

## Social wellbeing among women living with cancer

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### Article Info

#### Article history:

Received Feb 4, 2020

Revised Feb 26, 2020

Accepted Mar 2, 2020

#### Keywords:

Breast cancer  
Cervical cancer  
Home activities  
Social wellbeing  
Women

### ABSTRACT

Women living with cancer are gradually increases in number due to the increase prevalence of breast and cervical cancer worldwide. The social impact of cancer is underappreciated compared to physical and psychological impacts. This study aimed to: 1) compare and analyze the social wellbeing (SWB) between women living with breast and cervical cancer, and 2) determine the best predictor of SWB in both groups. This cross-sectional study involved 58 and 47 women living with breast and cervical cancer (n=105). Questionnaire of QOL-CS part III was used in data collection. Various statistical tests were used in data analysis ( $\alpha < 0.05$ ). Sufficient SWB was mostly found in both cases. Family stress, work life, home activities, worryness, social support, personal relation, sexuality, social isolation, and financial burden were significantly different between cases ( $p=0.021$ ,  $p=0.027$ ,  $p=0.004$ ,  $p=0.022$ ,  $p=0.000$ ,  $p=0.000$ ,  $p=0.000$ ,  $p=0.000$ , and  $p=0.001$  respectively), resulted in significant difference in overall SWB between cases ( $p=0.000$ ). Home activities were the best predictor of SWB in both cases ( $R^2=0.680$  and  $R^2=0.840$  respectively) with more influences on cervical cancer (84% of influence). SWB was better in women living with breast cancer.

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## 1. INTRODUCTION

Cancer involves the damaged of certain genes that control the process of cell regeneration which grow abnormally [1]. More than 2 million women globally are diagnosed with breast or cervical cancer every year [2]. In Indonesian cancer statistics (2014), the incidence of breast cancer ranked the first, followed by cervical cancer in 2<sup>nd</sup> rank [3]. Three years after (2017), breast cancer still ranked highest in Indonesian cancer statistics for new cases and deaths, also followed by cervical cancer in 2<sup>nd</sup> rank [4]. In 2018, prior study results in six Public Health Centers (PHC) in Surabaya showed that nowadays in Surabaya's communities most women who live with cervical cancer are older than those with breast cancer, but longer life expectancy was found in these older women; even more cervical cancer respondents with advanced stage were found to be long-term survivors (> 5 years) [5].

Wellbeing has been associated with physical health and longevity, social prosperity and satisfaction, as well as occupational success [6-8]. Hedonic scholars believe that wellbeing is a reflection of life satisfaction and that happiness stems from an individual's ability to balance positive affect and negative affect [9]. Alternatively, eudemonic scholars believe that wellbeing is the degree to which an individual is fully functioning and engages in meaningful endeavors; genuine wellbeing focuses on the fulfillment of human potential [9]. Social well-being is aligned with the eudaimonia perspective [10, 11].

Keyes (1998) defined social well-being as an appraisal of an individual's quality of his or her relationship with people in their community and society [11]. Particularly, social well-being assesses the individual judgement about their social relationships, others' responses onto them, and their interaction with social institutions and communities [10-12]. Keyes (1998) developed a theory of social wellbeing that identifies five dimensions of social wellbeing, namely: 1) social integration, means the evaluation of belongingness quality in a society, 2) social acceptance, means the society construal through the others' character and qualities as a generalized category, 3) social contribution, means the evaluation of individual perceived value in a society, 4) social actualization, means the evaluation of the potential and the trajectory of society, and 5) social coherence, means the perception and understanding of the machinations of one's society [11].

According to social determination theory, wellbeing is predicted on the basis of environmental conditions in which an individual is nested, by satisfying the basic psychological needs for autonomy, competence, and relatedness [13]. The surrounding social environment influence the behavior and wellbeing of cancer survivors [14]. A study towards 376 cancer survivors in the United States (US) showed that social wellbeing could be predicted significantly by social support from family members and friends [15]. In the other hand, Ferrel, et al. (1995) found that social wellbeing in cancer survivors could be assessed through family stress, work life, home activities, worriness, social support, personal relation, sexuality, social isolation, and financial burden [16].

