Empowerment-Based Palliative Care to Improve Psychological" Well Being and Quality of Life in Women with Breast Cancer

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Empowerment-Based Palliative Care to Improve Psychological Well Being and Quality of Life in Women with Breast Cancer

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A B S T R A C T

Patients with breast cancer at the terminal stage often experience a decrease in quality of life and problems in psychological well-being. Management of patients with terminal illnesses requires end-of-life care, which is comprehensive care for chronic diseases that are nearing death, which involves multidisciplinary collaboration of health workers with the main focus of care being a peaceful death. The aim of this research is to develop empowerment-based palliative care to improve psychological wellbeing and quality of life of breast cancer patients.Explanatory research with a cross sectional approach to develop a model. The sample of this study were 125 breast cancer patients. The variables in this study consisted of self- management, delivery systems, decision support, clinical information, community resources, palliative care, empowerment, quality of life and spiritual wellbeing which were measured using a modified questionnaire whose validity and reliability were measured. The data were then analyzed using Smart PLS and used in formulating strategic issues for focus group discussions and expert consultations. The output of this study was an empowerment-based palliative care module on the quality of life and psychological well-being of breast cancer patients as well as scientific publications in the Scopus International journal, a module that already prepared will be arranged in the ISBN and Intellectual Property Rights

INTRODUCTION

End of life care (End of life care) is comprehensive care for chronic diseases that are close to death, involving multidisciplinary collaboration from health workers (de Oliveira Valentino et al., 2020), with the main focus of care being a peaceful death (Krikorian, Maldonado and Pastrana, 2020). A chronic disease that still ranks as the highest cause of deathis cancer with a mortality rate of 20.3% of 23.4% of cancer cases in the world (Tatemichi, 2018). The high mortality from cancer is dominated by breast cancer in women (30%) and prostate cancer in men (20%) (Tatemichi, 2018; American Cancer Society, 2019), this shows that deaths in women from breast cancer are still very high (Tatemichi, 2018; Siegel, Miller and Jemal, 2019).

Deaths from breast cancer increased by 40% (375,900 cases) throughout 1975-1989 inthe World (American Cancer Society, 2019) and in Indonesia the number of cases of breastcancer increased to 43.1% with a mortality rate of 12.9% (Pusdatin , 2015; RI Ministry ofHealth, 2018). The causes of the high mortality rate are due to delays in diagnosis, successfultherapy, accompanying symptoms, complications and psychological status of patients (Chopraand Davies, 2020). One of the problems faced by breast cancer sufferers is readiness to facedeath, resulting in a good quality of life and a peaceful end of life (Chopra and Davies, 2020).

The full end of life of breast cancer patients is influenced by many factors and is holisticin nature, one of which is the patient's psychological well-being and quality of life (Winefieldet al., 2012; de Oliveira Valentino et al., 2020). Based on previous research in South Korea, itwas found that long-term therapy for breast cancer can worsen the psychology and quality of life of patients, the appearance of depressive symptoms in patients increases by 15% after 5 years of diagnosis (Park et al., 2019). Depression in patients appears due to long-term therapythat requires the patient's struggle against the disease, so that it has the potential to cause psychological stress, decreased body image, rejection of disease and a sense of giving up on treatment (Rutherford et al., 2019). This condition is supported by previous research regardingthe quality of life of breast cancer patients in Malaysia, which stated that 15% of patients had a poor quality of life and 25% were dissatisfied with their lives (Dominic et al., 2018).

Psychological well-being and quality of life of breast cancer patients must be consideredby health care providers so that patients have the strength to face the disease (Van Den Block et al., 2020). One form of care that can be given is palliative care (Pallotti et al., 2020). Palliative care has been shown to play a very important role in the care of oncology patients, this treatment involves multidisciplinary care with 8 important domains to improve the qualityof life of cancer patients (Franciosi et al., 2019). The main focus of palliative care is to optimizepatient and family care to improve quality of life by anticipating, preventing and treating suffering holistically (Amano, Baracos and Hopkinson, 2019).

