al. (2020) also showed new teaching strategies, including flipped classrooms, problem-based learning (PBL), workshops, computer-assisted instruction (CAI), and team-based learning (TBL), promoted deeper learning, more participation, and student satisfaction compared to the lecture-based learning method (Al-Hammouri et al., 2020; Sharma et al., 2017).

Traditional teaching methods can no longer respond to the needs of the educational system (Tularam et al., 2018). Today, instructors seek methods that lead to active learning among students and strengthen their critical thinking and decision-making skills (Horntvedt et al., 2018; McCurry & Martins, 2010). Although numerous studies have emphasized utilizing novel approaches in nursing student education (Fisher & King, 2010; Nouri et al., 2014), traditional methods such as lectures are still the top priority of many faculty members in Iran. This method can be used to explain academic terms well and teach a large number of learners at a low cost (Ross & Bruderle, 2018). Ghojazadeh et al. (2015) stated that novel teaching methods could not be accurately and standardly executed in Iran unless they are accompanied by time, place, and personnel arrangements.

A review of existing literature showed a lack of studies on nursing instructors' perspectives concerning the reasons for not adopting novel teaching methods. Consequently, the researchers decided to explore the challenges and strategies associated with implementing these methods among nursing faculty members through brainstorming sessions. By analyzing the results, steps could be taken toward planning for employing novel teaching techniques in nursing education. Thus, the present study aimed to assess the instructors' perspectives regarding the reasons for not using novel teaching methods and the challenges against selecting and utilizing these techniques.

2. Methods

2.1 Research design

This study employed a descriptive-analytical design to explore the challenges and executive barriers against the utilization of novel teaching approaches from the perspectives of nursing instructors.

2.2 Setting and samples

The study was conducted in 2020 among nursing instructors from three nursing schools in Fars Province, Southwest Iran, utilizing total population sampling. Inclusion criteria for the study involved nursing instructors with a minimum of one year of experience in applying novel teaching methods and a willingness to participate. Meanwhile, individuals with incomplete questionnaires or needing more physical or mental preparedness were excluded. Initially, the study targeted 174 nursing instructors. However, 11 were subsequently excluded due to reasons such as maternity leave (n=3), continuing education (n=5), and incomplete questionnaires (n=3). Consequently, 163 questionnaires were successfully completed, achieving a response rate of 93%.

2.3 Measurement and data collection

The data were collected using a questionnaire developed by the researchers and validated in two stages. The first stage involved designing a questionnaire to identify challenges and strategies for overcoming barriers to using novel teaching methods in nursing education from the perspective of nursing instructors. The questionnaire items were formulated through a literature review and a nominal group technique. Thirty nursing instructors, primary participants in the study, were invited to a six-hour nominal group technique session aimed at identifying challenges and barriers against the employment of novel teaching techniques. This session gathered ideas from instructors regarding reasons for not using novel teaching methods and associated executive barriers. These ideas were categorized into three groups based on similarities: challenges related to instructors, students, and structural-managerial aspects. Subsequently, the questionnaire was developed and distributed among participants to assess the importance and scores of the items. By employing group consensus and thorough examination of participant ideas, challenges in utilizing novel teaching techniques were comprehensively explored from the perspectives of experts and stakeholders. The goal was to devise strategies for the effective implementation of these techniques through collective wisdom. The finalized questionnaire included demographic questions (age, sex, work experience, and educational degree), along with 17 items categorized into three domains: challenges related to students (n=4), challenges related to instructors (n=8), and structural-managerial challenges (n=5). Items were scored on a five-point Likert scale ranging from 4 (very important) to 0 (unimportant).

In the second stage, face and content validity were employed to assess the questionnaire's validity. The quantitative face validity was evaluated using the impact score, where scores >1.5 indicated item appropriateness (Heale et al., 2015). According to 20 nursing instructors (part of this study's respondents), all questionnaire items' impact scores exceeded 1.5. Content Validity Ratio (CVR) and Content Validity Index (CVI) were used to investigate content validity. The experts determined the items' necessity as 'necessary,' 'useful but not necessary,' and 'not necessary' considering CVR (Goldin et al., 2015). In doing so, we collected 15 nursing instructors' opinions, and values greater than 0.49 were considered acceptable based on the Lawshe table (Ayre & Scally, 2014). Regarding CVI, the experts' group included nursing professors skilled in designing and validating tools and were requested to evaluate the items in relevance, clarity, and simplicity. In this respect, scores above 0.79 were considered acceptable (Kovacic, 2018). The total content validity of the questionnaire was computed using S-CVI/Ave, where the minimum score of 0.79 was considered acceptable (Connell et al., 2018). Based on the results, the S-CVI/Ave of the questionnaire was found to be 0.96. Finally, the reliability of the questionnaire was assessed using the test-retest method. In doing so, the questionnaire was given to 100 nursing instructors (part of the respondents of this study) in two stages with a two-week interval. The reliability coefficient of the questionnaire was found to be 0.89.

In this study, each question was assessed using a five-point Likert scale, ranging from 4 (very important) to 0 (not important). Hence, applying parametric tests for direct comparison would not be appropriate. The total score of each domain was calculated by summing the responses to questions (ranging from 0 to 16, 0 to 32, and 0 to 20, respectively, for challenges related to

students, instructors, and structural-managerial challenges). However, the summed total scores offer a wide range suitable for parametric tests. Subsequently, each domain's range was divided into two equal categories: low and most important (0 to 8, 9 to 16 for challenges related to students; 0 to 16, 17 to 32 for challenges related to instructors; 0 to 10, 11 to 21 for structural-managerial challenges). The normality of distribution was confirmed through the Kolmogorov–Smirnov test.

After obtaining permission from the university officials, the faculty members meeting the inclusion criteria were approached, briefed on the study objectives, and requested to complete the questionnaire. The questionnaires were administered between April and June 2020.

2.4 Data analysis

The study data were entered into the IBM SPSS software (version 22, IBM Corporation, Armonk, NY, USA) and were presented by frequency distribution, mean, and standard deviation (SD). Kolmogorov–Smirnov test was used to assess the normality distribution of variables. The results confirmed the normality assumption for all three instructors, students, and structural domains. The independent t-test was used to compare three instrument domains between genders and between educational levels. Three instrument domains were compared between work experience levels by ANOVA. A *p*-value less than 0.05 was considered to be a significant level.

2.5 Ethical considerations

All participants provided written informed consent to participate in the study. The present study was conducted following the principles of the revised Declaration of Helsinki, a statement of ethical principles that directs physicians and other participants in medical research involving human subjects. The participants were assured of the anonymity and confidentiality of their information. Moreover, the study was approved by the local Ethics Committee of Fasa University of Medical Sciences, Fasa, Iran (Ethical code: IR.FUMS.REC.1398.124).

3. Results

3.1 Profile of participants

Among the 163 nursing instructors under investigation, 96 (58%) were female, and 67 (42%) were male. Furthermore, 70 participants (43%) held Ph.D. degrees, while 93 (57%) held MSc degrees. Also, the participants' mean age was 39(1.65) years, and their mean work experience was 8(4.83) years.

3.2 Challenges related to instructors, students, and structural-managerial aspects

The mean scores of the challenges related to students, challenges related to instructors, and structural-managerial challenges were 12.31(3.93), 25.24(7.16), and 17.14(3.64), respectively, and all were the most important challenges. Regarding the challenges associated with students, the highest score was related to students' lack of familiarity with novel teaching methods. Considering the challenges associated with instructors, the highest scores were related to instructors' unfamiliarity with novel teaching methods and lack of mastery and skills. Finally, many students and the lack of support and encouragement from educational institutions obtained the highest scores in structural-managerial challenges (Table 1).

Domain	Effective factors and barriers	Mean (SD)	Interpretation
Challenges related to students	Lack of motivation Resistance against change Unfamiliarity with novel teaching methods	2.84(1.18) 2.55(1.45)	
students	Non-applicability of teaching content Total score of the challenges related to students	3.67(0.60) 3.25(0.98) 12.31(3.93)	Most Important
Challenges	Resistance against change	2.51(1.32)	
related to instructors	Unfamiliarity with novel teaching methods Lack of motivation	3.73(0.58) 2.73(1.23)	

Table 1. The mean (SD) scores of the items in the three domains (n=163)

Table 1. Continued

Domain	Effective factors and barriers	Mean (SD)	Interpretation
	Satisfaction with and trust in the common teaching	3.03(0.97)	
	methods	()	
	Lack of privilege	3.43(0.79)	
	Difficulty of evaluation in novel teaching methods	3.33(0.86)	
	Not having lessons plans based on the teaching method	2.92(1.15)	
	Lack of mastery and skills	3.57(0.72)	
	Total score of the challenges related to instructors	25.24(7.16)	Most Important
Structural-	Time restrictions	3.43(0.77)	
managerial	Large number of students	3.57(0.62)	
challenges	Difficulty in class management	3.30(0.78)	
	Lack of appropriate physical space	3.35(0.90)	
	Lack of support and encouragement from the university	3.49(0.72)	
	Total score of structural-managerial challenges	17.14(3.64),	Most Important

3.3 Correlation of gender, educational degree, work experience, and teaching challenges
The independent t-test results revealed a significantly higher score of females than males in all three domains: Students, Instructors, and Structural, with p<0.001 (Table 2).

Table 2. Mean (SD) scores of the three domains based on gender (n=163)

Teaching Challenges	Female (n=96) Mean (SD)	Male (n=54) Mean (SD)	- t	<i>p</i> -value
Students (0 to 16)	14.92(1.31)	7.67(2.46)	20.130	<0.001
Instructors (0 to 32)	29.91(2.52)	16.94(4.81)	18.429	< 0.001
Structural (0 to 20)	19.57(0.98)	12.81(2.4)	19.817	< 0.001

As shown in Table 3, this study also indicated a significantly higher score of the Ph.D. group than the M.Sc. group in all three domains: Students, Instructors, and Structural (p<0.001). It can be concluded that nursing instructors with a higher academic degree have a broader perspective and greater competence in identifying and overcoming new teaching challenges.

Table 3. Mean (SD) scores of the three domains based on the educational degree (n=163)

Teaching Challenges	Ph.D. (n=60)	Ph.D. (n=60) M.Sc. (n=90)		m realise
	Mean (SD)	Mean (SD)	ι	<i>p</i> -value
Students (0 to 16)	15.82(0.5)	9.97(3.44)	13.067	< 0.001
Instructors (0 to 32)	31.67(0.66)	20.96(6.25)	13.206	< 0.001
Structural (0 to 20)	20.00(0.0)	15.23(3.6)	10.233	< 0.001

Moreover, this study also indicated a significant relationship between lower work experience and the high scores of the three domains: Students, Instructors, and Structural (p<0.001) (Table 4). This suggests that longer work experience notably impacts how instructors see and tackle challenges tied to implementing innovative teaching methods.

4. Discussion

This study investigated the challenges and barriers faced by nursing instructors in utilizing innovative approaches for nursing students across three domains: challenges related to students, instructors, and structural-managerial aspects. The findings indicated the highest scores in challenges related to instructors and structural-managerial aspects, while the scores were lower in challenges related to students. Utilizing novel teaching methods in nursing education can lead

to active and deep learning and long-term maintenance of the learned materials in students' minds (Shirani Bidabadi et al., 2016).

Teaching Challenges —	<5 (n=96)	5-10 (n=57)	>10 (n=60)	- F	<i>p</i> -value
	Mean (SD)	Mean (SD)	Mean (SD)	- г	
Students (0 to 16)	15.82(0.58)	14.63(1.26)	8.17(2.78)	132.046	<0.001
Instructors (0 to 32)	32.00(0.0)	29.26(2.13)	17.70(5.11)	238.134	< 0.001
Structural (0 to 20)	20.00(0.0)	19.61(0.77)	13.22(2.6)	64.853	< 0.001

Table 4. Mean (SD) scores of the three domains based on work experience (n=163)

In the present study, the most pronounced challenges and obstacles in the student domain were unfamiliarity with novel teaching methods and non-applicability of teaching content. In this regard, the results of a previous study by Safapour et al. (2019) also showed that the lack of sufficient knowledge and awareness among learners had been one of the obstacles and challenges of using modern teaching methods. Implementing innovative teaching approaches often requires students to be adaptable and familiar with different learning methods. The difficulty in adjusting to these new methods could arise from educational systems that mainly focus on traditional teaching styles, as highlighted by Safapour et al. (2019). Adapting to this modern teaching style demands students to shift their learning approaches, needing increased awareness and knowledge to use these modern teaching methods effectively. Additionally, when teaching content aligns differently from these new methods, students may perceive a disconnect between what they are taught and how it is taught.

Based on the study results, the challenges and obstacles affecting the instructor domain with the highest scores included unfamiliarity with novel teaching methods, the difficulty of evaluation in novel teaching methods, and lack of mastery and skills. In this regard, a study by Torabizadeh et al. (2018) also explored the effective barriers to using novel approaches in the clinical evaluation of nursing students in clinical environments based on nursing instructors' viewpoints. The results revealed that the most important challenges included nursing instructors' unfamiliarity with novel clinical evaluation techniques and the difficulty of evaluation in novel teaching methods, which align with the findings of the present investigation. Moreover, in a study by Wentink et al. (2019), instructors' lack of skills and unfamiliarity with novel teaching methods were introduced as challenges and obstacles affecting the use of new teaching methods. It was recommended that the instructors gain the necessary training and skills in this field (Wentink et al., 2019). This emphasizes the critical need for instructors to acquire the necessary skills and training to employ modern teaching techniques effectively.

Implementing modern teaching techniques is highly significant. Scicluna (2012) stated that the professional capabilities of the learners must be emphasized in medical education. Such education must improve critical thinking skills, including clinical judgment, reasoning, and decision-making, which can be achieved by employing novel educational approaches. Thus, instructors should familiarize themselves with different novel educational approaches and gain the necessary awareness and preparedness (Scicluna et al., 2012). Rafiee et al. (2014) and Jamshidi et al. (2016) also reported that instructors' lack of sufficient knowledge and lack of support from educational institutions were effective challenges and barriers to the utilization of novel teaching approaches. So, educational system managers should use the necessary plans to empower the professors using modern teaching methods (Henning et al., 2019).

Another challenge and obstacle against the utilization of novel teaching methods for nursing students from the perspective of nursing instructors was a structural-managerial challenge and obstacle. In this domain, the highest scores included the challenges related to time restrictions, the large number of students, and the lack of appropriate physical space. These findings align with the results of the study by Buch et al. (2021), which reported that time restrictions, lack of suitable infrastructure and educational equipment, and lack of motivation and support from the educational manager are some of the challenges and obstacles affecting the use of new educational methods and techniques. These collective challenges underscore the imperative need for addressing structural and managerial deficiencies to foster the effective integration of innovative teaching techniques in nursing education.

Furthermore, this study also indicated a significant relationship between the level of education and competence in using new methods of education in all three domains: student, instructor, and structural-managerial challenges. It can be concluded that nursing instructors with a higher academic degree have a broader perspective and greater competence in identifying and overcoming new teaching challenges. Similarly, the results of a study by Torabizadeh et al. (2018) showed that nursing professors with a Ph.D. or master's degree paid more attention to identifying and coping with new challenges in the evaluation of nursing students, which is consistent with the results of the present study. Moreover, the results showed a significant relationship between work experience and the scores of the three domains of Student, Instructor, and Structural-managerial challenges. This correlation suggests that an extended duration of work experience significantly influences how instructors perceive and address the challenges associated with implementing innovative teaching methods.

5. Implications and limitations

The present study aimed to assess instructor perspectives regarding the reasons for not using novel teaching methods and the challenges against selecting and utilizing these techniques. Based on the results, necessary steps could be taken toward eliminating executive barriers and planning for employing novel teaching techniques in nursing education. The educational system's senior managers and policymakers should use the necessary planning and measures to solve the challenges and obstacles affecting the use of new educational approaches and develop new educational methods in educational programs.

This study has certain limitations. The individuals participating in the content and face validity tests were included among the study participants. While the questionnaire's face and content validity, as well as reliability, were confirmed, the construct validity of the questionnaire was not assessed. Therefore, it is advisable that future studies using this questionnaire also evaluate its construct validity.

6. Conclusion

This study showed that the most pronounced challenges in implementing novel teaching methods were observed in the domains of instructors and structural-managerial aspects, while comparatively lower challenges were identified within the student-related domain. Considering the challenges associated with the instructors and students, the highest score was related to their unfamiliarity with the novel teaching methods. Indeed, the large number of students and time restrictions obtained the highest scores in structural-managerial challenges. The study findings indicate that applying novel approaches in nursing education requires infrastructure and the elimination of executive barriers. Instructor and student familiarity with novel teaching methods, their executive processes, and the support and encouragement of the managers of educational institutions for executing these methods could help promote the utilization of these techniques and improve the quality of education. It is recommended to carry out similar studies, especially in the form of qualitative studies, in other countries to identify and eliminate the obstacles affecting the utilization of novel teaching methods in nursing and medical education.

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Author contribution

MB, ZM, SHK, ZHF, and MH assisted in the conceptualization and design of the study, oversaw data collection, conducted data analysis, and drafted the manuscript. MB, MMN, and ZM conceptualized and designed the study, assisted in data analysis, and reviewed the manuscript. LN assisted in study conceptualization and reviewed the manuscript. All authors read and approved the final manuscript.

Conflict of interest

Authors declare no conflict of interest.

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ORIGINAL RESEARCH

Financial Toxicity and Its Associated Factors in Cancer Patients: A Cross-sectional Study in Indonesia



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Abstract

Background: Financial toxicity has been shown to negatively affect cancer patients' quality of life, depression, anxiety, and even mortality rates. However, there is only limited data on financial toxicity and its associated factors, which are needed to address this problem in Indonesia.

Purpose: This study aimed to identify factors associated with financial toxicity in cancer patients in Indonesia.

Methods: This study was a cross-sectional study that recruited respondents at a cancer health center in Indonesia using a convenience sampling method. A total of 110 adult cancer patients undergoing treatment took part in the study. The questionnaires comprised sociodemographic data, clinical characteristics, and the Comprehensive Score for Financial Toxicity (COST). Logistic regression was performed to achieve the study's aim.

Results: The median value of the financial toxicity index was 3.01 (min-max=1-5), indicating a medium level of financial toxicity. Occupational status was the only factor found to be associated with financial toxicity in this study. The participants who were unemployed were 2.389 more likely to have a higher financial toxicity level compared to those who were employed (OR=2.389; p=0.048).

Conclusion: Unemployment was identified to be associated with financial toxicity among cancer patients. Nurses should assess and assist patients in utilizing financial resources and develop strategies to manage extra costs that burden them financially. Future nationwide studies are essential to provide more robust evidence on multifaceted factors influencing financial toxicity and inform policy-making aimed at effectively addressing financial toxicity.

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1. Introduction

Cancer is one of the leading causes of death globally (Sung et al., 2021). According to the Global Cancer Observatory (Globocan), approximately 10 million deaths worldwide in 2020 were attributed to cancer (Sung et al., 2021). Globocan also reported 234,511 cancer-related fatalities in Indonesia, as well as 396,914 new cancer cases in 2020 (Sung et al., 2021). Moreover, based on a national health survey, there has been an increase in cancer prevalence in Indonesia, rising from 1.4 per 1,000 people in 2013 to 1.79 per 1,000 people in 2018 (Ministry of Health, Republic of Indonesia, 2018). These figures highlight the magnitude of cancer issue in Indonesia. The Ministry of Health of the Republic of Indonesia has also classified cancer as one of four catastrophic diseases, along with heart disease, stroke, and uro-nephrology, which urges prioritization of healthcare services in the country (Ministry of Health Republic of Indonesia, 2022).

One emerging phenomenon in cancer care worldwide is financial toxicity. Financial toxicity can be defined as the adverse impacts of the financial burden associated with cancer diagnosis and therapy on patients and their families (Desai & Gyawali, 2020). A systematic review describes that financial toxicity refers to the objective financial burden that arises from cancer care and the subsequent financial distress experienced by patients (Abrams et al., 2021). The financial burden can span from healthcare-related expenses and transportation to hospitals, as well as indirect financial strains owing to lost income during cancer trajectory (Fabian et al., 2023).

A growing number of evidence indicates the serious impact of financial toxicity on cancer patients. Financial toxicity causes not only psychological stress and treatment discontinuation but also a variety of other negative repercussions (Chan et al., 2019; Knight et al., 2018; Yousuf Zafar et al., 2015). Large-scale studies and systematic reviews have demonstrated the links between financial toxicity and reduced quality of life, increased cancer symptom manifestations, and even contributes to cancer-related mortality (Afiyanti et al., 2019; Perrone et al., 2016; Susilowati & Afiyanti, 2020; Xu et al., 2022).