Cervical and breast cancer has different etiology, symptoms, and complications. While awareness is growing of physical and psychological impact of cancer and its treatment, the social impact of cancer is underappreciated. Naturally, human is a social creature. An individual cannot live alone in his survival. All of us live in our own social context. Therefore, social wellbeing in women living with cancer is really important to be studied, so that intervention could be developed to address those in need. This study aimed to: 1) compare and analyze the social wellbeing between women living with breast and cervical cancer, and 2) determine the best predictor of social wellbeing in both groups. By knowing this study results, it will be beneficial for developing adequate social support multidisciplinary and determining which group more in need. It is important to address the social needs of women living with cancer to assure optimum quality of life.

## 2. RESEARCH METHOD

This cross-sectional study involved 58 and 47 women living with breast and cervical cancer respectively (n=105) in three districts of Surabaya (Rangkah, Gading, and Pacarkeling), Indonesia. Inclusion criteria: 1) adult, 2) cancer diagnosis was confirmed, and 3) supervised by one palliative volunteer under the authority of Rangkah PHC, Surabaya. Exclusion criteria: 1) denied informed consent, 2) very poor condition, and 3) consciousness loss or disorientation. "Very poor condition" was measured qualitatively by the researcher. The clinical signs were: unable to wake up from the bed (bed rest), avoiding guest, extremely fatigue; so that the researcher cannot meet the individual. Total sampling was applied and sample size of 105 was obtained. The researcher got the patients' data from Rangkah PHC via the head of the palliative volunteer group. The researcher then did "door to door" data collection by companion of the palliative volunteer because the researcher was unfamiliar for the patients.

Questionnaire of Quality of Life-Cancer Survivors (QOL-CS) part III which developed by Ferrel, et al. (1995) was used in data collection [16]. It consists of nine items assessing family stress, work life, home activities, worriness, social support, personal relation, sexuality, social isolation, and financial problem as the aspects of social wellbeing. Social wellbeing in women living with cancer were assessed by the time of data collection (actual condition). Likert scale of 0 to 10 representing none to severe was used to distinguish individual response regarding how much is the tendency of impairment in each item: 1) none=0, 2) mild=1-3, 3) moderate=4-6, and 4) severe=7-10. Total score then categorized into three, namely" 1) optimum wellbeing (1-30), 2) sufficient wellbeing (31-60), and 3) low wellbeing (61-90); but this category was made to ease the data presentation only in result section, and not for statistical analysis purposes. After instrument testing procedure, this instrument was proved to be valid and highly reliable ( $r=0.655-0.861$ ; Chronbach's Alpha= $0.765$ ). Data were collected since February until March, 2018. Ethical clearance was issued by Faculty of Nursing, Universitas Airlangga, Surabaya, Indonesia, with certificate number of 681-KEPK.

Descriptive statistic, independent sample T test, Mann-Whitney U test, and simple linear regression test were used in data analysis ( $\alpha < 0.05$ ). Data of family stress, work life, home activities, worriness, and overall social wellbeing were normally distributed ( $p=0.059$ ,  $p=0.078$ ,  $p=0.063$ ,  $p=0.065$ , and  $p=0.688$  respectively), therefore independent sample T test was used to analyzed the data. In the other hand,

data of social support, personal relation, sexuality, social isolation, and financial burden were not normally distributed, therefore Mann-Whitney U test was used to analyzed the data (all  $p < 0.05$ ).

### 3. RESULTS AND DISCUSSION

There were 58 and 47 women living with breast and cervical cancer who participated in this study respectively. All study respondents expressed their agreement to participate in this study, and they had signed the consent form. More women living with breast cancer participated in this study (55.24%). They had better educational background, occupational status, and Gross Domestic Product (GDP) compared to those with cervical cancer. Generally, most respondents were married housewives. Older women were found to have cervical cancer more than breast cancer. More single women were found to have breast cancer in this study. Table 1 shows the demography characteristic of study respondents in details.