LITERATURE REVIEW

Palliative care has been used worldwide in providing care for breast cancer patients andis still being applied and developed to improve the quality of life of patients (Alshammaray etal., 2019). Based on research on successful situations of palliative care, it shows that chronic diseases who are given palliative care show better clinical outcomes than only given medical therapy, because palliative care pays attention to the patient's biological, psychological, socialand spiritual aspects (Reck et al., 2019). The importance of care for the end of life makes researchers interested in continuing to develop the quality of palliative care (Alshammaray et al., 2019).

Breast cancer patients need high support to increase motivation in undergoing treatment,especially patients who are in an advanced stage (end stage) (Serpentini et al., 2019). Support from partners, family and the social environment can foster patient motivation and confidencein the perceived psychological burden (Kaasa et al., 2018). So far, the treatment of patients forchronic diseases that has been carried out is to involve the family in providing support and reminding patients to routinely undergo therapy. The importance of reminders and patient self-management must be maintained so that the patient's condition does not deteriorate rapidly, sothat active patient participation is needed in an empowerment (Kaasa et al., 2018; Faller et al.,2019).

Empowerment has been recognized as one of the important benefits of individual participation in an active involvement in a program. Breast cancer patients, the majority of whom are women, need support from one another from their peers (McCorkle et al., 2011). The function of peers is to provide motivation, a place to complain and share experiences witheach other to survive against cancer. The integration of peer support in palliative care is very important, but there are no standards governing the role of peer groups, especially empoweringwomen with breast cancer (Toija et al., 2019). The empowerment model developed by CESESMA shows that there are three important factors in the success of an empowerment, namely capacity, conditions/opportunities, and self-confidence (Shier, 2019).

Palliative care in breast cancer patients must pay attention to the importance of caring forpatients with chronic diseases. The chronic patient care model or Chronic Care Model (CCM)is a model of care used and developed to provide care for chronic diseases, including breast cancer. CCM involves linking the health care system with the community in the implementation of the model, through health workers. The goal of CCM is to improve the clinical and functional outcomes of disease management through productive interactions between patients and healthcare professionals. The six components of CCM are a collaboration of intrinsic and extrinsic elements to strive for the best care for patients (Shier, 2019).

Based on the phenomena found above, palliative care is an important care for the end oflife. The author is interested in developing a palliative care model that is integrated with women's empowerment to improve Psychological Well Being and Quality of Life in Breast Cancer patients.

METHODOLOGY
Study Design
The study used an explanatory design with the aim of developing a palliative care model with empowerment in improving psychological well-being and quality of life of breast cancer patients with a cross-sectional approach, namely a research design in which causal variables are examined and measured at the same time. This research will explore the findings of facts and theories related to factors that can affect palliative care services in breast cancer patients. At this stage factors that influence palliative care will be explored which consist of self- management support (assessment, comfort, communication, reminders, alertness, planning), delivery system design (coordination, timeline, policy, content, network and design), decision support, clinical information system and community resources and policies on psychological well being and quality of life of breast cancer patients.

Population, Samples, and Sampling
The population in this study were breast cancer patients at the Indonesian Cancer Foundation in Surabaya. The research sample was determined by taking into account the following criteria:

1. Inclusion criteria:
a. Patients diagnosed with breast cancer at least 1 month from the results of a diagnostic examination
b. Age 20 – 64 years
c. Willing to be a respondent
d. Can read and write
2. Exclusion criteria:
a. Patients with mental disorders
b. Not willing to fill out the questionnaire

The size of the research sample was determined using simple random sampling, namely by selecting respondents randomly as the research sample.

The sample size calculation is done by setting the Z table value for $\alpha = 0.05$ to be 1.96 and the Z table for β (type II error) of 10% is 1.28. The results obtained from the calculation of the estimated sample size are as many as 122 respondents.