The issue of financial toxicity was first raised in the United States, where cancer is the most expensive medical condition to treat, with the country's total spending on cancer services increasing by 39% from \$125 billion in 2010 to \$173 billion in 2020 (Mariotto et al., 2011). Subsequently, more studies found that financial issues among cancer patients are a global concern, extending to countries with universal healthcare coverage, such as Germany (Fabian et al., 2023) and Canada (Ezeife et al., 2019). In many countries, patients' out-of-pocket expenses for cancer treatment (those not covered by health insurance) have significantly increased recently (Desai & Gyawali, 2020).

A previous study conducted in ASEAN countries, including Indonesia, known as ASEAN Costs in Oncology (ACTION), found that the percentage of patients experiencing financial hardship one year after a cancer diagnosis is remarkably high at 48% % (Kimman et al., 2015). However, this study did not provide detailed information on the types of expenses that patients and their families must bear beyond government or private health insurance. Moreover, research on financial toxicity in Indonesian cancer patients is scant. A study in Jakarta, the capital of Indonesia that assessed risk-taking behaviors in 194 cancer patients suggested that the cancer patients experienced financial toxicity (Pangestu & Karnadi, 2018). A previous study focusing on Indonesian gynecological cancer patients also found that one of the patients' unmet primary needs was financial support and information regarding government financial assistance (Afiyanti et al., 2019). Another study conducted at a public hospital in Central Jakarta, Indonesia, assessed the financial toxicity of the breast cancer patient population recruited using consecutive sampling (Susilowati & Afiyanti, 2021). This study measured the financial toxicity and sociodemographic factors of breast cancer patients and found that the number of dependent and household income were correlated with financial toxicity (Susilowati & Afiyanti, 2021). Yet, those identified correlations cannot be generalized to other cancer patient population

Given the serious potential consequences of financial toxicity in cancer patients and the scarcity of information on the subjects in Indonesia, a study to examine financial toxicity in detail, including its most important influencing factors, is urgently needed. Previous investigations on the associated factors of financial toxicity have mostly been undertaken in developed countries, largely in the United States, as indicated in a recent robust meta-analysis (Ehsan et al., 2023). Ehsan's review (2023) highlighted that financial toxicity is more prevalent in lower- and middle-income countries/LMICs (78.8%) as opposed to 35.3% in high-income countries. However, the LMICs included in that review were only Iran, India, Haiti, and Kenya (Ehsan et al., 2023). As previously mentioned, previous studies in Indonesia are still limited in number and generalizability (e.g., Susilowati & Afiyanti, 2021, only focused on breast cancer patients). This current study added the study population into patients with all cancer types and the potential influencing factors of financial toxicity. Thus, this study aimed at identifying factors associated with financial toxicity in cancer patients.

2. Methods

2.1. Research design

This study employed a cross-sectional design. This study design is appropriate to determine influencing factors of the studied phenomenon at the one time point. The focus of this study was the financial toxicity of Indonesian cancer patients. Cross-sectional studies are suitable to examine the prevalence of a condition or trait and its association with other factors (Kesmodel, 2018).

2.2. Setting and samples

Participants were recruited from a National Cancer Center, in Jakarta, Indonesia, using a convenience sampling strategy. This hospital is a comprehensive cancer center that provides leading-edge cancer treatments for patients from across Indonesia. Its services encompass cancer

prevention, clinical services, and research. This hospital serves around 1,000 patients in the outpatient unit every day. Meanwhile, its inpatient units have 350 beds, which are normally 90% occupied. In this study, the inclusion criteria were patients: 1) aged 18 years or older; 2) being diagnosed with cancer; 3) undergoing any cancer treatment (e.g., chemotherapy, hormonal therapy); and 4) willing to participate in the study. Patients were excluded if they had an altered level of consciousness or mental status that would hinder them from completing the questionnaires. Sample size calculation was conducted using G*Power 3.1 (Faul et al., 2009). A sample size of 110 participants was needed to yield a power of 0.80 to detect an effect size = 0.162 (Susilowati & Afiyanti, 2021) at alpha = 0.05 (two-tailed).

2.3. Measurement and data collection

This study used a set of questionnaires comprising sociodemographic characteristics and the Indonesian version of the Comprehensive Score for Financial Toxicity (COST). The sociodemographic characteristics were categorized into two for the bivariate and multivariate analyses. The sociodemographic variables were categorized as follows: 1) age $(a. \ge 18-55)$ years old or b. >55 years old); 2) marital status (a. married or b. not married: single, widowed/divorced); 3) education (a. low: did not complete elementary school, elementary school, junior high school or b. high: senior high school, university/college); 4) occupational status (a. employed or b. unemployed (including housewife and quit working); 5) monthly family income (a. low: IDR <2.9 million; IDR 2.9-4.33 million or b. high: \geq IDR 4.33 million); 6) number of hospital visits (a. \leq 2 or b. >2); 7) breadwinner (a. myself or b. my spouse/partner/relatives/ other); 8) cancer type (a. qunecological: endometrial, cervical, ovarian cancer or b. non-qunecological: breast, lung, bone, other cancer); 9) cancer stage (a. early: stage 0-1, 2-3 or b. late stage: stage 4); 10) cancer therapy (a. surgery/hemotherapy/radiation or b. combination); 11) health financing (a. National Social Security Agency on Health/Badan Penyelenggara Jaminan Sosial-BPJS or b. non-BPJS); 12) communication with health care providers regarding financial issues (a. yes or b. no); 13) indirect costs (a. transportation or b. other (accommodation and other)); 14) number of dependent (a. \leq 2 or b. > 2); and 15) distance from the hospital (a. near \leq 36.5 km or b. far >36.5 km).

The COST questionnaire was originally developed by de Souza et al. (2014) in a group of 155 patients with stage IV cancer receiving chemotherapy in the United States. They validated the instrument in 233 patients with the same characteristics and demonstrated the COST's excellent internal consistency (Cronbach's alpha of 0.92) and test-retest reliability (intra-class correlation of 0.80; 95% confidence interval, 0.57-0.92). The results of factor analyses showed that the COST possessed a coherent, single, latent factor, that is the financial toxicity (de Souza et al., 2017). These results suggest that the COST is a valid and reliable tool to measure cancer patients' financial toxicity in relation to cancer treatments (de Souza et al., 2017).

The COST measure consists of 11 items with a 5-point Likert scale ranging from "completely disagree" (1) to "completely agree" (5) (de Souza et al., 2014). The average of the scores was calculated to get an index value. The COST's index values closer to 5 indicate worse financial toxicity (de Souza et al., 2014). The internal consistency of the Indonesian version of the COST questionnaire is good (Cronbach's alpha = 0.895) (Susilowati & Afiyanti, 2021).

The researcher was assisted by staff nurses from the National Cancer Center in approaching and recruiting potential participants at the outpatient and one-day care units in October 2023. After providing written informed consent, participants filled out the paper-based questionnaire. The research team accompanied the participants while completing the questionnaire to answer any emerging questions and check the completeness of their responses.

2.4. Data analysis

Descriptive statistics were performed to analyze the sociodemographic characteristics according to the financial toxicity levels of the participants. The median value of 3.01 for the financial toxicity index was used as a cut-off point to categorize higher and lower levels of financial toxicity in this study. A median split was used due to the heavy-tailed distributions of the financial toxicity values. Then, the significant sociodemographic data were analyzed against the financial toxicity level using Chi-square analysis and multivariate analysis with logistic regression. SPSS version 25 (SPSS Inc., Chicago, IL., USA) was used for the statistical analysis.

2.5. Ethical considerations

Ethical clearance for this study was obtained from the Institutional Review Board of the Dharmais National Cancer Center (No. 080/KEPK/II/2023). The ethical principles outlined in the Declaration of Helsinki were adhered to throughout the research process. All participants were given sufficient information regarding the study objectives, procedures, potential risks and benefits, and their rights as participants prior to signing the consent. Data were kept anonymous and confidential to fulfill ethical considerations. Data were only labeled with a number, and to maintain confidentiality, the researcher kept the data for approximately five years, and the detailed data will only be used for analysis in the study.

3. Results

3.1. Participants' characteristics

A total of 110 participants completed the questionnaires. The majority of the participants were aged 18 to 55 years or older (61.8%), married (83.6%), and had completed senior high school (41.8%). Notably, most participants (70.9%) were unemployed, either as housewives or had quit their jobs due to their illness. Almost half of the participants (49.1%) had a monthly family income of 2.9-4.33 million rupiahs, which can be considered low for covering living expenses in most regions of Indonesia. Furthermore, the most frequent cancer diagnosis among the participants was breast cancer (42.7%) at stages 2-3 (61.8%). Nearly all participants used government insurance, namely the National Social Security Agency on Health, to cover their healthcare expenses. However, the majority of them (80%) still had to pay out of their own pockets for transportation to and from the hospital. Table 1 provides a complete overview of the participants' sociodemographic and clinical characteristics. Meanwhile, the median value of the financial toxicity index was 3.01 (min-max: 1-5), indicating that, on average, the participants reported a medium level of financial toxicity (Table 1).

Table 1. Participants' characteristics (n=110)

Characteristics	f	%
Age		
≥18-55 years old	68	61.8
>55 years old	42	38.2
Marital status	•	-
Single	8	7.3
Married	92	83.6
Widowed/divorced	10	9.1
Education		
University/college	30	27.3
Senior high school	46	41.8
Junior high school	21	19.1
Elementary school	12	10.9
Did not complete elementary school	1	0.9
Occupational status		
Employed	32	29.1
Unemployed (housewife/quit working)	78	70.9
Monthly family income		
≥ IDR 4.33 million	18	16.4
IDR 2.9-4.33 million	54	49.1
IDR < 2.9 million	38	34.5
Number of hospital visits apart from cancer treatment		
≤ 2	72	65.5
> 2	38	34.5
Breadwinner		
Myself	33	30.0
My spouse/partner/relatives/other	77	70.0

Table 1. Continued

Characteristics	f	%
Cancer type		
Breast cancer	47	42.7
Endometrial cancer	2	1.8
Lung cancer	6	5.5
Cervical cancer	12	10.9
Ovarian cancer	2	1.8
Bone cancer	1	0.9
Other	40	36.4
Cancer stage		
Stage 0-1	14	12.7
Stage 2-3	68	61.8
Stage 4	26	23.6
Unknown	2	1.8
Cancer therapy		
Surgery	10	9.1
Chemotherapy/Radiation	52	47.3
Combination	48	43.6
Health financing		
National Social Security Agency on Health (BPJS)	108	98.2
Private insurance	1	0.9
Out-of-pocket	1	0.9
Communication with healthcare providers regarding financial issu	ies	
Yes	75	68.2
No	35	31.8
Indirect costs	00	Ü
Transportation	88	80.0
Accommodation	14	12.7
Other	8	7.3
Number of dependent		, .0
≤ 2	54	49.1
> 2	55	50.0
None	1	0.9
Financial toxicity index (Median: 3.01; Min-max: 1-5)		

In this study, the relationship between sociodemographic and financial toxicity levels was assessed using Chi-square analysis. The results are presented in Table 2.

Table 2. Relationship between participants' characteristics and financial toxicity (n=110)

	Financia	l Toxicity	- Total		
Characteristics	≤ 3.01	>3.01	- Totai	OR (95%CI)	p
	f (%)	f (%)	f (%)	_	
Age				0.614	
≤18-55	39 (42.6)	39 (57.4)	68 (100)	0.614 (0.28;1.33)	0.216
>55	23 (54.8)	19 (45.2)	42 (100)	(0.26,1.33)	
Marital status					
Not married	5 (62.5)	3 (37.5)	8 (100)	1.950	0.370
Married	47 (46.1)	55 (53.9)	102 (100)	(0.44; 8.59)	
Education					
High	36 (47.4)	40 (41.3)	76 (100)	0.495	0.976
Low	16 (47.1)	18 (52.9)	34 (100)	(0.41; 0.59)	
Occupational status	20 (62.5)	12 (37.5)	32 (100)	2,396	
Employed	32 (41.0)	46 (59.0)	78 (100)	(1.02;5.58)	0.040*
Unemployed	32 (41.0)	40 (39.0)	/0 (100)	(1.02,5.50)	
Income					
High	10 (55.6)	8 (44.4)	18 (100)	1.488	0.442
Low	42 (45.7)	50 (54.3)	92 (100)	(0.53;4.11)	

Table 2. Continued

	Financia	l Toxicity	m-4-1			
Characteristics	≤ 3.01	>3.01	- Total	OR (95%CI)	p	
	f (%)	f (%)	f (%)	_		
Number of hospital visits apart from						
cancer treatment				1.621		
≤2	37 (51.4)	35 (48.6)	72 (100)	(0.73;3.60)	0.234	
>2	15 (39.5)	40 (60.5)	38 (100)	(0./3,3.00)		
Breadwinner				1.055		
Myself	17 (51.5)	16 (48.5)	33 (100)	1.275 (0.56;2.88)	0.560	
My spouse/partner/relatives/other	35 (45.5)	42 (54.5)	77 (100)	(0.50;2.88)		
Cancer type						
Gynecological	26 (41.3)	37 (58.7)	63 (100)	0.568	0.144	
Non-Gynecological	26 (55.3)	21 (44.7)	47 (100)	(0.26;1.2)		
Cancer Stage				2.844		
Early stage	11 (68.8)	5 (31.3)	16 (100)	(0.91;8.83)	0.063	
Late stage	41 (43.6)	53 (56.4)	94 (100)	(0.91,6.63)		
Cancer therapy						
Surgery/ Chemotherapy/ Radiation	27 (43.5)	35 (56.5)	62 (100)	0.710	0.374	
Combination	25 (52.1)	23 (47.9)	48 (100)	(0.33;1.51)		
Health financing						
National Social Security Agency on				0.740		
Health (BPJS)	52 (48.1)	56 (51.9)	108 (100)	0.519	0.497	
Non-BPJS	0 (0%)	2 (100%)	2 (100)	(0.43; 0.62)		
Communication with healthcare						
providers						
Yes	38 (50.7)	37 (49.3)	75 (100)	1.541	0.297	
No	14 (40)	21 (60)	35 (100)	(0.68;3.47)		
Indirect cost						
Transportation	42 (47.7)	46 (52.3)	88 (100)	1.096	0.849	
Transportation and else	10 (45.5)	12 (54.5)	22 (100)	(0.42;2.79)	0.649	
Number of dependents						
<2	25 (46.3)	29 (53.7)	54 (100)	0.866	0.697	
>2	26 (47.3)	29 (52.7)	55 (100)	(0.42;1.78)	0.09/	
None	1 (100)	o (o)	1 (100)			
Distance				1 505		
Near	47 (49)	49 (51)	96 (100)	1.727	0.354	
Far	5 (35.7)	9 (64.3)	14 (100)	(0.53;5.53)		

Notes. *Significant, *p*<0.05

3.2. Factors associated with financial toxicity

Bivariate selection with Chi-square analysis was performed to select variables that affect financial toxicity (p<0.25). After bivariate selection, five variables (age, occupational status, number of hospital visits, cancer type, and cancer stage) were included in the logistic regression (Table 3).

The logistic regression test would be excluded gradually starting from the variable with the largest *p*-value. The first excluded variables were age, cancer type, and cancer stage. When excluding the variables of number of hospital visits and type of cancer, the *p*-value of the core variables changed so that the variables of number of hospital visits and type of cancer were still included. Occupational status, number of hospital visits, and cancer type were identified as factors associated with financial toxicity in this study. Furthermore, potential covariates that might confound the relationships between our independent and dependent variables were analyzed. A confounding test analysis was conducted to determine the presence of potential confounders that could affect the relationship between factors that influence financial toxicity.

The confounding factor was determined from the difference in OR values before and after each of the variables was excluded. If the difference in OR value is >10%, then the variable is a confounding factor in the relationship between employment status and financial toxicity, and we found no confounders (Table 4).

Table 3. Initial model in regression analysis (n=110)

Variables	Coefficient	S.E	Wald	df	p	OR		95%
Variables	Coefficient	5.E	waiu	uı	Р	OK	Min	Max
Constant: -2.004								
Occupational status								
Employed	0.717	0.465	2.379	1	0.123	2.047	0.824	5.089
Unemployed								
Age								
≤18-55	-0.310	0.448	0.478	1	0.489	0.734	0.305	1.765
>55								
Number of hospital visits								
≤2	0.581	0.431	1.818	1	0.178	1.788	0.768	4.159
>2								
Cancer type								
Gynecological	-0.354	0.446	0.630	1	0.427	0.702	0.293	1.682
Non- Gynecological								
Cancer stage				<u> </u>		•		
Early stage	0.561	0.632	0.787	1	0.375	1.752	0.508	6.049
Late stage								

Table 4. Confounding analysis

Independent variable	Confounding potential	C	OR		
	Comounting potential	Before	After	- ΔOR	
Occupational status	Number of hospital visits	2.389	2.304	8.5%	
	Cancer type	2.389	2.486	9.7%	

^{*}as confounding factors

The final model demonstrated that participants who were unemployed were 2.389 times more likely to have a higher financial toxicity level compared to those who were employed (OR = 2.389; p=0.048). The number of hospital visits and cancer type yielded insignificant p-values (p<0.05). It means that we cannot conclude that these variables affect financial toxicity.

Table 5. The final model of the logistic regression

Variables	Coefficient	SE	Wald χ²	p	OR	95% Min	6 CI Max
Constant = -1.368 Occupational status Employed	0.871	0.441	3.901	0.048*	2.389	1.007	5.668
Unemployed Number of hospital visits ≤2	0.588	0.424	1.926	0.165	1.801	0.785	4.134
>2 Cancer type Gynecological Non-Gynecological	-0.559	0.402	1.933	0.164	0.572	0.260	1.257

^{*} Significant at p<0.05

4. Discussion

This study aimed to identify factors associated with financial toxicity in cancer patients. It revealed that cancer patients undergoing therapy experienced a medium level of financial toxicity. Notably, this value was lower than that reported in a recent study of Indonesian breast cancer patients (Susilowati & Afiyanti, 2021). The lower median financial toxicity index was influenced by sample variation related to the study site being selected as a national cancer referral center, which allows for variable sample conditions. In contrast, previous studies among head and neck cancer patients in the United States indicated a high prevalence of financial toxicity (Beeler et al., 2020; Mady et al., 2019). Furthermore, a survey of patients with multiple myeloma who had

insurance found that 71% of patients experienced financial burdens due to treatment and additional costs not covered by insurance (Huntington et al., 2015). In the current situation in Indonesia, the government only covers cancer treatment costs while other costs, such as accommodation, have not been covered, resulting in unmet needs, especially finding about financial support and government benefits (Afiyanti, 2019). Recent meta-analysis on financial toxicity among cancer patients in lower and middle-income countries (LMICs) reported that more than half (56.96%; 95%CI, 30.51-106.32) of cancer patients experienced objective financial toxicity measured by the total amount of direct and indirect medical costs and non-medical costs, spent by the cancer patients (Donkor et al., 2022). Importantly, financial toxicity was not limited to LMICs; it also affected cancer patients in high-income countries (HICs) with publicly funded healthcare systems, such as Canada, the United Kingdom, Germany, Australia, Finland, the Netherlands, and South Korea (Longo et al., 2020). Variations between countries, even among developing countries, might occur due to the varied health financing system and capacity, daily living costs (including transportation, meals, and housing), and the financial status of the people in the respective countries.

Another significant finding of this study was that occupational status was the sole influencing factor significantly associated with financial toxicity among the study participants. This finding appeared to diverge from prior research results, including those summarized in several meta-analyses on financial toxicity. A meta-analysis by Donkor et al. (2022) concluded that the financial toxicity level was higher in cancer patients undergoing multiple cycles of chemotherapy, those from larger households (more than four members), and those receiving treatment at private health facilities. Similarly, a scoping review of cancer treatment-related financial toxicity in LMICs also found that lower socioeconomic status and lack of insurance were associated with a higher level of financial toxicity (Udayakumar et al., 2022). In HICs with universal health coverage, financial toxicity was more likely to affect cancer patients with more severe cancer types and those in the early stages of their disease trajectory (Longo et al., 2020). Employment status in cancer patients certainly affects total income, and often, the cancer, in certain situations, makes it difficult for patients to remain employed, and the chance of no longer working is even higher. Reduced income and some office-related insurance are factors that trigger financial toxicity.