Table 1. Demography characteristic

Characteristic	Cervical Cancer (n=47)		Breast Cancer (n=58)	
	Frequency	%	Frequency	%
1. Age (years old)				
a. < 21	0	0	1	1.72
b. 21-30	0	0	5	8.62
c. 31-40	5	10.64	10	17.24
d. 41-50	11	23.40	15	25.86
e. 51-60	17	36.17	15	25.86
f. 61-70	13	27.66	8	13.79
g. > 70	1	2.13	4	6.90
2. Religion				
a. Catholic	0	0	1	1.72
b. Christian	7	14.89	11	18.97
c. Islam	40	85.11	46	79.31
3. Ethnic				
a. Javanese	40	85.11	57	98.28
b. Maduranese	6	12.76	0	0
c. Chinese	1	2.13	1	1.72
4. Educational background				
a. Primary school	15	31.91	11	18.97
b. Secondary school	14	29.79	5	8.62
c. High school	13	27.66	26	44.83
d. Diploma/Bachelor degree	2	4.25	15	25.86
e. Uneducated	3	6.38	1	1.72
5. Marital status				
a. Single	3	6.38	8	13.79
b. Married	39	82.98	36	62.07
c. Widow	4	8.51	14	24.14
d. Divorce	1	2.13	0	0
6. Living at home with				
a. Spouse	39	82.98	30	51.72
b. Children	17	36.17	35	60.34
c. Alone	3	6.38	2	3.45
d. Parents	0	0	11	18.97
e. Sibling	0	0	2	3.45
7. Occupational status				
a. Full-timer	2	4.25	11	18.97
b. Part-timer	3	6.38	2	3.45
c. Retired	0	0	4	6.90
d. Housewife	40	85.11	37	63.79
e. Seeking for a job	0	0	1	1.72
f. Unemployed	2	4.25	3	5.17
8. GDP per month				
a. Less than minimum wage	34	72.34	34	58.62
b. Minimum wage - IDR 5 million	8	17.02	14	24.14
c. More than IDR 5 million	3	6.38	6	10.34
d. No income	2	4.25	3	5.17

Most respondents were long term survivors because they were diagnosed before 2014. We can see that the survival rate of both cases was long enough making them needed long term care. Surgery was the top choice of therapy in breast cancer, while those with cervical cancer took a modification of surgery and chemo-radiotherapy. Table 2 explains the primary data in details.

Table 2. Year of 1<sup>st</sup> diagnosed with cancer, and the type of received therapy

Characteristic	Cervical Cancer (n=47)		Breast Cancer (n=58)	
	Frequency	%	Frequency	%
1. Firstly diagnosed				
a. 2018	0	0	4	6.90
b. 2017	7	14.89	16	27.59
c. 2016	12	25.53	7	12.07
d. 2015	5	8.62	10	17.24
e. 2014	5	8.62	3	5.17
f. < 2014	18	38.30	18	31.03
2. Type of therapy				
a. Surgery	5	8.62	26	44.83
b. Chemotherapy	13	27.66	8	13.79
c. Surgery + chemotherapy	2	4.25	11	18.97
d. Surgery + radiotherapy	0	0	1	1.72
e. Chemotherapy + radiotherapy	7	14.89	1	1.72
f. Surgery + chemotherapy + radiotherapy	17	36.17	5	8.62
g. Surgery + chemotherapy + radiotherapy + analgesic	1	2.13	0	0
h. Surgery + chemotherapy + radiotherapy + medicine	1	2.13	0	0
i. Surgery + chemotherapy + oral medicine	0	0	1	1.72
j. Oral medicine (various types)	0	0	4	6.90
k. Untreated	1	2.13	1	1.72

More sufficient to optimum social wellbeing was found in women living with breast cancer (91.38% in total) compared to most sufficient wellbeing in those with cervical cancer (74.47%). Social wellbeing was better in those with breast cancer. If we look closely into each determinant of social wellbeing, most respondents in both cases reported moderate family stress, severe worries, and high social support. Disturbance or impairment in work life, home activities, personal relation, sexuality, and social isolation, as well as financial burden were found to be worst in women living with cervical cancer compared to those with breast cancer. Table 3 explains the comparison of social wellbeing between women living with breast and cervical cancer in details.