Instruments
The research process requires measuring instruments known as research instruments, the instruments used in this study are:

1) Respondent Demographic Data
Measurement of the demographic data of respondents used a demographic data questionnaire sheet which was filled in briefly by the parents of the children which included the child's initials, age, gender, address, parent's last education, parent's occupation, and flood events in the last 5 years. Demographic data was then recapitulated by researchers and made into the frequency of demographic data.

2) Questionnaire

This study used a research instrument in the form of a questionnaire. The questionnaire is a data collection tool in the form of a list of written questions used to obtain the required information from respondents (Arikunto, 2010). The questionnaire will first be tested for validity and reliability.

Data Analysis

The analysis used is the PLS (Partial Least Square) approach. By using the PLS approach it is possible to model structural equations with a relatively small sample size and does not require multivariate normal assumptions. PLS is a method with strong analysis because it can be applied to all data scales, it doesn't require a lot of assumptions and the sample size doesn't have to be large. PLS besides being able to be used as a confirmation of theory can also be used to build relationships that do not yet have a theoretical basis or for testing propositions.

RESULTS

Table 1. Demographic Factors of Breast Cancer Clients (n=104)

Indikator	Kategori	Frekuensi	Persentase (%)
Umur	26-35 tahun	10	9,6%
	36-45 tahun	32	30,8%
	46-55 tahun	58	55,8%
	56-65 tahun	4	3,8%
Pendidikan	SD	52	50,0
	SMP	19	18,3
	SMA	26	25,0
	PT	7	6,7
Pendapatan	Dibawah UMR	68	65,4
	UMR	15	14,4
	Diatas UMR	21	20,2
Pekerjaan	Ibu Rumah	68	65,4
	Tangga PNS	6	5,8
	Wiraswasta	30	28,8
Status Pernikahan	Belum menikah	7	6,7
	Menikah	66	63,5
	Janda	31	29,8

Table 1 shows that the majority of respondents aged 46-55 years (55.8%), with formal education at least elementary school (50%), income below the East Java UMR in 2019, namely IDR 3,871,052 (65.4%) work as housewives, (65.4%) with married status (63.5%).

- Measurement Model Analysis (Outer Model)

Evaluation of the outer model is carried out by calculating construct validity (convergent test), which is known through the loading factor value and reliability of a construct, each test result is explained as follows:

a. Construct Validity Test (Convergent Test)

Evaluation of construct validity is carried out by calculating convergent validity. Convergent validity is known through the loading factor (λ) value. An instrument is said to meet the convergent validity test if it has a loading factor (λ) above 0.5 and a T statistic above 1.96.

Tabel 2. Research Convergent Validity Testing Results

Variabel Laten	Variabel Observe	Loading Factor	T Value	Cut Off	Keterangan
(X1) Self management support	X1.1 Penilaian	0,956	11,212	0,5	Valid
	X1.2 Kenyamanan	0,834	9,340	0,5	Valid
	X1.3 Komunikasi	0,795	8,889	0,5	Valid
	X1.4 Pengingat	0,913	10,224	0,5	Valid
	X1.5 Kewaspadaan	0,975	12,114	0,5	Valid
	X1.6 Perencanaan	0,784	8,765	0,5	Valid
(X2) Delivery system design	X2.1 Koordinasi	0,820	9,231	0,5	Valid
	X2.2 Timeline	0,713	5,222	0,5	Valid
	X2.3 Kebijakan	0,711	3,467	0,5	Valid
	X2.4 Konten	0,895	9,823	0,5	Valid
	X2.5 Jaringan	0,923	10,374	0,5	Valid
	X2.6 Design	0,985	13,129	0,5	Valid
(X3) Decision support	X3.1 Dukungan Keluarga	0,940	11,987	0,5	Valid
	X3.2 Dukungan Sebaya	0,802	9,765	0,5	Valid