However, our finding regarding occupational status remained relevant to a previous study focused on breast cancer patients in Indonesia, suggesting that the position of the wage earner influenced financial toxicity (Susilowati & Afiyanti, 2021). In the context of that study, the participants were exclusively women who were financially dependent on their spouse, partner, and other family members. While our study included cancer patients regardless of their diagnosis and gender, the majority of our participants were housewives relying on their husband's income. Some participants in this study also gave up their jobs due to their cancer and lengthy treatment periods. Although our participants mentioned that their treatments were primarily covered by national insurance, they still incurred substantial expenses for transportation to the hospital, which was located in Jakarta, the capital city of Indonesia. Some participants were referred from smaller regions in Indonesia with inadequate healthcare facilities for cancer patients, requiring them to rent accommodations near the hospital and cover daily living expenses in Jakarta, which is more expensive than in other regions in Indonesia. Longo et al. (2020), in their systematic review, also found that out-of-pocket costs, including travel expenses, were the most common and significant burden related to cancer, as observed from the perspectives of both cancer patients and caregivers.

In addition, our study results were relatively consistent with the findings of several studies conducted in HICs. A Dutch study analyzing its national registry revealed a connection between unemployment and financial toxicity among long-term cancer survivors (Pearce et al., 2019). Pearce et al. (2019) reported that participants without paid employment were more likely to report financial toxicity, with no significant difference observed between working and non-working patients. Another study among American cancer survivors, based on a nationally representative sample, indicated that unemployment or loss of income and low baseline income were associated with financial toxicity (Yabroff et al., 2016). The findings from the Netherlands, with its publicly funded healthcare system, and the United States, with its user-pays healthcare system, suggest that unemployment is a universal risk factor for financial toxicity. Nevertheless, a systematic review demonstrated that a larger proportion of American cancer patients reported

financial toxicity, highlighting the significant burden faced by patients in a healthcare system lacking universal coverage (Altice et al., 2017).

The cancer type variable does not show a statistically significant effect on financial toxicity. Financial toxicity can occur in all types of cancer. This is in accordance with a previous study (Pangestu & Karnadi, 2018). The number of hospital visits did not have a statistically significant effect on financial toxicity, but the higher frequency of visits will affect the amount of costs incurred by each patient (Souza et al., 2014).

5. Implications and limitations

This study emphasizes the importance of nurses including financial well-being as a part of the holistic assessment of cancer patients, particularly those who are unemployed or working as housewives. This assessment is especially crucial at significant milestones in the cancer journey, such as after diagnosis and primary treatment. Nurses should integrate financial assessment and support into the nursing care plan, even during long-term follow-up. Nurses can educate and assist patients in utilizing financial resources and developing strategies to manage the additional costs that create financial burdens. Furthermore, nurses can collaborate with patient navigators or social workers who possess specialized knowledge about financial assistance programs and community resources.

The present study, however, has several limitations. It was a single-centered cross-sectional study, limiting the generalizability of the findings. Additionally, this study only assessed subjective financial toxicity, which might be susceptible to biases such as social desirability and recall biases. The financial toxicity problem among cancer patients in Indonesia warrants a larger, preferably nationwide, longitudinal study with a more comprehensive examination that encompasses objective financial toxicity (actual reports of the financial costs incurred by the patients) and additional financial support, as well as the determinants and impacts of financial toxicity.

6. Conclusion

The study results lead to the conclusion that financial toxicity is a prevalent issue among cancer patients at the National Cancer Center in Indonesia. Patients without employment face a higher risk of experiencing elevated levels of financial toxicity. These findings contribute further evidence to the significance of addressing employment-related issues in the context of financial toxicity. Future research with a nationally representative sample size encompassing more comprehensive aspects of health financing and patients' multidimensional factors should be conducted to address the financial toxicity problem in cancer patients in Indonesia.

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Author contribution

DH conceptualized the study, conducted data collection and analysis, and wrote the first draft of the manuscript. YA conceptualized the study, supervised data collection and analysis, and contributed to manuscript drafting.

Conflict of interest

No conflict of interest related to this study.

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ORIGINAL RESEARCH

Determinant Factors of Diabetes Prevention Behavior in Students with Diabetes Mellitus Risk



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Abstract

Background: The trend of diabetes cases has shifted to younger ages, starting at the age of 15 years old, due to unhealthy lifestyles. Researchers have discovered that health students also tend to have a poor lifestyle. Students are associated with emotional activity and busyness, but no research has examined the relationship between these conditions and diabetes prevention behavior.

Purpose: This study examined determinant factors affecting diabetes prevention behavior in college students with diabetes mellitus risk.

Methods: This study used a cross-sectional design, utilizing random sampling to gather data from 209 college students with diabetes risk. The instruments used in this study included adaptations of the Diabetes Prevention Behavior questionnaire, the modified Diabetes Management Time Questionnaire (DMTQ), the Perceived Behavioral Control, and the Trait Emotional Intelligence Questionnaire. Data analysis encompassed One-way ANOVA, Mann-Whitney, Kruskal-Wallis, Spearman's rank, and multiple linear regression.

Results: The study found a significant relationship between diabetes management time (p=0.001) and emotional intelligence (p=0.000) with diabetes prevention behavior. Emotional intelligence emerged as the dominant influencing factor (B=0.332). Conversely, no significant relationships were observed between perceived behavior control (p=0.223), class (p=0.734), gender (p=0.231), study major (p=0.263), age (p=0.064), and diabetes mellitus risk (p=0.664) with diabetes prevention behavior.

Conclusion: This study revealed a significant relationship between diabetes management time, emotional intelligence, and diabetes prevention behavior. Emotional intelligence emerged as the key factor affecting diabetes prevention behavior, highlighting the need for focused interventions to enhance emotional intelligence and improve diabetes management among college students.

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1. Introduction

Diabetes Mellitus (DM) is a progressive chronic disease that can cause microvascular and macrovascular complications to the risk of death. Cases of death due to DM until now have reached 6% of the total death cases in the world. Indonesia, as the most significant contributor to diabetes cases in Southeast Asia, experiences an increase in DM cases, reaching 0.5% every year. In addition, there has been a shift in the trend of sufferers aged 15 years and over (Ministry of Health, Republic of Indonesia, 2020; Isnanda, 2019). This condition is also supported by a statement from the United Nations Children's Fund (UNICEF) about increased diabetes risk factors in the form of obesity over the past two decades in Indonesia (Karana, 2021; Suminar et al., 2020).

Adolescents at risk of diabetes include those with a family history of diabetes, obese adolescents, or those with both factors. Diabetes risk can be prevented and managed by adopting specific prevention behaviors, such as regular health check-ups, attending diabetes-related education, engaging in vigorous physical activity or exercise for at least 30 minutes per day four times a week, maintaining a diet rich in fiber and fruits, and avoiding smoking (Beigrezaei et al., 2019; Hamasaki, 2016; Magliano et al., 2020; Suminar et al., 2020). Adolescents generally have a good perception of the importance of diabetes prevention behavior, but obstacles make it difficult for them to implement these behaviors (Lestari et al., 2018). This statement is supported by several studies which show an increase in eating frequency, reduced physical activity, and poor

weight control in the community, especially at a young age (Atmadja et al., 2020; Suminar et al., 2020). Another study by Finurillah (2021) on 376 students in a public university in Indonesia reported that 51.3% had a moderate eating pattern and only 42.3% had high physical activity. Not practicing diabetes prevention behaviors from a young age can increase the risk of developing DM in later years (Feldman et al., 2017; Huang & Goran, 2003).

Understanding human behavior involves numerous influencing factors. One of the theories Ajzen (2020) put forward is linked to planned behavior, commonly referred to as the theory of planned behavior. According to Ajzen (2020), perceived behavior control is a factor that helps individuals control behavior. Individuals with high perceived behavior control are motivated and encouraged to continue trying to overcome their difficulties (Mahyarni, 2013). In addition, internal factors also contribute to influencing the appearance of behavior. Internal factors such as emotional intelligence are a person's ability to manage emotions so that they can determine the right behavior to appear. Individuals with high emotional intelligence have a better quality and wellbeing of life (Goleman, 2006; Pérez-Fernández et al., 2021; Trigueros et al., 2019). The next factor related to obstacles in generating behavior is the improvement of time constraints (Lestari et al., 2018). Time management is an individual's ability to manage time so that they can organize activities, especially in maintaining health (Nakao et al., 2020; Wolters & Brady, 2021). Good time management is known to improve self-care in diabetes patients who are still productive at work (Summers-Gibson, 2021).

Based on the planned behavioral theory of Ajzen and Fishbein, the researchers conducted a preliminary study on students from health science programs in a public university in Indonesia in August 2021. The focus on this cohort stemmed from their transition from late adolescence to adulthood, where age-related changes impact behavior and lifestyle (González-Valero et al., 2020; Pigaiani et al., 2020). Previous research by Choi (2020) showed increased eating behavior due to perceived stressors, while the study by Multazami (2022) contradicted this, finding no direct link between stress and student eating behavior. Lestari et al. (2018) identified time constraints as a key obstacle for students in adopting diabetes preventive measures. However, no specific study has investigated student time management concerning diabetes prevention behavior, revealing a significant research gap in this area.

The preliminary study involved 10 students with a history of DM. The findings indicated that 80% of respondents had low levels of diabetes prevention behavior, yet 51.75% exhibited high levels of perceived behavior control. In addition to questionnaire data, open interviews were conducted to better understand respondents' perceptions of barriers to implementing diabetes prevention strategies. The majority of participants highlighted time and workload constraints, although the completion rate for the time management questionnaire was approximately 60%, indicating strong time management skills among respondents. Furthermore, the emotional intelligence survey showed that 50% of participants exhibited moderate emotional intelligence.

The low diabetes prevention behavior among health science students with a family history of diabetes, coupled with research gaps and unexplored factors, motivated the researchers to investigate the determinant factors influencing diabetes prevention behavior in college students at risk of diabetes mellitus. This study aimed to address this gap by identifying the primary factors influencing diabetes prevention behavior in this specific group.

2. Methods

2.1. Research design

This quantitative study employed a cross-sectional design to look for relationships between variables and find those that dominantly influence diabetes prevention behavior.

2.2. Setting and samples

This study was conducted at a public university in Central Java, Indonesia. Data collection was completed in March 2022. The inclusion criteria comprised college students having a risk of DM, such as a family history of DM and/or obesity, and being willing to participate. The exclusion criteria included students who were unreachable for contacts or did not fully complete the questionnaire. The initial population consisted of 363 students who either have obesity or a parental history of DM. Subsequently, a sample calculation was conducted employing the Slovin formula, accounting for a 5% margin of error and an estimated dropout rate of 10%, resulting in a determined sample size of 209. Respondents from this sample were selected using

randomization techniques employing an Excel formula. The data were sorted from the smallest to the largest based on the generated random numbers.

2.3. Measurement and data collection

This study employed four questionnaires for data collection. The first questionnaire, initially developed by Ajzen (2029), was the Perceived Behavioral Control questionnaire. This tool measures individuals' perceptions regarding their ability to perform crucial behaviors in managing diabetes. Comprising two domains, the questionnaire consists of six items each for control beliefs and power of control. Questions inquire about confidence levels (ranging from very not confident=1 to very confident=4) for control beliefs and the assessment of impact size (ranging from very small=1 to very large=4) for the power of control. The unfavorable question components were assessed inversely for each section. The researcher then multiplied the items in questionnaire parts 1 and 2, totaling six items for each part. The resulting multiplication from the six items was summed up, generating a single score for Perceived Behavior Control. The resulting scores ranged from 6 to 96 on an interval data scale. In this study, the Indonesian version of the Perceived Behavioral Control questionnaire by Ulfah (2018) was used, displaying validity scores of 0.393–0.773 for control beliefs dimensions and 0.417–0.867 for power of control dimensions, with a reliability value of 0.913.

The second questionnaire in this study was the Diabetes Time Management Questionnaire (DMTQ), developed by Nakao et al. (2020) to measure time allocation and management concerning diabetes care activities. Originally in English, this questionnaire consists of four dimensions, each containing four favorable items, summing up to 16 questions. These dimensions cover job adjustment (items 1 to 4), time control (items 5 to 8), goal setting and behavior aligned with personal values (items 9 to 12), and adjustment of the rhythm of life (Items 13 to 16). Utilizing a Likert scale ranging from 0 (strongly disagree) to 5 (strongly agree), the questionnaire generates results from 0 to 80, representing a ratio data scale. The original questionnaire showed the goodness of fit index (GFI) of 0.876 and a Cronbach alpha of 0.896. For this study, the researchers adapted the questionnaire by translating and subjecting it to testing with three experts who are lecturers in surgical medical nursing, focusing on diabetes-related health matters. The expert test and Content Validity Index (CVI) were administered. The expert test evaluated item clarity on a scale of 1 (unclear) to 4 (clear, no need for revision). Meanwhile, the CVI measured relevance, ranging from 1 to 4, resulting in 0 for scores of 1 to 2 and 1 for scores of 3 to 4. Cumulative scores were tallied to derive the final CVI value, which indicated a CVI of 1 (valid) for all items.

The third questionnaire, the diabetes prevention behavior used assess the behaviors that individuals adopt to prevent the onset or progression of diabetes, was adopted from Anggraini's (2016) study. It comprises 21 items divided into three sub-questions rated on a Likert scale. The favorable responses include "routinely" (3), "often" (2), "sometimes" (1), and "never" (0), while unfavorable responses are rated inversely: "routinely" (0), "often" (1), "sometimes" (2), and "never" (3). The scoring ranges from a minimum of 0 to a maximum of 63. This questionnaire consists of three dimensions. The first relates to health control, involving favorable items from 1 to 4. The second pertains to diet, including favorable components in items 7, 9, 10, 11, and 14, while unfavorable elements are evident in items 5, 6, 8, 12, 13, and 15. The third dimension focuses on sports, with favorable components spanning items 16 to 20 and unfavorable components in item 21. The diabetes prevention behavior questionnaire exhibited a CVI validity test result of 0.83, with a Cronbach's alpha of 0.737 (Anggraini, 2016).

The fourth questionnaire was the Indonesian version of the Trait Emotional Intelligence Questionnaire-Adolescent Short Form (TEIQue-ASF), adopted from previous studies by Musyarrafah (2016) and Gandhi (2015). This questionnaire assesses individuals' emotional intelligence traits concerning diabetes management. It consists of four dimensions: wellbeing, emotionality, self-control, and sociability, comprising a total of 30 items. The questionnaire uses a Likert scale, ranging from choices 1 to 7 for favorable responses, while unfavorable responses are assessed differently. The scoring generates an interval data scale, resulting in a score range of 10 to 70. The validity and reliability of this questionnaire were examined with r = 0.285-0.536 and a Cronbach alpha of 0.83 (Musyarrafah, 2016).

The data collection was conducted using a Google Form. Respondents randomly selected through an Excel table were personally contacted to inquire about their willingness to participate and were asked to fill out the questionnaire using the Google Form.

2.4. Data analysis

The data analysis in this study, which consisted of univariate, bivariate, and multivariate analyses, was conducted using the SPSS application. Univariate analysis employed frequency distribution and measures of central tendency, meanwhile, bivariate analysis utilized one-way ANOVA, Mann-Whitney, Kruskal-Wallis, and Spearman rank tests. The findings of the bivariate analysis with p<0.25 were considered for inclusion in the multivariate analysis, employing the multiple linear regression test with the backward method.

2.5. Ethical considerations

This study obtained ethical approval from the Health Research Ethics Committee of the Faculty of Health Sciences, Universitas Jenderal Soedirman (number 666/EC/KEPK/II/2022). The applied ethical principles included respect for persons, which involved introducing the researcher's identity and research purpose and seeking the respondent's consent to participate. Respect for privacy and confidentiality ensured that all information obtained in the research process remained undisclosed, whether in public or private domains. Respect for justice entailed equal treatment of all respondents, providing them with the same instrument and explanations, irrespective of their religion, ethnicity, race, or culture. Beneficence and non-maleficence were upheld by ensuring that the research did not cause harm, whether material or physical, to the respondents. Additionally, all respondents signed informed consent for their participation.

3. Results

3.1. Respondent characteristics, emotional intelligence, diabetes time management, perceived behavior control, and diabetes prevention behavior

Table 1 indicates that the majority of respondents were from the Department of Nutrition (34%), class of 2021 (34.4%), and females (78.9%). Most respondents, with a median age of 19, often inherited the risk of DM from their parents (60.8%). Their observed diabetes prevention behavior was notably lower, with a median score of 26 within a range of 0 to 63. However, emotional intelligence and diabetes time management showed promising scores, with median values of 47 and 57, respectively. Conversely, perceived behavior control displayed lower scores, with a median of 38 within a range of 6 to 96.

Table 1. Description of class, majors, gender, DM risk, age, emotional intelligence, diabetes time management, perceived behavior control, and diabetes prevention behavior

Variables	Frequency	Percentage (%)	Median (Min-Max)	Range
Class				
2018	33	15.8		
2019	45	21.5		
2020	59	28.2		
2021	72	34.4		
Major				
Public health	21	10		
Nursing	53	25.4		
Nutrition science	71	34		
Pharmacy	37	17.7		
Physical education	27	12.9		
Gender				
Man	44	21.1		
Woman	165	78.9		
DM Risk				
Parental History	127	60.8		
Obesity	39	18.7		
Parental history and obesity	43	20.6		
Age			19 (17 – 22)	
Emotional intelligence			47 (15 – 70)	10 - 70
Diabetes Time management			57 (15 – 80)	o – 80
Perceived behavior control			38 (17 – 84)	
Diabetes prevention behavior			26 (8 – 49)	0 - 63

3.2. Relationship between respondent characteristics, emotional intelligence, diabetes time management, perceived behavior control with diabetes prevention behavior

Table 2 shows no relationship between class (p=0.734) and majors (p=0.263) with diabetes prevention behavior. There was no significant relationship between gender (p=0.231), DM risk (p=0.664), age (p=0.064), and perceived behavior control (p=0.223) with diabetes prevention behavior. However, there was a relationship between emotional intelligence (p=0.000) and diabetes time management (p=0.001) with diabetes prevention behavior.

Table 2. Relationship between class, majors, gender, DM risk, age, emotional intelligence, diabetes time management, and perceived behavior control with diabetes prevention behavior

	Diabe				
Variables	Mean (SD)	Median (Min–Max)	95% CI (Min – Max)	R	<i>p</i> value
Class****					
2018	26.82(6.33)		24.57 - 29.07		
2019	27.04(5.96)		25.25 - 28.84		0.734
2020	26.03(6.15)		24.43 - 27.64		
2021	25.85(6.90)		24.22 - 27.47		
Major**					
Public health		25 (12 – 39)			
Nursing		26 (8 – 40)			0.263
Nutrition science		26 (15 – 49)			0.203
Pharmacy		25 (13 – 39)			
Physical education		29 (20 – 35)			
Gender*					
Man	114.69(6.03)		25.44 - 29.11		0.231
Woman	102.42(6.47)		25.06 - 27.05		
DM Risk**					
Parental history		26 (8 – 41)			
Obesity		26 (12 – 41)			0.646
Parental history and obesity		26 (15 – 49)			
Age***				0.128	0.064
Emotional intelligence***				0.285	0.000
Diabetes time management***				0.234	0.001
Perceived behavior control***				0.085	0.223

Note: *Mann-Whitney **Kruskal-Wallis ***Rank Spearman ****One-way ANOVA

3.3. Dominant factors related to diabetes prevention behavior in students with diabetes risk

In this study, variables with p<0.25 and numerical data scales, such as age (p=0.064), emotional intelligence (p=0.000), diabetes time management (p=0.001), and perceived behavior control (p=0.233), underwent multivariate analysis. The multivariate analysis involved multiple linear regression tests using the backward method. Table 3 reveals that variables with p>0.05 were excluded from the model due to their lack of association with diabetes prevention behavior, namely diabetes time management (p=0.304), perceived behavior control (p=0.168), and age (p=0.201).

The analysis results of the coefficient of determination in Table 3 show that the collective impact of the independent variables could explain 11.3% of diabetes prevention behavior. The regression model equation can be presented as: Diabetes prevention behavior = 16.286+0.213*EI. The positive constant value of 16.286 signifies the positive effect of the independent variable on emotional intelligence. The EC regression coefficient of 0.213 indicates that for every one-unit increase in KE, the Diabetes prevention behavior will increase by 0.213. Table 3 shows that the emotional intelligence variable has the most influence on diabetes prevention behavior, with a correlation coefficient (Beta) of 0.332.