Descriptive statistic results showed that Mean and standard deviation (SD) of social wellbeing in the case of cervical cancer was 46.62 and 12.07 respectively, while for breast cancer was 34.88 and 18.12 respectively. This indicates that averagely sufficient social wellbeing was found in both cases, but the data of social wellbeing in CCS was more homogenous compared to BCS because of lower SD, and BCS had slightly better social wellbeing than CCS because of lower Mean. Family stress, work life, home activities, worryness, social support, personal relation, sexuality, social isolation, and financial burden were significantly different between women living with breast and cervical cancer ( $p=0.021$ ,  $p=0.027$ ,  $p=0.004$ ,  $p=0.022$ ,  $p=0.000$ ,  $p=0.000$ ,  $p=0.000$ ,  $p=0.000$ , and  $p=0.001$  respectively), resulted in significant difference in overall social wellbeing between cases ( $p=0.000$ ). Table 4 explains the significant differences in social wellbeing between cases based on results of statistical analysis.

It is known that social wellbeing in cancer survivors could be assessed through family stress, work life, home activities, worryness, social support, personal relation, sexuality, social isolation, and financial burden (16). We tried to determine which one of all these aspects being the best predictor or major determinant of social wellbeing in women living with breast and cervical cancer. Simple linear regression test results showed that home activities were the best predictor of social wellbeing in women living with breast and cervical cancer ( $R^2=0.680$  and  $R^2=0.840$  respectively), but it gave more influence on those with cervical cancer (84% of influence). Table 5 explains the influence of each determinant towards social wellbeing in details.

Most respondents were housewives in this study context Table 1, therefore their work life is closely related to home activities or household work, such as: cooking, cleaning, washing, ironing, caring for husband and children, etc. As prior study results showed that cervical cancer survivors reported more severe cancer symptoms compared to those with breast cancer [19], therefore there is a big possibility that most respondents experienced impairment in their household work life. In this study, women living with cervical cancer reported more impairment in her work life compared to those with breast cancer Table 3. Not only being housewives, 17.14% respondents are still actively working, especially those with breast cancer. Macmillan Cancer Support (2016), an organization of millions of people affected by cancer, supporters, professionals, volunteers, and campaigners; stated that cancer can cause uncertainties in individual's work life [22]. The patients may not know how it will affect work in the short term or in the future. Some patients do not work during cancer treatment, and some while in the recovery phase after treatment, while the other make some adjustment in the working hours or shift, but there are also some people who are stop working because of the bad health condition, or they choose to do something else which

is easier or less demanding. In this study context, occupation was assessed in the period of living with cancer, while respondents' previous occupation before being diagnosed with cancer was not identified. Therefore, work life crisis and changes after having cancer was not analyzed further.