	X3.3 Dukungan Sosial	0,899	10,453	0,5	Valid
(X4) Clinical information system	X4.1 Kondisi Klinis	0,784	7,116	0,5	Valid
	X4.2 Terapi Penyakit	0,750	6,543	0,5	Valid
(X5) community resouces and policies	X5.1 Sumberdaya	0,743	5,122	0,5	Valid
	X5.2 Ketersediaan Faskes	0,793	5,432	0,5	Valid
	X5.3 Situasi Lingkungan	0,965	9,650	0,5	Valid
(X6) Palliative Care berbasis empowerin g	X6.1 Proses caring	0,733	6,225	0,5	Valid
	X6.2 Aspek Holistik	0,856	7,554	0,5	Valid
	X6.3 Perawatan end oflife	0,706	5,502	0,5	Valid
	X6.4 Etik dan legal aspek	0,982	8,345	0,5	Valid
(Y1) Psychologic al Wellbeing	Y1.1 Penerimaan Diri	0,894	7,123	0,5	Valid
	Y1.2 Hubungan positif	0,704	5,887	0,5	Valid
	Y1.3 Penguasaan lingkungan	0,741	6,067	0,5	Valid
	Y1.4 Tujuan hidup	0,813	7,221	0,5	Valid
	Y1.5 Pertumbuhan pribadi	0,722	5,987	0,5	Valid
	Y1.6 Otonomi	0,994	8,876	0,5	Valid
(Y2) Kualitas hidup	Y2.1 Aspek Fisik	0,928	8,423	0,5	Valid
	Y2.2 Aspek Psikologis	0,914	8,012	0,5	Valid

Y2.3 Tingkat Kemandirian	0,755	6,912	0,5	Valid
Y2.4 Hubungan Sosial	0,799	7,886	0,5	Valid
Y2.5 Kesehatan Lingkungan	0,755	6,745	0,5	Valid
Y2.6 Spiritualitas	0,758	6,916	0,5	Valid

The results of construct validity testing using the convergent test (Table 5.9) can be seen by looking at the loading factor (λ) value, where the indicator of a research variable is declared statistically significant or valid in forming or measuring variables if $\lambda \geq 0.5$ and the statistical T value ≥ 1.96 (Lowry and Gaskin, 2014). In Table 5.9, after the outer model was measured, it shows that the results of testing the construct validity of the indicators tested showed that all indicators were valid in forming and measuring latent variables and showed a good measurement model (outer model).

Based on the results of the analysis, it is known that the outer loading value for all latent variables shows a result of $\lambda \geq 0.5$ and a statistical T value ≥ 1.96. Valid variable measurements are self management support, delivery system design, decision support, clinical information system, community resources and policies, empowering-based palliative care, psychological well-being and quality of life.
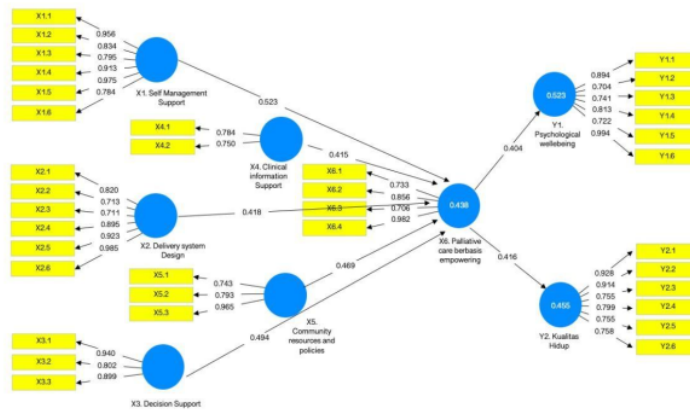

Figure 1. Outer Loading Value for Model Development Research

b. Reliability Test

Composite reliability tests the reliability value of indicators on a variable. Reliability can also be seen from the Average Variance Extracted (AVE). A variable is said to meet composite reliability if it has a composite reliability value of 0.7 and the AVE is above 0.50. The composite reliability and Cronbach's alpha values for each variable can be seen from Table 5.12 as follows:

Table 3. Reliability Test Results of Model Development Research

Variabel Laten	Cronbach's Alpha	rho_A	Composite Reliability	Average Variance Extracted (AVE)
(X1) Self management support	0,891	0,882	0,706	0,726
(X2) Delivery system design	0,905	0,907	0,708	0,744
(X3) Decision support	0,960	0,968	0,755	0,740
(X4) Clinical information system	0,986	0,994	0,917	0,879
(X5) community resouces and policies	0,830	0,827	0,870	0,783
(X6) Palliative Care berbasis empowering	0,977	0,951	0,886	0,899
(Y1) Psychological Wellbeing	0,985	0,977	0,955	0,843
(Y2) Kualitas Hidup	0,975	0,974	0,943	0,899

Table 2 above, namely the reliability test on latent variables, shows that the composite reliability value meets the requirements, namely more than 0.7. Likewise with Cronbach's alpha values > 0.6 and AVE > 0.50. Thus, it can be concluded that all latent variables in the research have met the reliability test.

3. Evaluation of the Inner Model

Evaluation of the structural model or inner model is a stage for evaluating goodness of fit, coefficient of determination, predictive relevance and hypothesis testing. Each is explained as follows:
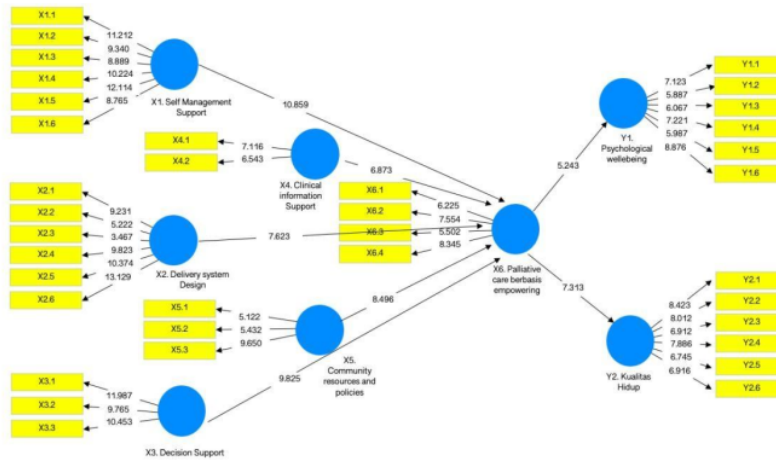
Figure 2. Results of Structural Model (Inner Model) Model Development Research

4. Coefficient of Determination (R2)

The Determination Coefficient (R2) is used to determine the magnitude of the ability of observational variables to explain the diversity of latent variables, or in other words to determine the magnitude of the contribution of observational variables to latent variables. The R-squared (R2) value is used to measure how much influence certain latent variables have on observational variables. According to Chin (1998) in Ghozali (2012: 27), the results of R2 > 0.67 indicate strong model strength; R2 > 0.33 indicates moderate strength and R2 > 0.19 indicates less weak strength (Chin, 1998). The R2 results can be seen in the following table.

Table 4. Results of the Coefficient of Determination (R2) of Model Development Research

Variabel	R Square	R Square Adjusted
(X6) Palliative Care berbasis empowering	0,438	0,432
(Y1) Psychological Wellbeing	0,523	0,552
(Y2) Kualitas Hidup	0,455	0,446

Table 3 shows that the R-square value for the empowering-based palliative care variable Wellbeing can be explained by variables namely self management support, delivery system design, decision support, clinical information system, community resources and policies, empowering-based palliative care at 0.552 (55.2%). Variable Y2 quality of life can be explained by variables namely self management support, delivery system design, decision support, clinical information system, community resources and policies, empowering-based palliative care of 0.446 (44.6%). This shows that the model strength is in the range R2 > 0.33, indicating moderate model strength.