Variables	В	Std. Error	Beta	T	p	\mathbb{R}^2
Constant	16.286	2.024	-	8.045	0.000	
Emotional intelligence	0.213	0.042	0.332	5.061	0.000	
Age	0.466	0.363	0.08	1.282	0.201	0.113
Perceived behavior control	0.503	0.363	0.091	1.384	0.168	
Diabetes time management	0.038	0.037	0.075	1.030	0.304	

Table 3. Dominant factors related to diabetes prevention behavior

4. Discussion

This study investigated determinant factors influencing diabetes prevention behavior in college students with diabetes mellitus risk. The findings indicated a significant relationship between diabetes management time and emotional intelligence with diabetes prevention behavior. In contrast, no significant relationships were observed between perceived behavior control, class, gender, study major, age, and diabetes mellitus risk with diabetes prevention behavior. Emotional intelligence emerged as the most dominant influencing factor.

4.1. Respondent characteristics, emotional intelligence, diabetes time management, perceived behavior control, and diabetes prevention behavior

The majority of respondents in this study were from the 2021 class and majored in nutrition, yet these factors did not correlate with diabetes prevention behavior. This lack of distinction might be due to shared knowledge among students, which is in line with prior studies showing that most students have good knowledge of diabetes (Finurillah, 2021; Kharono et al., 2017). Knowledge plays a role in decision-making, as noted by Hailu et al. (2019), linking knowledge about diabetes to individual efforts in prevention. However, in this study, knowledge did not correlate, possibly because all students were health science majors. Also, the quota for new student admissions increased by 10% in the 2021/2022 period, thereby increasing the proportion of respondents from the 2021 batch. Additionally, the dominance of respondents from the Department of Nutrition is estimated to be related to their cooperative willingness to become respondents.

Concerning gender, this study revealed that most respondents were women. This aligns with the research of Antwi et al. (2020), indicating that the majority of respondents with diabetes risk are female. The hormonal influence of the monthly cycle makes the accumulation of body fat easier, increasing the risk of diabetes, particularly obesity, in women (Chen et al., 2023). In this research, gender did not correlate with diabetes prevention behavior, possibly because gender is known to have no direct effect on behavior (Venkataramani et al., 2019).

The respondents' ages in this study ranged from 17 to 22 years, with a median of 19, categorizing them as young adults, according to Dyussenbayev (2017). This result is in line with a study by Rao et al. (2017) regarding diabetes prevention behavior among health science students in India, in which the majority of respondents were at a young age, ranging from 17 - 35 years, with a median of 24.5. In this study, age did not show a relationship with diabetes prevention behavior, possibly because all respondents fell within the young age range. This is commonly associated with a low-risk perception among young individuals, potentially leading to neglect of diabetes prevention behavior (Antwi et al., 2020; Lestari et al., 2018).

Furthermore, the majority of respondents in this study had a risk of DM which was inherited from their parents. While this risk is associated with an increased likelihood of developing the condition, it does not directly affect behavior (Sirait et al., 2015). In this study, diabetes risk did not correlate with prevention behavior. This could be linked to individuals' varying levels of awareness regarding their risks and knowledge about appropriate preventive measures for diabetes (Ali et al., 2019; Mongiello et al., 2016; Setyopranoto et al., 2021).

This study observed a median value of 47 for the emotional intelligence variable, ranging from 15 to 70. According to the two-category formula by Azwar (2012), this emotional intelligence value is considered good as it surpasses the cut-point value. The dimension of sociability, highlighting social interaction abilities, had the highest value. This shows the good ability of respondents to socialize, contributing to increased self-confidence. This aligns with a previous study by Trigueros et al. (2019) that found that the most influential factor for emotional intelligence is social support in the form of peer interaction. Strong social support helps individuals get through times of crisis

and stress, thereby increasing self-confidence, which is a part of emotional intelligence that influences the implementation of diabetes prevention behaviors (Hill-Briggs et al., 2021; Lopez-Zafra et al., 2019).

The diabetes time management variable in this study exhibited a median value of 57, ranging from 15 to 80, which, based on Azwar's two-category formula (2012), indicates good time management as it surpasses the cut point value. Notably, the diabetes time management dimension with the highest score is goal setting and behavior that is consistent with personal values. This illustrates that the majority of respondents already have life goals and values to be achieved in the form of education, health, and overall life goals. The research of Alshutwi et al. (2019) also indicates that the majority of students maintain a daily priority record. Humans move on the basis of goals to be achieved. The ability to set goals affects time management, especially in daily health-related behavior, such as nutritional fulfillment and diabetes self-care (Indreica, 2019; Summers-Gibson, 2021).

The perceived behavior control variable in this study demonstrated a median value of 38, ranging from 17 to 84. It indicates low control according to the two-category formula by Azwar (2012) because the value is smaller than the cut-point value. The item in the perceived behavior control scoring highest was related to the "go green campus policy," which acted as a driving factor for implementing diabetes prevention behavior. This corresponds with Antwi et al.'s findings (2020), indicating students' relatively low perception of diabetes risks, with 30% uncertain about adopting healthy lifestyles, particularly for preventing type-2 diabetes mellitus.

Regarding diabetes prevention behavior, the variable showed a median value of 26, ranging from 8 to 49, falling into the low category based on Azwar's two-category formula (2012). Respondents indicated a preference for packaged drinks over water, and few engaged in health checks. Similarly, Finurillah (2021) also highlighted low diabetes prevention behavior among college students, with 158 respondents exhibiting poor dietary habits and 141 showing low levels of physical activity. This could be attributed to varying levels of awareness, which research has shown plays a pivotal role in adopting preventive behaviors against diseases (Abrignani et al., 2019; Mongiello et al., 2016; Setyopranoto et al., 2021). Implementing strategies such as a tenweek SMS reminder system for routine blood sugar checks and educational programs on diabetes prevention may help raise awareness among students (Damayanti et al., 2021). In addition, health services can also provide education with a self-instructional training system through experience-based health education (Wahyuni et al., 2021).

4.2. The relationship between emotional intelligence and diabetes prevention behavior

This study found that emotional intelligence correlated with diabetes prevention behavior. This finding is in line with a study by Pérez-Fernández et al. (2021), reporting that emotional intelligence helps individuals manage themselves related to diabetes. This is thought to be related to the respondent's ability to manage stress. Uncontrolled stress can increase blood sugar levels and reduce a person's ability to carry out daily activities, especially in maintaining their health (Sarrionandia & Mikolajczak, 2020). Based on multivariate analysis, emotional intelligence became the dominant factor influencing diabetes prevention behavior in this study. Previous research has stated that emotional intelligence helps people control their emotions, reduce anxiety, and adapt to social environments. This ability is certainly needed by every individual, especially among young people in implementing diabetes prevention behavior. Emotional intelligence helps a person consistently behave in various situations (Zeidner et al., 2012).

The level of emotional intelligence of respondents in this study is good but is at the lower limit, so it needs to be increased. Social support and knowledge can increase a person's emotional intelligence (Lolaty et al., 2014). Social support may come from family or peers, but at a young age, peer support is more dominant (Trigueros et al., 2019). Increasing peer influence can be done through collaboration with campus communities and organizations (Sabbah et al., 2020). Health activities involving communities and student organizations can reach young participants so that health promotion related to diabetes can be more targeted (Kristjansson et al., 2020). In addition, knowledge also affects a person's level of emotional intelligence, especially in determining decisions (Venkatesh & Fischer, 2019). Good knowledge of diabetes helps a person understand the risks that trigger the disease so that he realizes the need to carry out preventive behavior (Kharono et al., 2017; Shiferaw et al., 2020).

4.3. The relationship between diabetes time management and diabetes prevention behavior

The statistical results in this study showed a significant relationship between diabetes time management and diabetes prevention behavior. The strength of the correlation is weak with a positive direction of the relationship. This finding aligns with a previous study by Summers-Gibson (2021), which stated that time management helps individuals manage their diabetes. This study shows that most respondents could take the time to manage their health and manage time for the things they wanted. Previous research stated that the ability to set goals and maintain interpersonal relationships helps individuals have clear targets, especially for health (Mohammadkarim et al., 2015; Nakao et al., 2020).

The time management of respondents in this study is at a good level, so it needs to be maintained. In line with another study by Alshutwi et al. (2019), the majority of students have activity records and assist in time management during lectures. This helps students manage college activities, health, and personal desires (Chanie et al., 2020; Hassanzabeh & Ebadi, 2007). Other research also shows that assertiveness is needed to help someone focus on targets and maximize time according to their goals (Moneva & Bolos, 2020). A person with good assertiveness is able to reject things that are not in line with his goals in a wise way (Larijani et al., 2017). Increasing assertiveness can be done by counseling to increase self-esteem and active empowerment (Oducado, 2021).

4.4. The relationship between perceived behavior control and diabetes prevention behavior

The statistical results in this study showed no significant relationship between perceived behavior control and diabetes prevention behavior. The strength of the correlation is very weak with a positive direction of the relationship. This result is not in line with a study by Isnanda (2019), which found that perceived behavior control correlated with preventive behavior for type-2 diabetes. This difference is thought to be due to the absence of measurements related to anxiety in diabetes prevention behavior. Perceived behavior control is a construct that is widely used to measure a person's psychological condition (Mardiyono et al., 2011). In this study, perceived behavior control focuses on measuring perceived perceptions, types of support, and barriers that influence diabetes prevention behavior in respondents. Other research states that barriers are factors that cause diabetes prevention behavior in students to be challenging to raise, one of which is a sense of laziness (Al-Harbi, 2017; Lestari et al., 2018). Laziness acts as an inhibiting factor that cannot be controlled. Laziness arises because of a person's low motivation (Mauliya et al., 2020). Meanwhile, motivation can be increased by establishing a supportive environment (Hill-Briggs et al., 2021). Social support can be done by involving the community in forming attractive health promotions and activities, as well as involving policy makers in making rules and providing awards (Busse & Miranda, 2018; Kristjansson et al., 2020). The low perceived behavior control in this study is estimated to be related to the respondent's age. All respondents are in the same age range, namely young age. Someone at a young age has a low awareness of the dangers of diabetes, so they tend to enjoy life in inappropriate ways despite having good knowledge about diabetes (Antwi et al., 2020; Mongiello et al., 2016). Raising awareness needs to be done by empowering individuals in various activities related to diabetes management (Lin et al., 2020).

5. Implications and limitations

This study provides substantial implications for nursing, particularly concerning the young adult population susceptible to diabetes mellitus. The identified significant relationship between diabetes management time, emotional intelligence, and diabetes prevention behavior highlights the pivotal role of emotional intelligence in influencing preventive actions against diabetes. This underscores the urgency for targeted interventions to enhance emotional intelligence and fortify diabetes management practices among college students. Nurses can use this insight to drive further research on diabetes prevention behavior in young adults. This involves exploring emotional intelligence enhancement methods and creating interventions suitable for this group's specific needs. By leading research efforts in this area, nurses can significantly advance our understanding of effective diabetes prevention strategies. In addition, educational institutions can develop programs by collaborating with campus groups or organizations to improve diabetes mellitus prevention activities.

The researchers are aware that this study has limitations. It used a cross-sectional research design, allowing observation of conditions only at that specific time. To mitigate bias, the researchers expanded the sample size appropriately and randomized the selection of respondents.

6. Conclusion

This study found no correlation between class, major, gender, age, diabetes mellitus risk, and perceived behavior control with diabetes prevention behavior. However, it revealed a significant relationship between emotional intelligence and diabetes time management with prevention behavior. Emotional intelligence emerged as the dominant factor influencing diabetes prevention behavior among at-risk students. Future research could examine student activities and emotional management strategies to comprehend their impact on supporting diabetes prevention behavior more effectively.

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Author contribution

Yolanda Sri Bhunga (YSB), Arif Setyo Upoyo (ASU), and Nuriya Nuriya (NN) have a mutually supportive role in making this research publication. YSB and ASU contributed to the study's design and conception, while NN aided in manuscript preparation. YSB took the lead in writing the final draft and conducting data analysis.

Conflict of interest

The researcher states that there is no conflict of interest in this study.

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ORIGINAL RESEARCH

Parents' Attitudes Toward COVID-19 Vaccination for School Children in Jordan



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Abstract

Background: Vaccination against COVID-19 is pivotal in curbing the spread of the virus among school children. However, there is a dearth of studies exploring parents' attitudes and acceptance levels regarding immunizing their children against COVID-19 in Jordan.

Purpose: This study aimed to assess parents' attitudes and key concerns toward administering COVID-19 vaccines to their school-aged children in Jordan. Additionally, it sought to identify the differences in parents' attitudes based on sociodemographic variables.

Methods: The cross-sectional and correlational study was conducted in AL-Mafraq governance within Northeastern Badia schools from March to May 2022 and involved 498 eligible parents. Stratifying the parent population based on school districts, data were conveniently collected using the Parent Attitude about Childhood Vaccines (PACV) scale. Statistical Package for the Social Sciences (SPSS) version 17 facilitated data analysis, incorporating descriptive and inferential statistics at a significance level of 0.05, with a 5% margin of error. The independent t-test and One-Way ANOVA were employed to depict differences between studied variables.

Results: The result showed that out of 600 distributed questionnaires, 498 were returned, resulting in a response rate of 83%. Findings revealed parental reluctance toward administering COVID-19 vaccination to their children. Notably, 65.9% of parents expressed concern about potential serious side effects, while 57.8% of parents harbored anxieties about vaccine safety and efficacy. Marital status emerged as a significant factor, with widowed parents exhibiting a more favorable attitude (p < 0.05).

Conclusion: Parents in Jordan are hesitant about COVID-19 vaccination for their school-aged children. Addressing these concerns necessitates educational campaigns through various channels, including social media and authorized TV and radio, to reassure parents about vaccine effectiveness and safety. This proactive approach is crucial to fostering broader acceptance and ensuring the success of vaccination initiatives.

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1. Introduction

Schools have contributed to the spread of the COVID-19 virus among school-age children, as well as an increase in the percentage of COVID-19 screening tests that are positive. As a precautionary measure, many countries closed their schools and shifted to online education, which had a severe impact on educational quality as well as emotional and psychological repercussions on schoolchildren (Dong et al., 2020). Schoolchildren vaccination is strongly advised for schools to restart safely (Kwok et al., 2021). Understanding parents' opinions toward vaccinating their children against COVID-19 is, therefore, critical to maximizing immunization rates among Jordanian children.

There is a global variance in parents' attitudes concerning vaccinating their children and the acceptability of the COVID-19 vaccine. For example, parents' perceptions of vaccination safety and efficacy may influence their decision to vaccinate their children (Bell et al., 2021; Humble et al., 2021). Unfortunately, due to conflicting information about the safety of the COVID-19 vaccine,

parents are becoming increasingly concerned about vaccinating their children. Based on their scientific expertise, parents were unable to decide which sources of information were reliable (Williams et al., 2013).

After receiving parental consent, the Jordanian Ministry of Health (MOH) and Ministry of Education (MOE) approved the COVID-19 vaccine for children aged 12 to 18. There is little information available to parents on the safety and effectiveness of the COVID-19 vaccine for children (Jordan Times, 2023). Parents in Jordan were concerned about their children's vaccinations, which stemmed from a lack of information and mistrust of government policies (Zein et al., 2021). Furthermore, high school (Tawjihi) students are now required to receive two immunization shots before taking their final examinations (Jordan Times, 2023). In Jordan, there is a scarcity of data on the factors that influence parents' opinions concerning their children's vaccination with the COVID-19 vaccine. This information is critical for better understanding these aspects and developing measures to improve parents' views and acceptance of vaccination for their children (Zein et al., 2021).

Typically, parents decide whether to vaccinate their children. Therefore, it is essential to comprehend parents' views, either acceptance or reluctance, regarding their children receiving the COVID-19 immunization. According to the researcher, no studies have been conducted on Jordanian parents' opinions toward their children's COVID-19 vaccinations. Moreover, to the researcher's knowledge, no studies have been published in Jordan that examine parents' attitudes and levels of acceptance for immunizing their children against the COVID-19 virus. This study is significant because it will be one of the first in Jordan to assess how parents feel about and how much they accept their children receiving the COVID-19 vaccine.

Accordingly, this study aimed to assess parents' attitudes toward the COVID-19 vaccine administration to their school-age children in Jordan and to identify key parental concerns about vaccinations. In addition, identifying the differences in parents' attitudes toward their children receiving the coronavirus vaccine based on a socio-demographic variable was also studied.

2. Methods

2.1 Research design

A cross-sectional and correlational study design was used. The data were collected at a single point in time to analyze relationships between variables. This approach allows for the examination of associations without manipulating factors, providing a snapshot of interconnections within a specific timeframe (Polit & Beck, 2017).

2.2 Setting and samples

The study was conducted in Al-Mafraq governance, located in the eastern-northern area of Jordan. Six conveniently governmental schools were selected from the six districts located in AL-Mafraq, and those conveniently selected schools had students aged between 12 and 18 years old. The selection of six conveniently chosen governmental schools from the six districts in Al-Mafraq aimed to ensure a representative and accessible sample for the study. Those schools were three schools with female students and three schools with male students from grade 7th to grade 12th, with about 1,366 students. This study targeted parents who had students aged 12–18 years old in the northeast Badia public schools. Inclusion criteria included parents with children aged between 12 and 18 years old. Exclusion criteria were parents who had children with some diseases, namely chronic diseases, autoimmune diseases, bronchial asthma, and having high allergic reactions because those children would never be vaccinated regardless of their parent's attitudes.

The sample size of the study participants was calculated based on a conventional power of 0.80, a conventional criterion of statistical significance of 0.05, and a medium effect size by using the G*Power 3.1.2 and selecting the t-test and ANOVA test (Faul et al., 2007). The minimum total number of participants of parents estimated for this study was 335. The sample was increased to 600 to control attrition and make our sample more representative. This study employed a stratified sampling technique. In the initial stage, the parent population in the Al-Mafraq governance was stratified according to school districts. Subsequently, a convenient sample of parents was selected from each stratum, ensuring a representation of diverse backgrounds and characteristics within the study area. One hundred questionnaires were then distributed in each school as part of the data collection process.

2.3 Measurement and data collection

Data collection was done using a set of questionnaires that was filled out by the students' parents using a paper survey. The first part included an introduction to the study, its aim, and its benefits. Also, it contained a consent form to participate in the study. The second part was the socio-demographic of the parents, such as gender, nationality, age, level of education, monthly income, marital status (married, separated), and parents' previous infection with COVID-19. The third part was the Parent Attitudes about Childhood Vaccines (PACV) tool that was developed and used in the United States of America to identify parents' attitudes toward vaccines (Opel et al., 2011). It has 15 questions. Two questions are related to childhood vaccination behaviors, four are related to safety and efficacy, and nine are related to general attitude and trust. Answers are with numeric scores ranging from 0=not hesitant, 1=do not know, and 2=hesitant. The higher the score, the higher the parent's hesitancy toward vaccination. The overall raw score was calculated by adding the item scores in an unweighted manner. The final step was to transform the overall raw score to a scale from 0 (least hesitant) to 100 (most hesitant). Participants with a score greater than or equal to 50 were defined as hesitant and disagreed with giving vaccinations to their children (Opel et al., 2011). In contrast, participants with a score of less than 50 were defined as not hesitant to give vaccination to their children (Opel et al., 2011). The original tool had been used in different countries, and it had an internal consistency ranging from 0.74 to 0.84 (Opel et al., 2011).

Permission to use the PACV tool had been taken from the author (Opel et al., 2011). The instrument was translated into Arabic by a linguistic expert. The PACV tool, initially in English, underwent a translation process to be rendered into Arabic. Subsequently, it was back-translated into English. The translated version was identical to the original questionnaire. The translated Arabic version of the instrument underwent a thorough examination of its content validity. A Content Validity Index (CVI) was calculated. The Individual Content Validity Index (I-CVI) scores were 0.90, indicating a high degree of agreement among experts. Seven experts participated in the evaluation process, confirming the robustness of the instrument in capturing the relevant aspects of parents' vaccine hesitancy in the Arabic cultural context. Additionally, Cronbach's alpha was used to make sure the instrument was reliable. It needs to be 0.70 or higher for the instrument to be considered reliable (Polit & Beck, 2017). The translated Arabic version's Cronbach alpha scores were 0.79, and the Arabic version could serve as a tool in the Arabic culture area in the evaluation of parents' vaccine hesitancy toward their children's vaccination (Alsuwaidi et al., 2020). This translated version was employed in a study conducted in the United Arab Emirates.