Table 3. Comparison of social wellbeing between cases

Characteristic*	Cervical Cancer (n=47)		Breast Cancer (n=58)	
	Frequency	%	Frequency	%
1. Family stress				
a. Severe	11	23.4	13	22.4
b. Moderate	31	65.9	20	42.6
c. Mild	3	6.4	17	29.3
d. None	2	4.3	8	13.8
2. Work life				
a. Severe	7	14.9	10	17.2
b. Moderate	31	65.9	12	20.7
c. Mild	5	10.6	18	31.0
d. None	4	8.5	18	31.0
3. Worryness				
a. Severe	28	59.6	20	42.6
b. Moderate	13	27.7	12	20.7
c. Mild	3	6.4	14	24.1
d. None	3	6.4	12	20.7
4. Home activities				
a. Severe	7	14.9	8	13.8
b. Moderate	28	59.6	13	22.4
c. Mild	9	19.1	19	32.8
d. None	3	6.4	18	31.0
5. Social support				
a. High	26	55.3	52	89.7
b. Moderate	21	44.7	4	6.9
c. Low	0	0	1	1.7
d. d. None	0	0	1	1.7
6. Personal relation				
a. Severe	7	14.9	4	6.9
b. Moderate	25	53.2	8	13.8
c. Mild	7	14.9	21	36.2
d. None	8	17.0	25	43.1
7. Sexuality				
a. Severe	14	29.8	14	24.1
b. Moderate	28	59.6	6	10.3
c. Mild	3	6.4	14	24.1
d. None	2	4.3	24	41.4
8. Social isolation				
a. Severe	3	6.4	6	10.3
b. Moderate	24	51.1	5	8.6
c. Mild	12	25.5	17	36.2
d. None	8	17.0	30	51.7
9. Financial burden				
a. Severe	12	25.5	9	19.1
b. Moderate	24	51.1	16	34.0
c. Mild	10	21.3	27	57.4
d. None	1	2.1	6	10.3
10. Overall social wellbeing				
a. Optimum	5	10.6	27	57.4
b. Sufficient	35	74.5	26	55.3
c. Low	7	14.9	5	8.6

\*Category was made to ease the data presentation only, and not for statistical analysis purposes.

Worry is a cognitive activity in which an individual possesses a series of negative thoughts as a result of uncertainty [23]. Situational or state-based worry is often triggered by an event, sometimes followed by attempts at problem-solving, but in the other time triggered by ambiguous or extremely distant events [24]. Women living with breast and cervical cancer mostly reported severe worries, especially they felt worry if their children will have a great risk to have the same disease as them Table 3. Newly diagnosed cancer patients likely experience significant situational worry, but even individuals who do not have cancer in their lives can feel worry towards cancer (i.e., trait-based cancer worry) [24]. Overall there were 25.71% respondents who were newly diagnosed with cancer (2017-2018), and more were found in those with breast cancer Table 2.

Table 4. Significant differences in social wellbeing between cases

DETERMINANT	CERVICAL CANCER (N=47)		BREAST CANCER (N=58)		MEAN DIFFERENCE (CI=95%)	t STATISTIC	p VALUE
	MEAN	SD	MEAN	SD			
Family stress	5.49	1.88	4.38	2.78	-2.05 - -0.17	-2.34	0.021
Work life	4.62	1.98	3.38	3.34	-2.33 - -0.14	-2.24	0.027
Home activities	4.55	2.04	3.02	3.07	-2.57 - -0.50	-2.94	0.004
Worriiness	6.34	2.43	4.83	3.89	-2.80 - -0.22	-2.32	0.022
Social support	7.13	1.65	8.66	2.02	-	-	0.000
Personal relation	4.06	2.49	1.83	2.19	-	-	0.000
Sexuality	5.51	2.51	2.97	3.46	-	-	0.000
Social isolation	3.57	2.04	1.91	2.88	-	-	0.000
Financial burden	5.34	2.16	3.91	2.59	-	-	0.001
Overall social wellbeing	46.62	12.07	34.88	18.12	-17.85 - -5.62	-3.81	0.000

Table 5. Predictors of social wellbeing in both cases

Determinant	R Square	% Of Influence	p Value
<b>Breast cancer (n=58)</b>			
Family stress	0.403	40.3	0.000
Work life	0.649	64.9	0.000
Home activities	<b>0.680</b>	<b>68.0</b>	<b>0.000</b>
Worriiness	0.576	57.6	0.000
Social support	0.020	-	0.284
Personal relation	0.458	45.8	0.000
Sexuality	0.594	59.4	0.000
Social isolation	0.555	55.5	0.000
Financial burden	0.382	38.2	0.000
<b>Cervical Cancer (n=47)</b>			
Family stress	0.674	67.4	0.000
Work life	0.796	79.6	0.000
Home activities	<b>0.840</b>	<b>84.0</b>	<b>0.000</b>
Worriiness	0.363	36.3	0.000
Social support	0.003	-	0.712
Personal relation	0.579	57.9	0.000
Sexuality	0.088	8.8	0.043
Social isolation	0.561	56.1	0.000
Financial burden	0.396	39.6	0.000