a. Predictive Relevance (Q2)

The Q2 value can be used to measure how well the observed values are produced by the model and also the estimated parameters. A Q2 value greater than 0 (zero) indicates that the model is said to be good enough, while a Q2 value less than 0 (zero) indicates that the model lacks predictive relevance. The following are the results of the Predictive Relevance (Q2) test:

Table 5. Results of Predictive Relevance Testing (Q2) Model Development Research

Variabel	SSO	SSE	Q^2 (=1-SSE/SSO)
(X6) Palliative Care berbasis empowering	840,000	657,415	0,217
(Y1) Psychological Wellbeing	1080,000	244,263	0,433
(Y2) Kualitas Hidup	957,000	623,423	0,359

The results in table 5.14 show that all variables produce Predictive Relevance (Q2) values greater than 0 (zero), which indicates that the model is said to be quite good.

b. Fit Models

Model fit shows that a model meets the criteria seen from the RMS Theta or Root Mean Square Theta value <0.102, SRMR or Standardized Root Mean Square value <0.10 and NFI value > 0.9 (Cangur and Ercan, 2015).

Table 6. Results of Model Fit Testing Model Development Research

	Saturated Model	Estimated Model
SRMR	0,101	0,098
d_ULS	8,313	8,313
d_G	4,903	4,903
Chi-Square	2215,232	2215,232
NFI	0,971	0,971
rms Theta		0,072

In accordance with the model fit image above, the RMS Theta value is 0.072 < 0.102 and the NFI value is 0.971 > 0.9. So based on these two model assessments, the model meets the model fit criteria. Likewise with the SRMR or Standardized Root

Mean Square value, the value is 0.098 < 0.10, so the model fits, so it can be concluded that the model fits the research data.

5. Results of Hypothesis Testing on Structural (Inner Model)

Significance testing is used to test whether there is an influence of the independent variable on the dependent variable. The test criteria state that if the T-statistics value is ≥ T-table (1.96) or the P-Value is <significant alpha 5% or 0.05, then it is stated that there is a significant influence of the independent variable on the dependent variable. The results of significance testing can be seen from Table 5.17 below:

7. Results of Model Development Research Hypothesis Testing

Hipotesis Penelitian	Original Sample (O)	T Statistics (|O/STDEV|)	P Values	Signifikansi
(X1) Self management support -> (X6) Palliative Care berbasis empowering	0,523	10,859	0,004	Signifikan
(X2) Delivery system design -> (X6) Palliative Care berbasis empowering	0,418	7,623	0,045	Signifikan
(X3) Decision support -> (X6) Palliative Care berbasis empowering	0,494	9,825	0,041	Signifikan
(X4) Clinical information system -> (X6) Palliative Care berbasis empowering	0,415	6,873	0,038	Signifikan
(X5) community resouces and policies -> (X6) Palliative Care berbasis empowering	0,469	8,496	0,014	Signifikan
(X6) Palliative Care berbasis empowering -> (Y1) Psychological Wellbeing	0,404	5,243	0,048	Signifikan
(X6) Palliative Care berbasis empowering -> (Y2) Kualitas Hidup	0,416	7,313	0,048	Signifikan

Based on the results of data processing, there is an evaluation of the structural model (inner model) to determine the validity of the model. It is known that all significant hypotheses with the strongest influence are (X1) Self management support -> (X6) Empowering-based palliative care.

DISCUSSIONS

According to Kozier (2014) nursing actions to help clients meet spiritual needs include providing prescence, supporting religious practices, helping to pray or praying, referring clients for spiritual counseling. Assistance is described as being present and one with the client, a term that describes the abilities/competencies that a professional nurse needs to have (Zerwekh, 1997, in Kozier, 2014). According to Petigrew (1990, in Kozier, 2014) there are four different styles of presenting: (a) giving oneself into a certain moment; (b) provide themselves as a whole; (c) listen, and do certain things with full awareness; and (d) making a meaningful presence of oneself to clients.