Data collection took place over a two-month period from January to March 2022. After obtaining IRB approval from AL-al-Bayt University and the Ministry of Education (MOE), the selected school's principles were approached. The questionnaires were then distributed to the specified students, via the classroom teachers, instructing them to ask their parents to complete and seal the questionnaires in an envelope. The students were asked to return the sealed envelopes the next day to their respective classroom teachers. These teachers, in turn, delivered the sealed envelopes containing the completed questionnaires to the principal's office. Returned responses were arranged and saved in a folder in the researcher's cabinet.

2.4 Data analysis

The Statistical Package for the Social Sciences (SPSS) program version 17 was used in the data analysis to generate descriptive and inferential statistics with α =0.05 and a margin of error of 5%. For continuous demographic variables, descriptive statistics of mean and standard deviation were generated, and for categorical demographic variables, frequency analysis was generated to describe demographic data among participants. Furthermore, tables were generated to facilitate reading means and standard deviations. Before answering the research questions and according to the tool author's scoring instruction, the raw total PACV scores were calculated by simply summing each item. Then, the raw scores were converted to a 0–100 scale using a simple linear transformation accounting for items. A total score of the PACV scale and the whole mean score of the scale for the whole sample were calculated (Polit & Beck, 2017). The total scores for items 8, 9, and 10 from the questionnaire were calculated separately. The total score for items 8, 9, and 10 measured parents' concerns regarding vaccination side effects, vaccination safety, and whether vaccination prevented the disease, respectively. After having the total score on the scale,

the independent t-test and One-Way ANOVA were used to describe the differences between studied variables (Polit & Beck, 2017).

2.5 Ethical considerations

This study obtained ethical approval from Al al-Bayt University's Institutional Review Board (IRB) (No. 5/2021/2022). Approval from the Ministry of Education (MOE) was also obtained to facilitate our access to the targeted schools. The cover letter at the beginning of the survey had an explanation of the aim of the study, benefits, and risks; the researcher's contacts; an explanation that their participation was considered a consent form; and their approval to participate in the study. To ensure the privacy of the information provided, no names or contact numbers were asked of participants. Participation was voluntary, and participants had the right to withdraw from the study at any time. Participants' demographic, personal, and response data were kept strictly confidential and electronically archived using a password-protected document. Only the researchers had access to the research data.

3. Results

3.1 Socio-demographic characteristics of the participants

Out of 600 distributed questionnaires, 498 were returned, resulting in a response rate of 83%. Table 1 shows participants' socio-demographic variables. Regarding age, the participants' mean age was 41.4 (SD=7.91) years. The majority of participants were male (79.5%), Jordanians (88%), were working as public sector employees (33.5%) and private-sector employees (25.6%), having secondary education or less (52.2%), married (77%), and had been previously infected with COVID-19 (61.3%). As many as 209 (42%) of the parents who participated in the study were willing to vaccinate their children with COVID-19 vaccinations.

1	<i>3</i> 1		,	
Demographic variables	f	%	Mean	SD
Age (year)			41.4	7.91
Gender				
Male	396	79.5		
Female	102	20.5		
Nationality				
Jordanian	438	88.0		
Non-Jordanian	60	12.0		
Job				
No Work	98	19.6		
Private sector	125	25.6		
Self-employed	111	22.7		
Public sector	164	33.5		
Education level				
Secondary education or less	260	52.2		
Diploma or Bachelor's level	203	40.7		
Post-graduate education	35	7.1		
Marital Status				
Married	382	77.0		
Separated or widow	106	17.1		
Previously infected with COVID-19				
Yes	305	61.3		
No	193	38.7		

Table 1. Participant socio-demographic characteristics (n=498)

3.2 Parents' attitudes toward vaccinating their children

Parents willingness to vaccinate their children

Yes

No

Table 2 indicates parents' attitudes toward their children's vaccination with COVID-19 vaccines (M=76.62, SD=15.07). These results, according to the (PACV) tool scoring results, meant that parents did not agree and were hesitant to give vaccinations to their children. The results of the study revealed diverse attitudes and behaviors regarding childhood vaccinations among

209

289

42.0

58.0

parents in Al-Mafraq governance. Notably, a significant portion of parents had delayed or chosen not to have their child receive certain shots (35.5%), while others expressed uncertainty (33.1%). Confidence in the recommended shot schedule was high, with the majority expressing ratings of o-5 (73%) on a scale of 0 to 10. While opinions varied on the perceived severity of preventable illnesses and the belief that children received too many shots, a majority disagreed (60.4%) with the notion that it was better for a child to develop immunity through illness rather than vaccination. Trust in information about shots and open communication with healthcare providers exhibited divisions among respondents. Concerns about side effects and safety were generally low (14.5% and 19.3%, respectively), and a majority expressed future hesitation about vaccinating their potential children (67.8%). Overall, these findings underscored the nuanced landscape of parental attitudes toward childhood vaccinations in the Al-Mafraq region.

Table 2. Parents	'attitudes toward	children's v	accination	(n=498)
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Attitude Toward Vaccination	Mean	SD	Yes/Agree/ Concerned/ 6-10 f(%)	No/Disagree/ Not concerned/o-5 f(%)	Do not know/ not sure f(%)	Confidence f(%)
Overall parents' attitude	76.62	15.07				
Parents' attitude per statement						
Delayed child's shot?			177(35.5)	156(31.3)	165(33.1)	
Skipped child's shot?			163(32.7)	212(42.6)	123(24.7)	
Sure about shot schedule?			135(27.0)	364(73.0)		
Kids get too many shots?			109(21.9)	122(24.5)	267(53.6)	
Severity of preventable illnesses			107(21.5)	200(40.2)	191(38.4)	
Better immunity by getting sick?			26(5.2)	301(60.4)	171(34.3)	
Fewer vaccines at once better?			96(19.8)	315(64.8)	75(15.4)	
Concern about serious side effects			72(14.4)	328(65.9)	98(19.7)	
Concern about shot safety			96(19.3)	288(57.8)	114(22.9)	
Concern shot might not prevent disease			62(12.4)	288(57.8)	148(29.7)	
Want future child to get all shots?			80(15.6)	335(67.8)	83(16.6)	
Overall hesitancy about shots			75(15.1)	291(58.4)	132(26.5)	
Trust information about shots			53(10.1)	280(56.8)	165(33.1)	
Discuss concerns with child's doctor			41(7.6)	318(64.6)	139(27.8)	
Trust child's doctor			171(34.3)	367(73)		36(7.2)

3.3 Parents' major concerns of vaccinating their children

Table 3 shows that the majority of parents (65.9%) were somewhat concerned and very concerned that their children might have serious side effects from a shot, while only 14.4% of respondents had not concerned that their children might have serious side effects from a shot. Furthermore, 57.8% of participants were somewhat concerned and very concerned regarding vaccine safety, while about (19.3%) were not concerned regarding vaccine safety. Moreover, 57.8% of the parents were somewhat concerned and very concerned if the vaccine could prevent the disease, while 12.4% had not concerned if the vaccine might prevent the disease.

Table 3. Parents' major concern of vaccination (n=498)

Parents' major concerns	Not at all concerned and not too concerned f(%)	Not sure f(%)	Somewhat concerned and very concerned f(%)
How concerned are you that your child might have a serious side effect from a shot?	72(14.4)	98(19.7)	328(65.9)
How concerned are you that anyone of the childhood shots might not be safe?	96(19.3)	114(22.9)	288(57.8)
How concerned are you that a shot might not prevent the disease?	62(12.4)	148(29.7)	288(57.8)

3.4 Parents' attitudes toward children vaccination according to socio-demographic characteristics

Tables 4 shows parents' attitudes toward vaccination by demographic variables. The results showed that there was a statistically significant difference in the attitude by marital status (t=7.24, p=0.01). Widowed or separated groups tend to be more hesitant to give vaccination to their children compared to married groups. The results also indicated no statistically significant differences in the attitude based on education level (F=1.74, p=0.209), gender (t=-1.71, t=0.088), age (t=2.0, t=0.073), nationality (t=0.56, t=0.523, and job (t=1.65, t=0.146).

Table 4. Parents' attitudes toward vaccination according to the socio-demographic characteristics (n=498)

Characteristics	n	Parents's Attitude		E/t togt	
		Mean	SD	F/t test	p
Gender					_
Male	396	76.04	14.39	t=-1.71	.088
Female	102	78.89	17.38		
Age					
Less than 30	153	76.30	13.67	t= 2.0	.073
30 and more	345	78.40	15.43		
Nationality					
Jordanian	438	76.82	.088	t= .56	.523
Other nationality	60	75.00	14.41		
Employment					
No work	98	77.80	12.24	F=1.65	.146
Private Employee	125	75.06	17.16		
Self-employed	111	74.87	16.79		
Public Employee	164	78.94	13.41		
Educational level					
Secondary education or less	133	76.83	15.68	F=1.47	.209
Diploma or Bachelor's level	127	75.83	17.10		
Post-graduate education	80	76.20	12.6		
Marital status					
Married	382	76.08	15.87	t=7.24	.001
Separated or widows	106	86.79	11.30		

Note. F: One-way ANOVA, t: Independent t-test

4. Discussion

This study aimed to assess parents' attitudes and identify key parents' concerns toward the administration of the COVID-19 vaccines to their school-aged children in Jordan. The findings showed that, regarding parents' attitudes toward their children's vaccination with COVID-19 vaccines, the parents in this study were hesitant and disagreed with giving their children the COVID-19 vaccination. Furthermore, only 42% of the parents who participated in the study were willing to vaccinate their children with COVID-19 vaccinations. The current study finding is similar to the rate of participating parents in Turkey, with 45.2% of parents accepting and wanting to give their children the COVID-19 vaccine (Yilmaz & Sahin, 2021). Parents' reluctance to vaccinate their children with COVID-19 may be due to a lack of information regarding the vaccine's safety or potentially negative effects. Furthermore, some parents feel that the immunizations will harm their children in the future.

Our study findings revealed a stark contrast in the beliefs and attitudes of parents in the current research context compared to previous studies. The study findings contrasted Canadian and Ecuador parents' beliefs and attitudes toward their children's COVID-19 vaccination. According to the Canadian study, 63% of participating parents wanted and were willing to vaccinate their children against COVID-19 (Humble et al., 2021), while in Ecuador, the number was 97% (Sallam, 2021). In another study, 65% of parents who visited 16 pediatric emergency clinics in Canada, the United States, Japan, Spain, Palestine, and Switzerland agreed to and planned to vaccinate their children with the COVID-19 vaccine (Goldman et al., 2020). As many as 82.61% of the Chinese parents who took part in the study were also willing to vaccinate their

adolescent children against the COVID-19 virus (Wu et al., 2022). Furthermore, in a Brazilian study, vaccine reluctance was found to be very low (2.8%) among parents, emphasizing the relevance of COVID-19 vaccination for the entire population, adults, and children (Bagateli et al., 2021). Upon further analysis, variations in the results between Jordan and Turkey compared to other countries may be attributed to cultural nuances, including religious beliefs and perspectives. For instance, religious beliefs may shape attributes toward vaccination, and these differences could manifest in the perceived relevance of certain aspects of vaccine hesitancy.

Based on socio-demographic characteristics, parents' opinions regarding their children receiving the COVID-19 vaccine were investigated. The findings indicated that there was a significant statistical difference in attitude by marital status in favor of the separated or widowed parents, who were more cautious about vaccinating their children with COVID-19 vaccinations than married parents. Separated status was substantially more related to COVID-19 vaccine reluctance in the UAE and Ghana than any other marital status (Alsuwaidi et al., 2020; Anokye et al., 2018). This can be explained by the fact that unmarried mothers make decisions about their children's vaccinations alone, making them more hesitant to make such an important decision.

On the other hand, the findings of this study revealed that there was no statistically significant difference in attitude by gender. This is an excellent opportunity to delve more into this subject. This finding is consistent with other investigations (Teasdale et al., 2021; Zhang et al., 2021). This can be explained by the fact that both fathers and mothers perceived the same number of COVID-19 hazards and vaccination against this danger. It can be concluded that gender may not play a significant role in shaping parents' attitudes. In contrast, a study published in Turkey in 2021 found that mothers' reluctance to vaccinate their children with the COVID-19 vaccine was statistically significant (Yilmaz & Kursat, 2021). Furthermore, in Italy, mothers were substantially connected with their children's reluctance to receive the COVID-19 vaccine (Fedele et al., 2021). The observed maternal connection prompts further analysis, suggesting potential influences such as heightened responsibility, emotional attachment, health-related anxieties, cultural norms, and societal expectations. According to the current study result, there was no statistically significant variation in attitudes based on education level. These findings are consistent with previous findings that found no statistically significant differences between levels of education and parents' desire or reluctance to vaccinate their children against the COVID-19 virus (Choi et al., 2021). This is an issue that requires greater exploration and research to provide an explanation. In contrast, this conclusion contradicts a study published in Turkey in 2021 that found that parents' reluctance to vaccinate their children with the COVID-19 vaccine was connected with primary and secondary school parents' education (Yilmaz & Kursat, 2021). In this study, age did not affect parents' attitudes toward immunizing their children with the COVID-19 vaccine. This finding is consistent with the findings of a Korean study, which discovered that age was not a significant determinant in parents' opinions toward their children's immunization (Choi et al., 2021). This could be explained by the fact that Jordan has a predominantly young population, and there is no difference in the age distribution of the parents in this study. Younger parents were significantly related to an unwillingness to vaccinate their children with the COVID-19 vaccine in Italy (Fedele et al., 2021), whereas older participants were associated with hesitancy and refusal of the COVID-19 vaccine for their children in Brazil (Bagateli et al., 2021).

In terms of parents' major concerns in vaccinating their children, over two-thirds of parents (65.9%) were concerned about their children experiencing major adverse effects from the COVID-19 vaccine, and only 14.4% of responders were not concerned that the vaccine would cause major negative effects in their children. This notable level of concern may be rooted in various factors, including uncertainties about vaccine effectiveness, perceived risks or side effects, and possibly misinformation circulating within the community. The majority of parents' concerns about their children's vaccinations were that vaccine preparations had not been sufficiently evaluated and that there was insufficient information about potential future consequences (Babicki et al., 2021). This concern was also highly related to the vaccine's safety. Parents had no concerns about the safety of the COVID-19 vaccine, and there was high trust in the safety that was signed as well to be related to parents' intention to vaccinate their children (Choi et al., 2021). One of the parents' worries about vaccines in the UAE was vaccine safety (28%) (Alsuwaidi et al., 2020). In our study, 57.8% of parents were concerned about the vaccine's ability to prevent the disease, while 12.4% were not concerned about the vaccine's inability to prevent the sickness. COVID-19 vaccine effectiveness and a lack of COVID-19 vaccine-related information were discovered to be key

sources of anxiety for parents and the principal cause of parents' reluctance to vaccinate their children against the COVID-19 virus (Pan et al., 2021).

The current findings reveal that parents were concerned about the safety and side effects of the COVID-19 vaccination, and they were still hesitant to vaccinate their children. These behaviors could be assumed to be attributed to a variety of factors, including the study period being associated with varying levels of knowledge from various resources via social media regarding the COVID-19 vaccination, spreading rumors about a variety of conspiracy theories, misleading, conflicting, manipulating, and misinformation about the vaccine. However, these assumptions need further investigation. Another factor that could influence the results was public trust in government decisions and parents' willingness to accept official advice. Another explanation could be that parents who feel compelled to conduct an activity may feel compelled to behave in the exact opposite way. Furthermore, parents may adopt the "wait and see" mentality and later become more concerned about their children's vaccination as a result of the trials. This perspective is in line with findings from Suran et al. (2022)'s study, which has reported a correlation between delayed vaccine acceptance and increasing concerns among parents. Acknowledging and addressing these concerns in public health communication can be crucial in fostering vaccine acceptance and understanding the dynamic nature of parental attitudes toward vaccination.

5. Implication and limitation

The current study is one of the most advanced studies in Jordan, and its findings are critical to understanding parents' attitudes, beliefs, and fears about their children's immunization with the COVID-19 vaccine to increase the COVID-19 vaccination acceptance rate. Both the Ministry of Health (MOH) and the Ministry of Education (MOE) play critical roles in raising awareness and providing necessary health education to increase parents' acceptability and willingness to administer COVID-19 vaccines to their school-age children. Community health nurses have an important role in implementing healthcare programs and initiatives, and they should focus on educating children about the value of the COVID-19 vaccine and its protection.

This is one of the few studies in Jordan targeted at examining parents' attitudes toward school-age immunization. However, the current study has limitations, including the fact that the study design is cross-sectional and descriptive, which has less robustness than other study designs in finding connections between study variables. The survey was only delivered in one government region (Mafraq), which may restrict the generalizability of the study outcomes. The risk of bias is that data were collected via a self-report questionnaire, which may alter the accuracy of the information reported.

6. Conclusion

The study's findings revealed that parents in Jordan were hesitant to vaccinate their children with the COVID-19 vaccine, and their concerns regarding vaccination's safety, side effects, and effectiveness in avoiding infection with the COVID-19 virus were high. In terms of marital status, there were substantial disparities in the arithmetic mean of parents' reluctance to vaccinate their children with COVID-19 vaccinations. There were no statistically significant variations in parents' reluctance to vaccinate their children with COVID-19 vaccinations based on age, gender, income, education level, or child features. Understanding the causes and factors that interfere with and are connected with parents' desire and reluctance to vaccinate their children with the COVID-19 vaccine may assist in improving parental acceptability and minimize parental reluctance. The Jordanian government should launch targeted public awareness campaigns, tailoring messages based on marital status, to address parental concerns about COVID-19 vaccination. Prioritizing accessible vaccination centers and community education initiatives can enhance vaccine uptake. Future studies should focus on qualitative aspects of parental reluctance, conduct longitudinal research, explore cross-cultural differences, and evaluate interventions to refine strategies and policies for improving parental acceptability of COVID-19 vaccination for children in Jordan.

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Author contribution

AAZ: Primary data collection, analysis of data, and writing up the research.

MS: Designing research methodology, overseeing data analysis, and follow-up research publication.

MAb: Ensuring research validity and contributing to the interpretation of statistical findings.

WT: Reviewing and synthesizing relevant literature.

MAj: Ensuring clarity and coherence in presenting the study's findings.

AAb: Contributing to the discussion section and ensuring the study's relevance to current nursing practices.

AAl: Contributing to the conclusion and recommendations.

Conflict of interest

The authors declare that there is no conflict of interest regarding the research, authorship, or publication of this manuscript.

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ORIGINAL RESEARCH

Home Health Care During Physical Distancing Affects Physical and Psychosocial Aspects, Self-Efficacy, Family Function, and Quality of Life of Families in Indonesia



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Abstract

Background: Physical distancing during the COVID-19 pandemic has impacted the activities of daily living (ADLs) of families, such as physical and psychosocial aspects, self-efficacy, family social function, and overall quality of life. However, research investigating the effects of home health care in enhancing these aspects during the physical distancing period remains limited.

Purpose: This study aimed to evaluate the effects of implementing home health care on physical and psychosocial aspects, self-efficacy, family social function, and quality of life of families in East Java Province, Indonesia.

Methods: A quasi-experimental study was conducted among 768 healthy families that were purposively recruited from April to May 2020. The home health care program was implemented for one month to provide nursing care to the families. Data were collected using self-administered questionnaires, and SPSS software was employed for data analysis. Chi-square tests were applied for categorical variables, while paired t-tests were used for continuous variables.

Results: Significant differences were observed in blood pressure, pulse, and temperature before and after the implementation of home health care during the physical distancing period (p<0.05). There was an increase in body mass index (23.29(5.59) vs. 23.78(7.53); p=0.001). Notably, significant differences were also found in COVID-19 exposure risk factors, personal risk factors, sleep patterns, and physical activity before and after home health care (p<0.05). Furthermore, improvements were noted in self-efficacy, family social function, and the quality of life of the families after one month of home health care (p<0.05).

Conclusion: Home health care during physical distancing positively affected the physical and psychosocial aspects, self-efficacy, family social function, and quality of life of the families. Thus, the guidance and support offered through home health care should be further developed to help families navigate the "new normal" era of COVID-19.