Fredriksson (1999, in Kozier, 2014) states that assistance is "giving oneself" which is carried out by nurses through maintaining an attentive attitude towards clients. There are various levels of assistance. Osterman and Schwartz-Barcott (1996, in Kozier, 2014) identified four ways of assisting clients: (a) presence (prescene), namely when a nurse is physically present but does not focus on the client; (b) partial presence, namely when the nurse is physically present and starts trying to focus on the client; (c) full presence, namely when the nurse is present beside the client physically, mentally and emotionally, and deliberately focuses on the client; (d) transcendent presence, namely when the nurse is present beside the client physically, mentally, emotionally, and spiritually.

The therapeutic presence of a nurse demonstrates the caring, empathy, and connection needed to build rapport and trust between nurse and patient. Attendance is considered as important in holistic nursing and is a core competency that must be mastered in contemporary nursing. True presence is being with the client, listening deeply while remaining in a close relationship between the two. Presence implies that nurses are available to be open to patients and their families, as well as fellow nurses. Presence facilitates sharing of suffering, encourages healing and relieves anxiety.

When the nurse is present with the client, gentle pats, nods or other forms that indicate a meaningful encounter with the client can be done. Presence also shows complementary and reciprocal exchanges between nurses and patients that involve deep concern, empathy, and recognition from nurses and the holistic needs of patients (Boeck, 2016). Assistance is often the best and sometimes the only intervention to support the client's suffering where medical intervention cannot overcome it (Kozier, 2014). When clients are hopeless, powerless, and vulnerable, assistance by nurses can be very beneficial (Taylor, 2002, in Kozier, 2014). During the assessment of the client, the nurse will obtain specific information about religious preferences and practices. Nurses need to consider certain religious practices that will affect nursing care, such as the client's beliefs about birth, death, dress, diet, prayer, holy messages and other sacred symbols.

Each religion has its own unique history, some recent and some dating back to ancient times. Each religion also has its own practices for daily life based on traditions, beliefs, values and rules. Not all of these religious practices apply to inpatient nursing care, even though they may be important in normal life. Some

examples of practices that do not apply could include adult baptism by immersion or immersion; or special practices in places of worship.

Sometimes an appropriate religious leader can assist with health care by relieving the client from religious duties (such as fasting) during periods of illness. Clients should be givenchoices about multiple treatments through informed consent without pressure from anyone to conform. In certain situations may contact appropriate religious leaders, to increase comfort and support to sick patients or to resolve issues related to conflicts between religious practice and nursing care.

Religious practice support can be done by helping clients to engage in spiritual-religiousactivities; refer to expert leaders (ustadz, priests); inform patients about resources; providing religious materials; facilitating prayer, meditation and other practices; and helping patients to attend religious services and related activities, practice religious rituals, pilgrimages, read holybooks or religious articles, and listen to sacred music (Saad, 2012).

Illness and illness can affect a client's ability to pray. Feelings such as anxiety, fear, guilt, hopelessness, and isolation can create barriers to relationships. In some instances clientsmay ask the nurse to pray with them. There are also praying with the client only if there is an agreement between the client and the nurse. Because praying involves deep feelings, nurses need to spend time with clients after praying, to give clients the opportunity to express their feelings (Kozier, 2014).

Spiritual care can be carried out by referring clients to members of the health team other than nurses, such as existing religious leaders/spiritual mentors. Therefore nurses need to identify spiritual resources (including spiritual counselors) that exist in the hospital and in thecommunity. According to Kozier (2014) referrals may be needed when nurses make a diagnosisof spiritual distress. In this situation, the nurse and religious counselor can work together to meet the client's needs.

CONCLUSIONS AND RECOMMENDATIONS

Should relate to the study aims, hypotheses, findings, and suggestions for furtherresearch.

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