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1. Introduction

The World Health Organization (WHO) reported the number of COVID-19 cases worldwide as 234,073, including 24,247 new cases, 9,840 deaths, and 1,061 new deaths (WHO, 2020a). Meanwhile, the number of COVID-19 in Indonesia based on the Ministry of Health's reports included 450 positive cases and 38 deaths (Ministry of Health Republic of Indonesia, 2020). This indicates a significant increase in the number of COVID-19 cases through transmission from positive patients to healthy people in the community. Thus, stringent control measures are required to prevent the spread of COVID-19 among healthcare providers in hospitals and their patients, especially among suspected patients in the community and within families.

To prevent the spread of COVID-19, a physical distancing program is implemented to maintain a distance of around two meters between individuals. COVID-19 spreads mainly among people who are in close contact (within about 6 feet) for a long time (WHO, 2020b). The government implements work-from-home or study-from-home to maintain physical distancing.

Research has shown that people who are infected, although they have no symptoms, may also play a role in the spread of COVID-19 (WHO, 2020c). However, until now, there has been a lot of controversy from families and communities regarding the program to maintain distance during the physical distancing period.

The WHO's second pillar, Risk Communication and Community Engagement, underscores the importance of effectively communicating COVID-19 risks and precautions to ensure the safety and welfare of families. In this regard, home healthcare providers play a crucial role in educating families to adopt behaviors that reduce transmission risks when caring for infected members. Effective communication and active family involvement can increase trust between providers and families, ensuring that care is provided safely and empathetically while maintaining activities of daily living (ADLs) (WHO, 2020d). Also, during the physical distancing period, families and communities still lack awareness about the need to remain at home. This lack of awareness stems from insufficient knowledge about the risk factors and transmission of COVID-19. Consequently, families and communities lack an understanding of appropriate actions during this physical distancing period (WHO, 2020d). Meanwhile, to avoid and prevent the spread of COVID-19, it is necessary to increase individual immunity, personal and environmental hygiene, adequate nutrition, optimal physical activity, stress management, and avoid risk exposures (WHO, 2020a; WHO, 2020b; WHO, 2020c).

During COVID-19 physical distancing, families face challenges affecting self-efficacy, family function, and both physical and psychosocial aspects of their quality of life. Greater COVID-19-related stress is linked to lower self-efficacy, while increased engagement in family routines during the pandemic is associated with higher self-efficacy (Meyer et al., 2022). Self-efficacy also positively maintains optimism and mental health (Zhou et al., 2021), mediating the stressful effects of COVID-19 beliefs (Meyer et al., 2022). Families experience fear, uncertainty, and stress, leading to significant changes in financial, emotional, and physical wellbeing (Zhou et al., 2021). Positive and negative COVID-19-related events impact family functioning, with declines in youth's reported open family communication and increases in parent functioning (Meyer et al., 2022). Additionally, the pandemic is significantly associated with intergenerational communication and satisfaction with social support (Stawnychy et al., 2023). This has impacted family employment, financial security, mental health, children's education, and overall wellbeing, leading to family income loss, economic difficulties, job loss, and increased stress and anxiety (Gayatri & Puspitasari, 2023).

Families require an effective adaptation pattern during physical distancing, necessitating active involvement from each family member to bolster family functioning and strength (Susanto, 2012) in fulfilling their activities of daily living, both physical and psychosocial aspects. Simultaneously, home health and personal home care organizations can implement a highly coordinated and consistently communicated approach to infection control, case identification, and employee screening (Mills et al., 2020). The management of ADLs, including aspects such as nutrition (Laviano et al., 2020), physical activity (Jakobsson et al., 2020), rest and sleep (Gulia & Kumar, 2020), and stress management (Cao et al., 2020), is essential for families during the COVID-19 pandemic within both family and community-based healthcare (Victoria et al., 2020a; Victoria et al., 2020b). However, maintaining these ADLs during physical distancing poses a significant challenge for families. Research has shown that optimizing family care through home health care facilitates self-efficacy (Moghadam et al., 2016) and enhances the family's overall quality of life (QOL) (Han et al., 2013; Peters et al., 2019). Home health care is designed to enhance a patient's health status, including physical activity, psychosocial wellbeing, self-efficacy, family social functioning, and overall family quality of life (Susanto et al., 2023). Health professionals can provide home health care to assist families in managing their ADLs.

While studies advocate the importance of family-based healthcare in optimizing self-efficacy and quality of life (Han et al., 2013; Moghadam et al., 2016; Peters et al., 2019), little research has focused on evaluating home healthcare's impact on physical and psychosocial aspects, self-efficacy, family function, and quality of life during the physical distancing period, particularly in East Java, Indonesia. Therefore, this study aimed to evaluate the effects of home health care on the physical and psychosocial aspects, self-efficacy, family function, and quality of life of families during the COVID-19 physical distancing period.

2. Methods

2.1. Research design

A quasi-experimental study with a pre-and post-intervention design without a control group was conducted among 768 healthy families in East Java, Indonesia, from April to May 2020.

2.2. Setting and samples

This study was conducted in the communities in Jember, Indonesia. A purposive sampling method was used to select the study participants that met the inclusion criteria. These subjects were the heads of the families of internship students, while other subjects included neighbors residing within approximately one kilometer of the internship students' houses. The heads of these families worked from home during the physical distancing period, and all family members were in good health and willing to participate. Exclusion criteria included individuals suspected or confirmed positive for COVID-19, those moving to another residence outside their town, and those with COVID-19 comorbidities (including the elderly, pregnant women, and individuals with non-communicable diseases such as hypertension, diabetes, heart diseases, and stroke).

During the COVID-19 pandemic, conducting community-based research posed significant challenges. In this study, subject selection was initiated through the student interns enrolled in the faculty of nursing at a public university in Jember, Indonesia. In April 2020, 91 student interns participated, with 455 families; in May 2020, 63 students participated, with 315 families. However, two families were excluded from the study due to relocation, resulting in a total of 768 families. The families participated in the home health care program for one month.

2.3. Intervention

Home health care was implemented for one month. Each family was supervised twice per week for one month. Therefore, eight home visits were conducted. During one month, each family received health education through teaching and practicing how to fulfill their ADLs during physical distancing at home by learning the module. The module encompassed content on ADL subjects, including the risk factors associated with COVID-19, nutrition, physical activity, sleep and rest, management of stress and loneliness, and psychosocial and spiritual needs (Table 1).

Table 1. Topics of module for health education during home health care visit

Topics	Sub Topics	Session
COVID-19 and risk	Explanation of COVID-19	1
factors	General risk factors of COVID-19	
	 Personal risk factors of COVID-19 	
Nutrition	Fulfillment of nutrition to improve immunity	2
	 Planning daily menus with calories, protein, minerals, and fiber 	
Physical activity	Arrangement of physical exercises at home	3
	• Practicing physical exercise for 15-30 minutes every day at home for stretching	
Personal and	Practicing hand-washing techniques and proper mask-wearing	4
environmental	Bathing and changing clothes after work or being outside of the	
hygiene	home	
	 How to clean home and maintain healthy sanitation 	
Sleep and rest	 Maintaining sleep and rest at home 	5
	Practicing relaxation to stimulate deep sleeping	
Psychological	 Maintaining stressors during COVID-19 	6
	Anger and stress management	
Social relationship	• Maintaining quality time by scheduling family time to share the daily experiences of each family member	7
	 How to make social contact with neighbors 	
	Defining family role during social distancing	
Spiritual	Praying and worship during the COVID-19 pandemic	8
	 How to use the house for worship and religious activities together during COVID-19 	

The internship students were supported in teaching one topic during each home visit with the family and providing supervised practice sessions, where the internship students could apply the intervention under the guidance of experienced mentors. This allowed for feedback and refinement of techniques and ensured consistency in the intervention delivery.

The module was developed by the investigator team regarding clustering to accelerate the handling of COVID-19 in Indonesia during the physical distancing period (COVID-19 Handling Acceleration Group, 2020), along with standards for managing ADLs during the COVID-19 pandemic (Razi et al., 2020). Each health education session lasted for 60 minutes. Throughout the home health care program, the internship students followed a standardized protocol when contacting families, which included hand-washing before and after interacting with families and wearing masks or face shields. Participants' blood pressure, pulse, and temperature were measured during every visit to monitor their daily health status. Additionally, they completed a self-administered questionnaire at the initial home visit before the first session and after the final session of health education to evaluate their physical and psychosocial aspects, self-efficacy, family function, and quality of life.

The internship students underwent a comprehensive training program encompassing orientation on COVID-19 handling and clustering methodologies, health education curriculum instruction, communication skills, and monitoring procedures. Emphasis was placed on the consistent use of personal protective equipment, adherence to standardized protocols during home visits, and the accurate administration of self-administered questionnaires. Continuous supervision and feedback, along with mock sessions, ensured that students were well-prepared and shared similar perceptions about the intervention, contributing to a cohesive and effective implementation of the home health care program in Indonesia.

2.4. Measurement and data collection

Self-administered questionnaires were employed to collect sociodemographic information about the subjects and assess their physical and psychosocial aspects, self-efficacy, family social function, and quality of life (QoL). Sociodemographic data included age, gender, religion, ethnicity, education, marital status, occupation, and family income.

Regarding the physical aspects, the participants' blood pressure, pulse, temperature, height, and weight were measured. Blood pressure was assessed by standard protocol with a stethoscope and sphygmomanometer, and body temperature was measured with a standard thermometer. Weight (kg) and height (m) were used to calculate Body Mass Index (BMI). Also, risk factors for COVID-19 exposure were evaluated through 15 items, categorized into three groups (low risk=0-5, moderate risk=6-10, and high risk=11-15). Personal risk factors for COVID-19 were assessed with 21 items, categorized into three groups (low risk=0-7, moderate risk=8-14, high risk=15-21). Physical activity was measured using the International Physical Activity Questionnaire (IPAQ), consisting of 7 items with three categories: low, moderate, and high (Craig et al., 2003). This instrument was translated into Indonesian by Dharmansyah and Budiana (2021). Furthermore, sleep patterns were assessed using the Indonesian version of the Pittsburgh Sleep Quality Index (Setyowati & Chung, 2020) and categorized into two groups (good ≤5, poor >5).

Psychosocial aspects, including loneliness, coping strategies, and family social function, were also assessed in participants. The Indonesian version of the UCLA Loneliness Scale version 3 (Nurdiani, 2019) was utilized, comprising 20 items and categorized into four groups (no loneliness=20-34, mild=35-49, moderate=50-64, and severe=65-80). Coping strategies were evaluated using the Indonesian version of the Jalowiec Coping Scale (JCS) (Ibrahim et al., 2021; Rafiyah et al., 2011), categorized into three groups (high ≥63, moderate=38-62, low <37). Family social function was measured with the APGAR Family Scale (Smilkstein, 1978) and categorized into three groups (mild=8-10, moderate=4-7, and severe=0-3). The Indonesian version of the APGAR Family Scale (Ridwan et al., 2022) was employed. Additionally, participants' spiritual activity was assessed using the Indonesian version of the Daily Spiritual Experience Scale (DSES) (Karomah, 2015) and categorized into three groups (low=15-40, moderate=41-65, and high=66-90).

Furthermore, the General Self-Efficacy Scale (GSES), developed by Schwarzer and Jerusalem (1995), was used to measure the family's self-efficacy during physical distancing and categorized into three groups (low=13-26, moderate=27-40, and high >40). The Indonesian version of the GSES (Lidya, 2020) was used. Lastly, the Indonesian version of the WHOQOL-BREF was used to

evaluate the family's quality of life (Anisah & Djuwita, 2019; Saputri et al., 2020), categorized into five groups (very poor=0-20, poor=21-40, moderate=41-60, good=61-80, very good=81-100).

All translated versions of the instruments in Indonesian demonstrated strong validity and reliability. The Indonesian adaptation of the IPAQ exhibited satisfactory validity, with each item showing a factor loading between 0.890 and 0.995 and a Cronbach's alpha coefficient of 0.884 (Dharmansyah & Budiana, 2021). The Pittsburgh Sleep Quality Index achieved a validity score of 0.69-0.72, with a Cronbach's alpha coefficient of 0.72 (Setyowati & Chung, 2020). The UNCLA Loneliness Scale version 3 exhibited reliability with an alpha coefficient of 0.92 and validity, as indicated by Chi-square = 98.83, *p*-value = 0.08674, and RMSEA = 0.036 (Nurdiani, 2013). The Indonesian version of the JCS ensured reliability with a Cronbach alpha of 0.91, and content validity was confirmed by expert consensus on all items (Ibrahim et al., 2021). The item test correlation of the Indonesian version of the APGAR Family Scale ranged from 0.77 to 0.90, with a Cronbach alpha of 0.89 (Ridwan et al., 2022). Meanwhile, the Indonesian version of DSES demonstrated valid scores ranging from 0.404 to 0.726, with a Cronbach alpha of 0.929 (Karomah, 2015). The GSES showed Pearson correlation values for the 10 items ranging from 0.528 to 0.707, with a Cronbach's alpha of 0.847 (Lidya, 2020), and the WHOQOL-BREF displayed r table values >0.361 and a Cronbach's Alpha of 0.880 (Anisah & Djuwita, 2019).

2.5. Data analysis

Data were analyzed using the IBM Statistical Package for Social Sciences software program, version 22.0. Statistic descriptive was used to determine the sociodemographics of the subjects with median (for numeric data) and percentage (for categorical data). Firstly, we tested the normality of data distribution. The variables—systolic blood pressure, diastolic blood pressure, pulse, temperature, and BMI—displayed normal distributions. Then, Chi-square tests and paired t-tests were conducted to compare categorical and continuous variables related to physical aspects, psychosocial aspects, self-efficacy, family social function, and the family's quality of life, respectively. A *p*-value <0.05 was considered statistically significant.

2.6. Ethical considerations

This study was approved by the Ethics Committee of the Faculty of Dentistry, Universitas Jember (No. 918/UN25.8/KEPK/DL/2020). The subjects in this study were heads of families who volunteered to participate. They provided written informed consent for their participation. They were also informed that they had the freedom to withdraw from the study at any time.

3. Results

3.1 Characteristics of the participants

The sociodemographic characteristics of the subjects (Table 2) reveal that the median age of the families was 50 years, with 85.2% being males. The predominant religion among subjects was Islam (97%), with 73.6% being of Javanese ethnicity and 39.6% having completed senior high school education. Also, the majority were married (86.1%) and entrepreneurs (30.2%).

Variables	Median	Frequency (f)	Percentage (%)
Age (year)	50		_
Gender			
Male		654	85.2
Female		114	14.8
Religion			
Islam		745	97.00
Christian		16	2.1
Catholic		5	0.7
Hindu		2	0.3
Ethnicity			
Javanese		565	73.6
Madurese people		170	22.1
Osing community		1	0.1
Mixed		32	4.2

Table 2. Characteristics of participants (n=768)

Table 2. Continued

Variables	Median	Frequency (f)	Percentage (%)
Educational background			
Elementary school		188	24.5
Junior high school		106	13.8
Senior high school		304	39.6
Bachelor degree		157	20.4
Master degree		13	1.7
Marital status			
Single		24	3.1
Married		661	86.1
Widow		25	3.3
Widower		58	7.6
Occupation			
Farmer		154	20.1
Public government		100	13.0
Entrepreneur		232	30.2
Private company		78	10.2
Seller		42	5.5
Others		162	21.1
Monthly income (IDR) (Min-Max=100,000 – 15,000,000	1,800,000		

3.2 Differences in physical health status before and after home health care implementation Table 3 shows differences in blood pressure, pulse rate, and temperature before and after the implementation of home health care (p<0.05). Both systolic (123.3(14.48) vs. 121.9(13.59)) and diastolic (81.1(10.05) vs. 80.1(9.5)) blood pressures, pulse rate (82.5(9.2) vs. 81.8(9.2)), and temperature (36.5(1.6) vs. 36.4(1.6)) were observed to decrease during home health care. Surprisingly, there was an increase in BMI after one month of physical distancing (23.29(5.59) vs. 23.78(7.53); p=0.001).

Table 3. The differences in physical health status before and after home health care (n=768)

Variables	Mean(SD)	Min-Max	$ ho ext{-value}$
Systolic blood pressure			
Before	123.3(14.48)	70-180	0.014*
After	121.9(13.59)	70-170	
Diastolic blood pressure			
Before	81.1(10.05)	50-130	0.012*
After	80.1(9.5)	50-120	
Pulse			
Before	82.5(9.2)	58-113	0.001^{*}
After	81.8(9.2)	60-112	
Temperature			
Before	36.5(1.6)	30-37	<0.001*
After	36.4(1.6)	30-37	
BMI			
Before	23.29(5.59)	11.46-38.05	0.001*
After	23.78(7.53)	15.56-36.85	

Notes. Significance is determined using a paired t-test. *Significant value

3.3 Differences in physical and psychosocial aspects, family social function, self-efficacy, spirituality, and quality of life before and after home health care

Table 4 figures out a significant difference in the risk factors for exposure and personal risk factors of COVID-19, sleep needs, and physical activity before and after home health care (p<0.05). The proportion of risk factors for exposure and personal risk factors related to COVID-

19 decreased during home health care. Meanwhile, the participants' sleep needs and physical activity improved during physical distancing. Furthermore, self-efficacy, family social function, and the quality of life of the families improved during one month of home health care (p<0.05). However, no differences in loneliness and spiritual activity were observed before and after home health care (p>0.05).

Table 4. Differences in physical and psychosocial aspects, family social function, self-efficacy, and quality of life before and after home health care (n=768)

Variable	Before	After	<i>p</i> -value
	f (%)	f (%)	p-varue
Risk factors for exposure to COVID-19			
Low	593 (77.2)	625 (81.4)	0.016*
Moderate	173 (22.5)	142 (18.5)	
High	2 (0.3)	1 (0.1)	
Personal risk factors for COVID-19			
Low	435 (56.6)	532 (69.3)	<0.001*
Moderate	303 (39.5)	221 (28.8)	
High	30 (3.9)	15 (2.0)	
Sleep need			
Good	576 (75.0)	731 (95.2)	<0.001*
Poor	192 (25.0)	37 (4.8)	
Loneliness			
No	20 (2.6)	22 (2.9)	0.596
Mild	286 (37.2)	296 (38.5)	
Moderate	444 (57.8)	428 (55.7)	
Severe	18 (2.3)	22 (2.9)	
Physical activity			
Low	86 (11.2)	58 (7.6)	0.002*
Moderate	591 (77.0)	601 (78.3)	
High	91 (11.8)	109 (14.2)	
Family social function			
Mild	538 (70.1)	556 (72.4)	0.039*
Moderate	214 (27.9)	208 (27.1)	
Severe	16 (2.1)	4 (0.5)	
Coping strategy			
Moderate	5 (0.7)	5 (0.7)	1.000
High	763 (99.3)	763 (99.3)	
Self-efficacy			
Low	163 (21.2)	133 (17.3)	<0.001*
Moderate	547 (71.2)	543 (70.7)	
High	58 (7.6)	92 (12.0)	
Spiritual activity			
Low	355 (46.2)	371 (48.3)	0.087
Moderate	371 (48.3)	366 (47.7)	/
High	42 (5.4)	31 (4.0)	
Quality of life			
Poor	623 (81.1)	597 (77.7)	0.011*
Moderate	1 (0.1)	0 (0)	2.022
Good	144 (18.8)	171 (22.3)	

Notes. Significance is determined using the Chi-square test. *Significant value

4. Discussion

This study assessed the impact of home health care programs on physical and psychosocial aspects, self-efficacy, family social function, and overall quality of life of families in East Java Province, Indonesia. The results revealed improvements in the physical aspects of families during the physical distancing period through home health care. Risk factors for exposure to and personal risk factors of COVID-19 decreased, while sleep needs and physical activity notably increased with the implementation of home health care. Furthermore, self-efficacy, family social function, and quality of life demonstrated improvement over the one month of home health care. This program helped families adapt to a new lifestyle in fulfilling their ADLs. However, the BMI also increased during this time.

The findings of this study identified a decrease in the proportion of individuals exposed to COVID-19 risk factors through home health care. This might occur because individuals were starting to develop awareness regarding the necessity of physical restrictions during the COVID-19 pandemic. Health education sessions conducted by professionals during this period helped families understand how to improve ADLs. This education, delivered during home health care, enhanced individual knowledge (Ashton & Oermann, 2014) about recognizing COVID-19 and its transmission. Thus, individuals began to develop new behaviors, such as reducing physical contact outside the home (Directorate General of Disease Prevention and Control, 2020) and maintaining personal hygiene by regularly washing hands and using masks during activities outside the home (Razi et al., 2020). Therefore, home-based socialization concerning COVID-19 is essential for minimizing families' exposure to risk factors and personal risks.

The study also revealed that the need for family physical activity increased during home health care. Health education provided during home health care sessions made families aware of the importance of ADLs. It is possible that the families began to realize the need for fitness and health during the COVID-19 pandemic (Jakobsson et al., 2020). This aligns with increased family sleep duration (Gulia & Kumar, 2020). Families acknowledged that exercise (Jakobsson et al., 2020) and sleep-rest balance (Gulia & Kumar, 2020) could improve immunity and overall health, thereby preventing the transmission of COVID-19. For this reason, families have begun regulating the need for rest and sleep at night and implementing a healthy community movement by doing a minimum of 15-30 minutes of moving exercises per day (Ministry of Health, Republic of Indonesia, 2017). However, there was a notable increase in family BMI. This could be attributed to the increased time families spend at home due to remote work and increased sleep needs. Therefore, the home health care program should anticipate potential future incidences of obesity during the physical distancing period.

This study also observed a positive correlation between home health care and enhancement of self-efficacy in participants. The personalized nature of care plans, coupled with education on self-management, empowered individuals to take an active role in their health. They exhibited increased confidence in managing their health conditions, adhering to prescribed treatments, and making informed decisions about their wellbeing. This aligns with previous research indicating that self-efficacy plays a crucial role in fostering positive attitudes and enhancing job performance among care workers (Cheng et al., 2023). Thus, by offering support, training, and resources to the families, home health care can contribute to the cultivation of their self-efficacy, subsequently leading to improved patient care and outcomes (De Maria et al., 2021).

Our findings identified that family coping strategies remained high before and after the home health care mentoring. This mentoring sustained the families in understanding and carrying out ADLs to improve their health. This also allows families to develop new values for healthy living during the COVID-19 pandemic (Wu et al., 2020). This is indicated by the significant increase in family self-efficacy during the personal distancing. Families learn with facilitation from internship students through learning healthy lifestyles so that they become psychologically comfortable with the stressors they are currently facing (Cao et al., 2020). For this reason, families with intensive assistance can develop good life values related to the stressors they face.

The families in this study were able to improve their social function significantly during home health care assistance. This improvement is probably because, during the physical distancing period, families have much time to interact with other family members at home (Hillis et al., 2010). Moreover, the families were able to fulfill their spiritual activities effectively with home health care support. By engaging in collective worship activities with other family members, the families can increase the functionalization of family values. This positive impact facilitated

families' time together, carrying out activities collectively during the physical distancing period (Dalmida et al., 2011; Sauer-Zavala et al., 2014). Furthermore, the quality of family life increased significantly during the physical distancing period with home health care support. The dimensions of the family life quality improved during the home health care program, aiming to establish new family life arrangements during the COVID-19 pandemic. Facing the COVID-19 pandemic, the implementation of home health care by nurses has become increasingly vital as an alternative to providing home health care for patients requiring ongoing monitoring or treatment. While loneliness, spiritual activity, and coping strategies are significant for individual wellbeing, they might not directly influence nurses' implementation of home health care. This is primarily because implementing home health care hinges more on medical expertise, clinical protocols, and infection prevention measures. Although loneliness might affect a patient's desire to receive home health care, spiritual activity, and coping strategies pertain to how individuals handle stress or seek meaning in challenging situations (Nurdiani, 2019; Rafiyah et al., 2011). Hence, while these three factors might influence a patient's quality of life and their response to care, they likely do not impact how nurses execute their clinical duties in the context of home health care during the COVID-19 pandemic.

5. Implications and limitations

The study's outcomes highlight the beneficial effects of home health care on various aspects of familial wellbeing during the COVID-19 pandemic in East Java, Indonesia. Enhancements were observed in the physical and psychosocial aspects, self-efficacy, family social function, and quality of life (OOL) of the families after the intervention. The research suggests that the intervention, facilitated by trained internship students, played a pivotal role in fostering adaptive coping mechanisms, promoting healthy lifestyles, and instilling family values during physical distancing. Nevertheless, the noticeable rise in family BMI signals a potential concern, emphasizing the necessity for the home health care program to address and monitor potential obesity issues arising from prolonged periods of remote work and increased sleep requirements. Moreover, the positive association between home health care and heightened self-efficacy suggests that personalized care plans and self-management education contribute significantly to empowering individuals in effectively managing their health. The implications of the study underscore the importance of sustaining and adjusting home healthcare interventions to support families in navigating the challenges posed by the COVID-19 pandemic, with a focus on addressing emerging health concerns and sustaining positive lifestyle changes. This study, however, has certain limitations. This research, serving as a pilot study for managing COVID-19 infectious diseases through home visits, requires further development to expand interventions into larger-scale RCTs applicable to similar infectious diseases in the community.

6. Conclusion

This study showed that implementing home health care during physical distancing affected the decrease in physical aspects such as blood pressure, pulse, temperature, risk factors for COVID-19 exposure, personal risk factors, sleep needs, and physical activity. Moreover, self-efficacy, family social function, and the family's quality of life improved during one month of home health care. This program facilitated the adoption of ADLs by families. Therefore, guidance and coaching provided through home health care should be developed to assist families in adapting to the new normal era of COVID-19. Future research should focus on enhancing home health care in families by comparing the physical distancing period with the new normal era of COVID-19.

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Author contribution

All authors (TS, RAY, EAS, FD) contributed substantially to the study design, data collection, data analysis, and manuscript preparation. All of the authors have agreed and approved the final manuscript.

Conflict of interest

There is no conflict of interest in this study.

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ORIGINAL RESEARCH

Physical Well-Being Needs of Bone Cancer Patients during Treatment in the Hospital: A Qualitative Study



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Abstract

Background: Bone cancer patients undergoing hospitalization require support to manage physical challenges for optimal healing and recovery. The physical aspects experienced by the patients significantly affect their physical well-being. Addressing these aspects is essential for nurses in providing care. However, comprehensive assessments of bone cancer patients' physical needs have not been thoroughly explored.

Purpose: This study aimed to explore the physical well-being needs of patients with bone cancer undergoing hospitalization.

Methods: This qualitative study with a phenomenological approach was conducted among 14 bone cancer patients selected through purposive sampling. The criteria included patients with a primary cancer diagnosis, undergoing hospitalization at a cancer center, and having good orientation and verbal communication abilities. Indepth interviews were employed to delve into the patients' well-being needs. To triangulate the data, 12 cancer nurses were involved. Data analysis utilized the Creswell method.

Results: This study found chronic pain and bone lumps as fundamental physical challenges, leading to disruptions in physical movement, sleep disturbances, and dependency on others for self-care. Six themes emerged regarding the physical wellbeing needs of hospitalized bone cancer patients: goals and needs for physical wellbeing, need for pain management, need for physical mobility, need for sleep and rest, need for self-care, and the meaning of physical well-being for patients. Physical well-being provides a significant meaning in achieving nursing goals.

Conclusion: This study shows the significance of addressing pain management, physical mobility, sleep and rest, and self-care for the physical well-being of bone cancer patients. Nurses should be able to identify various physical complaints and help improve the physical well-being of bone cancer patients.

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1. Introduction

Bone cancer is a relatively rare disease, usually affecting the long bones of the arms and legs (Hernandez et al., 2018). According to the World Health Organization, the highest incidence of bone cancer is osteosarcoma, which occurs in around 4–5 per 1,000,000 inhabitants of all populations, and it is estimated that 1,072–1,340 new patients occur per year (Prabowo et al., 2020). The incidence of bone cancer continues to increase, reaching 8–11 cases per 1 million population per year in the age range of 15–19 years (Dewi, 2017; Kamal, 2020). Research shows that the incidence of primary malignant bone cancer in China reached 11,655 from 2000 to 2015 (Xi et al., 2023); meanwhile, the incidence of bone cancer of osteosarcoma type at Dr. Cipto Mangunkusumo Hospital, Indonesia, reached 219 cases (16.8 cases per year). Osteosarcoma is the most common type of bone malignancy (70.59%), followed by chondrosarcoma, Ewing's sarcoma, and chordoma (Kamal & Prasetyo, 2018).

The prevalence of cancer in Central Java, Indonesia, is higher than in other provinces, namely at 2.11% or 132,565 cases (Ministry of Health Republic of Indonesia, 2018). The comparison of

bone cancer in men and women is 3:2. Primary bone cancer occurs in adolescents in the second decade of life, and 60% more occurs in those under 25 years of age (Ferguson & Turner, 2018). The incidence of bone cancer increases at the age of 60 years with a bimodal distribution. Secondary bone cancer develops in adulthood due to the spread of cancer cells to bone tissue (Kamal, 2020; Prabowo et al., 2020).

The diagnosis and management of bone cancer require a multidisciplinary approach, including the role of nursing and medical oncology. Hospital health professionals are expected to play an optimal role in providing good healing (Kaasa et al., 2018). Treatment of bone cancer in medical care includes surgical amputation, chemotherapy, or radiotherapy using high-energy radiation (Bala et al., 2020; Ministry of Health Republic of Indonesia, 2018). Bone cancer patients experience various complaints that cause a decrease in well-being. This problem affects the emergence of further health complaints in various dimensions of life, affecting the patient's ability to be independent in daily activities (Keilani et al., 2019). Decreased physical condition is related to changes in daily activities and physiological responses to illness and its treatment (McManimen et al., 2019).

Bone cancer patients may experience limited self-care, resulting in decreased quality of life and impaired physical, psychological, and spiritual well-being (den Hollander et al., 2020). The physical problem most often felt by cancer patients is discomfort in the form of sensations like pain. The pain that the patients feel can impact impaired physical mobility, decreased self-care, and disturbed sleep and rest (Martins et al., 2019). Furthermore, impaired physical well-being can worsen the condition of cancer patients, leading to a decrease in life expectancy. Physical complaints can trigger psychological stress that interferes with thoughts and unpleasant feelings in dealing with illness, thus affecting psychological adjustment (Martins et al., 2019). Changes due to the inability to deal with stress can result in the development of disease and the complexity of problems. Various medical care efforts include the administration of analgesic drugs to reduce pain and symptoms (Coleman et al., 2020).

The oncology treatment requires optimizing the hospital nurses' role to identify patients' needs and improve their well-being during the treatment period (Hasselaar & Payne, 2016). Their role is crucial, especially in meeting the various needs of the patients. Likewise, doctors and healthcare teams, including nurses, also have an important role in improving the well-being of patients and families. As the healing concept approach is holistic and comprehensive, utilizing the basic principles of various sciences and involving the role of the healthcare team on an ongoing basis is necessary (Martins et al., 2019; Singer et al., 2017). Hence, efforts must be made to establish relationships between nurses and healthcare teams with individuals and families in identifying priorities and integrating possible therapies from various disciplines and traditions (Istambouly, 2021; Smith & Oeffinger, 2020).

A preliminary study conducted by the researchers in three cancer hospitals in Central Java, Indonesia, has established the foundation for understanding the challenges faced by bone cancer patients. This investigation revealed an average incidence of 1-4 bone cancer cases per month in these hospitals, comprising 25% primary cases with an average age of 10-30 years and 75% secondary cases with an average age exceeding 45 years. Notably, the majority of patients were males, Muslims, and worked in the private sector. The identified physical well-being problems included chronic and fluctuating pain, impaired physical mobility and self-care, and sleep disturbances. Pain was found to be a major problem that resulted in other physical complaints, and narcotic analgesics such as morphine were given to patients with moderate to severe pain. The non-pharmacological approach used relaxation and distraction techniques, such as deep breathing, taught by nurses without structured guidance, monitoring, or evaluation both before and after the procedure. If the pain were not treated in a special condition, it would be further referred to the pain management team, consisting of anesthesia consultants and nurses.

Despite the evident complexity of physical problems, assessments of physical needs have not been thoroughly and specifically explored in the existing literature. This gap in knowledge becomes a focal point, especially concerning the role of nurses in delivering comprehensive nursing care. The necessity for more concrete nursing interventions tailored to address the diverse life-dimensional problems threatening the physical well-being of patients, particularly those with bone cancer, emerges as a critical concern. Recognizing physical well-being as a principal indicator in nursing services emphasizes the urgency of obtaining patient-experience-based information. In light of this, a phenomenological study focused on the physical well-being needs

of hospitalized bone cancer patients becomes imperative. Such a study is essential to provide a comprehensive overview and a foundation for delivering optimal services that meet the specific physical needs of this patient population. Accordingly, this study was conducted to explore the physical well-being needs of patients with bone cancer undergoing hospitalization.

2. Methods

2.1. Research design

This study employed a qualitative descriptive design with a phenomenological approach, according to Vagle (2018). The study aimed to explore in-depth the physical well-being needs of bone cancer patients. The reporting of the results of this study used the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist (Dossett et al., 2021).

2.2. Setting and participants

This study was conducted among bone cancer patients from three major referral hospitals in Central Java, Indonesia, who were selected using purposive sampling. The inclusion criteria were patients with bone cancer undergoing hospitalization in the adult care room at the hospital's cancer center, who had good orientation and could communicate verbally. Data saturation was reached in the 12th participant. However, the researchers added 2 participants to strengthen the data and confirm additional data in patients undergoing surgery, chemotherapy, and radiation therapy. Therefore, a total of 14 patients participated in this study.

2.3. Data collection

This study was conducted over four months, from November 2021 to February 2022, with 14 bone cancer patients. Before collecting data, the research team submitted research permits to the three research hospitals. The researchers also coordinated with the hospital's education and research divisions and presented the research feasibility test to the hospital ethics committee, the head of the medical and nursing services division, the doctors in charge, and the cancer nurses at the hospitals. After obtaining research permits from the hospitals, the researchers coordinated with the person in charge of cancer care for the data collection process.

The data were collected through in-depth interviews that lasted approximately 60 minutes for each participant. Interviews were conducted in bone cancer treatment rooms in three referral hospitals in Central Java. The researcher made audio recordings with MP4 during the interviews. Investigative questions were asked by the principal investigators (PP) during the interviews. Prior to data collection, the research team provided participants with written forms containing research information, written consent, and interview guidelines when they met at the hospital. All selected participants gave written informed consent. The in-depth interview guide utilized twelve openended questions developed by the researchers during the data collection (Table 1). Strategies suggested by Creswell and Creswell (2017) and Fain (2020) for producing qualitative research data through interviews, observation, narratives, and focused discussions were considered during data collection.

Table 1. Question guidelines

List of Questions for the Participants

- Can you tell me about the physical complaints that you felt while in the hospital?
- Please tell me, how is your current physical condition?
- How was your physical well-being during your stay at the hospital?
- How do you currently feel your need for physical well-being?
- How will your strategy improve it?
- How does it impact the complaints you feel?
- Do you report physical complaints to the nurse?
- What is the nurse's response?
- Does the nurse meet your needs?
- What are your hopes for physical well-being while in the hospital?
- How do you think nurses should address the need for physical well-being for bone cancer patients?
- What does physical well-being mean to you?

2.4. Data analysis

Qualitative data analysis was carried out simultaneously with data collection based on findings. The researchers reviewed the results of the interviews and identified interview needs by developing, verifying, and adding descriptions of the phenomena. The interview data on the tapes were transcribed into a verbatim narrative accompanied by notes on nonverbal responses by the researchers (PP, BB). Other researchers (DB, AFK) analyzed significant statements, concluded the meaning, and developed essence descriptions. The researchers also identified important statements and made special notes on data management. Concerning the data interpretation, the researchers studied the data and read explanations of phenomena word by word. They extracted important statements by marking or shading with different colors based on the category, subtheme, and theme, described and interpreted the meaning of statements in the context of the verbatim of each informant, as well as organized sets of meaning into theme groups (Bengtsson, 2016; Kenny et al., 2020).

2.5. Rigor/trustworthiness

In this study, the researchers built trust through credibility, transferability, dependability, and confirmability. In terms of credibility, the researchers ensured that the research steps were in accordance with the researchers' competencies. The primary researcher is a medical-surgical nursing specialist nurse who has specialized competencies in managing cancer cases. Regarding transferability, the data could be applied to larger population conditions. The researchers selected participants from three referral hospitals with bone cancer patients from different regions so that they could represent the population. In terms of dependability, if the same method is used with the same participants, the same results will be obtained. The researcher used the same method with each participant so that accurate information was obtained. In terms of confirmability, the researchers' objectivity recognized the confidence to make decisions; they objectively conducted the research without any conflict of interest with certain parties.

Furthermore, Creswell and Creswell (2017) state that to build trust in research results, source validation is needed through collecting data on topics from different sources. Nurses' experiences are very helpful in validating data findings from the participants because they have an important role in providing direct care to patients for 24 hours. They also understand various complaints and physical conditions of patients. In addition to bone cancer patients, the researchers involved 12 nurses and the person in charge of the cancer treatment room to validate the data. The collected data were validated through focus group discussions (FGDs) to obtain information from nurses' experiences in providing bone cancer care.

2.6. Ethical considerations

This study received ethical approval from the Ethics Committee of the Faculty of Nursing, Universitas Indonesia (No. Ket-239/UN2.F12.D1.2.1/PPM.00.02/2021) and also the Ethics Committee of the hospital where the study was conducted. Potential participants were informed about the study's objectives, and their participation was voluntary, with the right to refuse and maintain confidentiality. Those participating voluntarily were instructed to choose a pseudonym to protect their anonymity. The voluntary response implied continued consent to participate.

3. Results

3.1. Characteristics of the participants

As shown in Table 2, the majority of participants were males aged 18-65 years old, with high school education, and identified as Muslims. Most participants had primary bone cancer and underwent surgical management, with a history of being in the hospital three or more times.

3.2. Analysis of findings

The findings of this study revealed six themes: (1) goals and needs for well-being, (2) the need for pain management, (3) the need for physical mobility, (4) the need for sleep and rest, (5) the need for self-care, and (6) the meaning of physical well-being for the patients.

3.2.1. Theme 1: Goals and needs for well-being

The participants in this study stated that they wanted the disease to recover quickly, not get worse and stay healthy. The well-being needs that participants expected during hospitalization

64.3

were the basic needs, which included eating, drinking, and assistance from family and nurses. This can be seen from the expression of Participant P1: Don't think too much about the illness you are experiencing so that it doesn't get any worse. Eat, drink, and get help from those closest to you (P1). Similarly, another participant said: Everyone is good here, providing help to be healthy (P4). Furthermore, Participant 7 had the expectation as follows:

Get well soon and be able to return to your activities. There are complaints of being sick, complaints of being bored; why do you have a disease like this so that it doesn't have to be medically cured? I wish I didn't have to undergo medical treatment. I don't have to have surgery because I'm afraid of surgery. (P7)

•	•
f	%
11	78.6
3	21.4
4	28,6
9	64.3
1	7.1
12	85.7
2	14.3
14	100
13	92.9
1	7.1
10	71.4
2	14.3
2	14.3
5	35.7
	11 3 4 9 1 12 2 14 13 1 10 2 2

Table 2. Demographic characteristics of the participants

3.2.2. Theme 2: Need for pain management

≥ three times

Most patients required treatment due to complaints of pain, including details such as onset, pain quality, time of occurrence, and pain intensity. Pain predominantly occurred at night, triggered by activity and surgery. The perceived quality of pain ranged from the most potent pain, throbbing, to a decrease in pain when going to sleep and in cold air at night. On a scale of 5-7, the average pain level fluctuated until it began to interfere with sleep and rest. Patients expressed hope that pain could be alleviated and managed through their own efforts, as well as the efforts of their families and the healthcare team, including nurses. Some participants stated: I feel the pain every night until I can't sleep, and it comes and goes..., given drugs and injections by nurses (P1); If the pain is excruciating, I compress it using warm water at home, and if I give a pain drug, it can heal (P3); When I was tired, I felt pain. After surgery, the pain was less severe and sedentary, and sometimes the pain increased due to fatique (P4); I had night pain, I could not sleep anymore, and I was given painkillers from the hospital and traditional medicine from home. I can endure the pain by stroking the affected area (P5); Since the last 4 months, I have been complaining of pain. The lump got bigger, and the pain spread to my waist, so I had to be hospitalized. I was given painkillers and vitamins for the bones (P6). Other participants also expressed the following:

I often feel pain from here to here (while pointing to the painful area). It started to swell a little, and now the swelling has been about six months. The pain has decreased. I took the herbal medicine for two months. (P7)

At first, it was painful, and then I had difficulty walking and limping, and over time, it got bigger. There was pain, tingling, and heaviness. Every night and morning, I suddenly felt pain. While in the hospital, I was injected with painkillers. (P8)

After surgery, the pain disappeared. When pain occurs, I go to the doctor and am given medicine such as capsules. The pain occurs in cold weather, in the morning, at night, and when I walk long distances. It is excruciating to sleep. (P10)

Additionally, two other participants stated: *I can't walk anywhere*; when *I lie down like this, when I want to stand up, I often feel like I am being electrocuted* (P9); *Pain is often felt in the morning or at night before going to bed; it is slightly less if I rub it* (P11).

3.2.3. Theme 3: Need for physical mobility

The participants stated that their physical movement was disrupted, so they needed the support of their families and nurses to improve their mobilization skills. Participants wanted help with daily activities, such as eating, drinking, walking, elimination, and personal hygiene, as well as reducing fatigue. This can be seen in the expression of Participant 1, as follows:

Moving is still possible but limited. Activities, such as sports, can be decreased. There was no problem at the hospital. If at the hospital, I often slept, ate, and went to the bathroom; thank God I could walk, but I had to be helped. (P1)

Meanwhile, some other participants revealed: Before the big lump, the movement was not disturbed at all; now, I needed help from family and nurses because I couldn't move too much. (P4); If I bend my knee, it hurts; usually, I can squat, but now I can't; then, when I stand, I only use one leg, and I get tired because I only have one leg (P5); At the moment, I can't walk, and I have to use assistive devices, but it just so happens that I didn't bring them from home. Yesterday, I was advised to use a cane (P6). Other participants stated: Now, the movement is limited, less free to move; it was made to hold it beforehand, but now it's a bit difficult (P7); The legs are sometimes difficult to move, and it is a bit difficult to move for too long, so I have to use U-shaped crutches (P9); When it's cold, in the morning, at night, when I walk, my legs feel longer, it's sometimes difficult to move, and I have to ask my family for help (P11).

3.2.4. Theme 4: Need for sleep and rest

The majority of participants needed adequate sleep and rest because they experienced sleep disturbances and wanted various efforts to be able to sleep. This can be seen in the expression of Participant 1 below:

Before the chemotherapy, the pain got worse every night, so I couldn't sleep. I was made to sit down, and then the pain disappeared. Then, when it was 12 o'clock onwards, the pain disappeared on its own. I could sleep because I was given drugs and injections. (P1)

This is almost the same as what Participant 12 said: The pain started around 7 p.m. I woke up at 11 p.m. and stayed until 2 a.m., and I didn't sleep again. Often, I wake up because of sudden pain, I play my cell phone so that I can sleep quickly (P12). While some other participants revealed: When it hurts, I can't sleep. Sometimes, I cry and scream at night. I try to walk even in the middle of the night, so I forget. After I get tired, I can sleep (P3); I can't sleep because of pain, I can't sleep because of myself, not because of the environment, and I often use drugs from the hospital so I can sleep (P4); I can rarely sleep well at night, but if I take it, I can sleep at night (P9).

3.2.5. Theme 5: Need for self-care

Most participants needed help with self-care and daily fulfillment of nutrition, fluids, hygiene, and elimination. They were unable to care for themselves, needing help from nurses, wanting to be independent, and not getting tired quickly. This can be seen from the participants' expressions, such as: *I am not disturbed*, *I am still able to take care of and care for myself*, *still*

able to wear clothes... They feel disturbed, maybe because they can't be free to do activities (P1); I can still be independent, I can still do things by myself, although not one hundred percent, like bathing. I can't clean it under certain conditions (P3). Other participants also stated: I can use my right hand, but it is now a little difficult to hold it. My ability to perform activities has decreased, and sometimes I need help (P7); I can still do activities but with support. I can still eat and drink alone (P8); I often ask for help from my family when going to the bathroom. My family has to prepare my clothes because I am not mobile (P13). Every day, I need help from my family to bathe, change clothes, and eat. Even now, I haven't bathed for two days (P14).

Furthermore, participant 2 also expressed the need for self-care as follows:

I have to use a wheelchair. I can't bathe, but I can eat by myself. However, I still need help from my family. After the second chemo, I don't vomit often, but my Hb has decreased, so I am weak and tired easily. (P2)

3.2.6. Theme 6: The meaning of physical well-being

The meaning of physical well-being, according to the participants, is being healthy and feeling comfortable, not experiencing complaints of pain, and being cared for and assisted with their physical needs. The participants expected to be given care and treatment so that the disease is resolved immediately, wounds heal quickly and no complaints arise that interfere with comfort. This can be seen from the participants' expressions, such as: *Hopefully, the problem of cancer will be resolved. I feel less prosperous. My family is less well-off, and there are no symptoms of the disease (P5); Well-being means no complaints of pain or comfort, because they have not achieved all their goals, this disease results in less activity and less income.* Participants 7 and 10 stated: *He recovered quickly and could return to his activities* (P7); *Well done, I've been treated. Suppose you take it before you are less prosperous. Everything is complete* (P10). Another participant also stated: *It wasn't as prosperous as it used to be. The wound was like blooming, so the bandage was often changed. Well-being was made to relax, and the staff took care of the patient. That was good, that was enough* (P9).

4. Discussion

This study explored the physical well-being needs of patients with bone cancer undergoing hospitalization. The findings revealed six themes, including the goals and needs for well-being, the need for pain management, the need for physical mobility, the need for sleep and rest, the need for self-care, and the meaning of physical well-being for patients. Each theme is discussed in the following section.

4.1 Goals and needs for well-being

The participants in this study expressed their aspirations for well-being, outlining specific goals and needs. Participants wanted food and drink and assistance from family and nurses. Conversely, when contemplating their needs during hospitalization, participants emphasized the importance of swift recovery, preventing deterioration, and maintaining overall health. Research by Nayak et al. (2017) underscores the challenges faced by cancer patients, one of which is due to the emergence of various complaints and worsening physical conditions. Participants expressed their desire to address the symptoms and complaints they experienced, such as pain, fatigue, and discomfort. This is in accordance with the suggestions of Martins et al. (2019) that having adequate food and drink needs is beneficial for maintaining health and energy, as well as attention and support from family and caregivers, and meeting physical needs and medical care. For individuals with bone cancer, the expressed need for proper nutrition during treatment underscores the critical role of adequate and nutritious food and drink intake. Adequate nutrition can help strengthen the immune system, speed recovery, and maintain overall health. This is in accordance with Fauske et al. (2015), who state that patients want a quick recovery so that their health condition does not worsen while in the hospital.

Therefore, nurses should pay attention to the patient's eating and drinking needs while undergoing treatment in the hospital. Forms of attention from families and nurses include emotional support, attention, and care provided by the family and health team. Participants stated

that the presence and assistance provided by those closest to them, including family and nurses, would provide a sense of comfort, reduce anxiety, and raise the spirit to recover. This is reinforced by Tønnessen et al. (2020) that health practitioners, including nurses, need to provide attention and support to patients and ensure that patients' food and drink needs are met. Therefore, help and support from family, friends, nurses, and other health workers can improve the patient's physical well-being.

4.2 The need for pain management

The findings showed that the main complaint of bone cancer patients is discomfort. Pain is the most common problem that patients complain about in the hospital. It is the most disturbing complaint in bone cancer patients. Several important aspects about this complaint include the onset of pain, the quality of the pain, the time it occurs, and the level of pain. Most participants stated that pain complaints often occurred at night and could be triggered by activities or the effects of surgery. Martins et al. (2019) in their research revealed that cancer pain is the worst pain experience in the lives of cancer patients. This finding is in accordance with research by Abbas and Rehman (2018), which states that the most common problem of cancer patients is discomfort, such as pain that comes from pressing cancer cells, surgery, chemotherapy, radiotherapy, and the possibility of infection.

Pain is caused by suppressing cancer cells in the bone tissue and its surroundings. Pain can originate from cancer itself as these abnormal cells grow and damage surrounding tissue (Wang et al., 2020). The pain that is felt gets worse and worse as the cancer grows. Cancer that continues to grow will cause pressure on nerves, bones, or organs, causing pain. Pain can come from chemicals released by cancer cells. Cancer pain is the most common source of pain, along with the spread of cancer in the bones and other organs (Zhu et al., 2015). The most common pain in bone cancer is that pain often occurs in multiple areas, which can be acute and chronic. Pain fluctuates from mild to severe to unbearable. Pain can appear suddenly, last a short time, or last longer. The pain that arises is also very diverse, ranging from a feeling of pressure, aching, soreness, burning sensation, or like being stabbed by a sharp object. There are various triggers for pain; some come and go intermittently, some are painful only during activities, and some arise continuously (Zajączkowska et al., 2019; Zhu et al., 2015).

Bone cancer pain often responds well to opioids, although doses are required to reduce pain. However, one difficulty in controlling this intermittent pain is that it produces various side effects and can reduce the quality of life (Mantyh, 2013). In addition, pain is an unpleasant sensory experience that can lead to other problems. Previous research shows that after recovery action, pain complaints can be felt to decrease. However, a combination of interventions/actions, such as chemotherapy, radiation therapy, administration of anti-inflammatory agents, narcotics, and drugs aimed at the central nervous system, often cannot eliminate pain permanently (Ahmad et al., 2018).

Cancer patients feel pain due to various factors, such as the location of the cancer and the cause of cancer, including the side effects of treatment. In addition, pain can arise due to side effects of cancer treatment, such as chemotherapy, healing, and drugs (Chu & Sartorelli, 2018). According to Ferguson and Turner (2018), pain in patients with bone cancer is the most common problem, and most complaints about the level of pain experienced by a person can vary because it is influenced by several factors, such as the type of cancer suffered, the stage and the patient's sensitivity to pain.

4.3 The need for physical mobility

The findings showed that most of the patients experienced impaired physical mobility. Bone cancer most often attacks the long bones in the body, and 95% of bone cancer occurs in the extremities, namely the feet and hands. Along with the increase in cancer mass, there will be changes in the shape and length of the bones, resulting in impaired movement function. That happens because of the growing mass, resulting in increased bone weight, joint space pressure, and decreased muscle strength (Heymann, 2014). Impaired physical mobility can be caused by decreased muscle strength, joint stiffness, musculoskeletal disorders, and pain (Biermann et al., 2013).

Physical movement is an individual's ability to move freely, quickly, and regularly to fulfill activity needs to maintain health. Participants stated that they had limited mobility, were unable

to walk, depended on mobility aids, lacked freedom of activity, and needed assistance or assistance with mobilization from family or caregivers. According to research by Martins et al. (2019), extensive surgery has a major impact on mobility, with reduced strength, instability, loss of flexibility, and poor balance. Therefore, they need to use technical aids for their mobility, such as crutches or canes or a wheelchair or mobility scooter. Functional disorders cause major disruption in every aspect of life. This is reinforced by Zhu et al. (2015), who explained that the cancer growth in the bones results in increased bone weight and space pressure in the joints, which can disrupt joint stability and reduce muscle strength. More flexible physical movement will increase self-reliance, improve health, and slow down disease processes, especially degenerative diseases, through homeostatic processes, both physiological and psychological (Heymann, 2014). Impaired physical mobility is a limited physical movement of one or more extremities independently. With conditions like this, patients tend to be bedridden more often, unable to carry out activities. In addition, patients often experience difficult situations moving, so they need help from other people in their activities (Tsuzuki et al., 2016). The impact of impaired physical mobility can affect body systems, such as changes in body metabolism, fluid and electrolyte imbalances, disturbances in nutritional requirements, impaired gastrointestinal function, changes in the respiratory system, changes in the musculoskeletal system, skin changes, changes in elimination (bowel and small bowel movements), and changes in behavior (Tsuzuki et al., 2016; Zajączkowska et al., 2019).

4.4 The need for sleep and rest

The findings showed that most of the participants experienced sleep disturbances. Rest disturbances are often triggered by complaints of pain at night and in the morning. Sleep as a physical need is essential for patients because it allows muscles to rest. Participants revealed that they experienced sleep disturbances due to pain. They have difficulty getting to sleep and often wake up at night. These findings indicate that participants needed more effort to start sleeping and get a good quality of sleep.

According to Cheville et al. (2021), when the patient sleeps, it will positively impact the work of the body's organs, including muscles, given the opportunity to rest. Each patient has different habits of starting to sleep and waking up. Everyone has a sleep-wake cycle that determines the right time to sleep. Several factors, including the emergence of complaints of pain, can support this time (Ancoli-Israel, 2015). Participants revealed that they experienced sleep disturbances due to pain. They have difficulty getting to sleep and often wake up at night. These findings indicate that participants needed more effort to start sleeping and get a good quality of sleep. According to Mogavero et al. (2021), when patients sleep, it will positively impact the work of the body's organs. According to Jacobs et al. (2016), patients with regular sleep-wake patterns show more quality of sleep and better performance than those with irregular patterns who are given the opportunity to rest. Each patient has different habits of starting to sleep and waking up.

Pain can awaken a person from regular sleep, prevent sleep, and contribute to energy loss or fatigue. Quality of sleep is needed for bone cancer patients who are undergoing treatment at the hospital. Rest is necessary to regenerate and repair body cells. Non-rapid eye movement (NREM) sleep stimulates growth hormone production, which helps repair body tissues. Meanwhile, rapid eye movement (REM) sleep is needed to maintain brain tissue and is vital for cognitive recovery (Jacobs et al., 2016). Quality of sleep serves to help optimize disease healing for bone cancer patients. Sleep quality will affect natural and cellular immune function (von Moos et al., 2017). This is in line with Hermayanti and Setyorini (2018) that sleep disturbances can occur in cancer patients undergoing chemotherapy, namely insomnia and circadian rhythm disturbances. In Indonesia, research publications regarding sleep quality in bone cancer patients have not been found. It is hoped that this research can provide information about the need for sleep and rest to provide information for nurses in nursing services in the hospital (Liu et al., 2019).

4.5 The need for self-care

The findings showed that most patients experienced a decrease in their ability to do self-care. Disease progression and treatment can exacerbate functional status, described as an inability to perform self-care (Valizadeh et al., 2020). Progressive and treatment of bone cancer can cause various side effects that can affect the emergence of more complex physical complaints. Poor self-care ability in bone cancer patients is more involved due to decreased physical mobility. As a result

of the findings, patients experience difficulties preparing food and clothing when going to the bathroom. Movements that are not free result in difficulties in carrying out activities, including taking care of their selves (Coleman et al., 2020; Martins et al., 2019).

The management of treatment side effects requires appropriate nursing interventions. In providing interventions, nurses must involve cancer patients and their families in all aspects of care. In addition, patients must be ready and get support to participate in patient care. One of the needs to fulfill self-care for bone cancer patients is to encourage and empower families to fulfill self-care. Fulfillment of self-care depends on the dependent care agency, namely the ability to meet self-care needs. If the patient does not have an adequate dependent care agency, there will be a decrease in self-care or self-care deficit. Almost every hospitalized patient fulfills his self-care needs with assistance from nurses and their families. However, many families are hesitant or worried about fulfilling self-care needs and expect nurses to help carry out self-care (Cleantis, 2017; Rustøen et al., 2014). Participants expressed that they could not care for themselves, needed help from nurses, and wanted to be independent. This can be explained by the fact that the need for self-care is directly related to limited physical mobility and activity tolerance due to fatigue.

Suppose the patient requires better support from a dependent care agency to carry out self-care; in that case, a self-care deficit may occur. Factors influencing self-care behavior include the abilities and skills of nurses, contributing to the achievement of good self-care behavior. The patient's ability to carry out self-care must be continuously improved by increasing knowledge and providing motivation. Good self-care behavior is emerging based on willingness, inspiration, and sufficient expertise so that a person can carry out daily self-care (O'Regan et al., 2019). In cancer management, nursing interventions that involve patients and families in all aspects of care are needed. This is in accordance with the suggestions of Madsen et al. (2023) that the active role of nurses together with patients and families in every action will increase the success of nursing care.

Bone cancer patients are very susceptible to fatigue due to physical exhaustion because of the long therapy process, including the effects of surgery and chemotherapy. Fatigue is a common symptom that occurs in cancer patients, which can lead to decreased self-care abilities. Fatigue will generally disappear with rest, whereas fatigue in cancer patients will tend to persist even though the patient has rested. The breakdown of free fatty acids from adipose fatty tissue will lead to a buildup of ketones in the body. These metabolic changes cause a decrease in metabolism or interference in ATP regeneration, in which ATP is the primary energy source for muscle-bone contraction. That makes the body feel exhausted because the cells cannot get enough oxygen and nutrients, so they cannot produce enough energy. This condition can trigger a decrease in self-care. Therefore, the role of reasonable physical assistance and management of self-care in hospitals helps the healing process go faster (O'Regan & Hegarty, 2017). This can happen to elderly bone cancer patients, who are more susceptible to fatigue and self-care problems. Therefore, the role of nurses is to help fulfill self-care needs and make patients independent by providing support and health education about the importance of independence in self-care.

4.6 The meaning of physical well-being for patients

The analysis of these findings aimed to understand the participants' perceptions regarding the meaning of well-being and the meaning of well-being while undergoing treatment in a hospital. Several participants expressed their feelings of not being prosperous, less prosperous, not yet prosperous, and prosperous after having their cancer removed through surgery. Participants also expressed views about the meaning of well-being. Several participants stated that physical well-being is a state of health, comfort, no complaints, and physical needs that must be met during treatment at the hospital.

Participants stated that well-being includes all of life's needs having been fulfilled, handled, and supported by the care and medical team. This is in accordance with the study of Fancourt and Finn (2019), which states that the condition of well-being for patients is that they are managed and fulfilled in the medical care and support they receive. Participants gave the meaning of well-being using different terms but referred to the same hope: achieving an optimal level of welfare. Some participants had disturbing complaints and discomfort about their life experiences with the disease and the treatment process they underwent. Some participants stated that they had less well-being because they faced painful symptoms, changes in physical functions, and pain that did

not subside. This provides an overview of the poor conditions experienced by patients due to bone cancer (Martins et al., 2019).

5. Implications and limitations

The findings of this study provide new insights into the physical well-being needs of patients with bone cancer undergoing hospitalization. Individuals with cancer undergo a decline in physical health due to the progression of the disease. The decreased physical well-being becomes a burden for others during hospitalization. Therefore, the nurse's role is to understand and help meet the well-being needs of these patients. This study offers new insights for nurses to provide a basis for better involvement in cancer patients, especially bone cancer. It is recommended that nurses and other healthcare teams assess the main complaints of bone cancer patients. Then, it is necessary to choose the right action in treating bone cancer patients, such as reducing complaints of pain and increasing physical mobility and time to sleep. In addition, strategies need to be developed to increase self-care independence. This can be done to accelerate the patient's healing process to save costs. In addition, discussions are needed between doctors, nurses, and the health team at the hospital to improve the quality of treatment and care for bone cancer patients, including counseling, motivation, physical assistance, attention, and support.

This study was conducted among patients from three cancer referral hospitals of different classes and types, resulting in variations in diagnostic strategies and medical management. Consequently, it yielded distinct patient experiences during the hospital treatment period. At the beginning of treatment, invasive and non-invasive diagnostic examinations were performed, affecting the length of treatment and different experiences for patients. The choice of standardized treatments, whether single or combination therapies, may lead to diverse perceptions and physical responses throughout the course of therapy or treatment. However, this study is limited to the patient's specific views without incorporating the family's opinions. While the patients' experiences provide the most current information describing well-being needs, additional insights from the families are valuable, as they may have different experiences while accompanying the patients in the hospital.

6. Conclusion

Nursing care services are expected to enhance recovery and improve bodily function. The physical well-being needs of bone cancer patients include several aspects, such as the need for pain management, increased physical mobility, the need for sleep and rest, and the need for self-care. In addition, nurses must be able to identify various disturbing complaints that can cause complex problems. Therefore, efforts to enhance physical well-being become the focal point of health services during patients' hospitalization. The recommendations for future research involve exploring intervention strategies to address well-being needs in the hospital, aiming for a more optimal healing process. Research endeavors can be conducted utilizing an evidence-based approach through nursing interventions with the goal of enhancing life expectancy.

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Author contribution

All authors (PP, AFK, DD, BB) contributed substantially to the design, data collection, analysis, and interpretation of data. DD and BB contributed to the data coder. AFK contributed to performing data interpretation and discussion. All authors were also involved in drafting or critically revising the manuscript for important intellectual content and providing the final approval. Every author has participated sufficiently on the job to take responsibility for all aspects, and any part of the job was adequately investigated and completed.

Conflict of interest

The authors declared that there is no conflict of interest in this study.

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