Over the years, studies have established empirical evidence for the association between social support and well-being [25]. The term social support is frequently used for a wide array of phenomena pertaining to the effects of social relationships on health and wellbeing (e.g. Cobb, 1976; Sarason, Sarason, Pierce, 1994; Thoits, 1995; Cohen, 2004) [15]. In this study, women living with breast and cervical cancer mostly reported severe high social support, but surprisingly this is the only determinant that give insignificant influence on social wellbeing in both cases Table 5. Social support was mostly come from the family, in which most respondents in both cases were living with their spouse and children (nuclear family). A study conducted by Ashing-Giwa, et al. found that social support for breast cancer survivors were most come from their family members and their peer groups [26]. Another study conducted by Chou, Stewart, Wild, and Bloom found that social support and social contact among breast cancer survivors are associated with higher survival rate post-cancer treatment [27]. Social support has been found to bring positive changes in cancer patient' lives [28]. Support from family members and friends is correlated with better wellbeing in cancer survivors [29]. There are four types of family support, namely: award, emotional, instrumental, and informational support [17].

Regarding personal relation, cancer and its treatment have many effects on patients' social and intimate relationships, especially on sexual functionality and capabilities as a sexual partner [30]. In this study, more women with cervical cancer reported impaired personal relation compared to those with breast cancer Table 3. This potentially related to their intimate relationship with their spouse and sexual life. More women with cervical cancer reported impaired sexuality compared to those with breast cancer Table 3. A study towards 99 cancer patients (66 were females) showed that although relationship satisfaction was high, respondents reported having sex less often following their cancer diagnosis; sexual and relationship quality were positively related in this study [31]. Another study towards 17 male cancer survivors showed that there was a dichotomy in sexual communication with partner: one pattern was good partner sexual communication that emerged in the presence of good partner support and a stable sense of one's own

self-efficacy, and another was poor sexual communication in the context of feelings of a lack of masculinity following sexual dysfunction and accompanying lack of partner support [32]. Similar study in female cancer survivors was not found yet. Practitioners can play an important role in helping cancer patients understand how cancer can alter their relationships and sexuality. Some of the barriers for physicians include lack of time, privacy, rapport, and the perception that discussions about intimacy and relationships are secondary to conversations about prognosis and survival [33].

Social isolation is a positive response towards question about living alone, losing spouse, less contact with others, no assistant for daily activities, and no emotional support [34]. There were more women living with cervical cancer reported impairment in social isolation compared to those with breast cancer Table 3. A study towards 7,699 patients with metastatic cancer showed that patients with social isolation were more likely older, female, ECOG  $\geq 2$ , and receive no systemic therapy; the greater the social isolation then the lower the systemic therapy uptake [34]. In this study, more women living with cervical cancer who were older and undertook systemic therapy found, such as chemotherapy Table 2. Prior study results showed that the therapy regimen between breast and cervical cancer was differed significantly [35]. Most women living with cervical cancer undertook a more complex regimen of modification of surgery and chemo-radiotherapy compared to those with breast cancer who undertook surgery only Table 2.

Cancer patients are more likely to have financial burden than people without cancer. Financial burden is a term used to describe problems a patient has related to the cost of medical care. Financial burden is also called economic burden, economic hardship, financial distress, financial hardship, financial stress, and financial toxicity. Financial burden can also affect a patient's quality of life and access to medical care. In this study, more women living with cervical cancer reported higher financial burden compared to those with breast cancer Table 3. This is potentially related to the therapy complexity in cervical cancer, which is a modification of surgery and chemo-radiotherapy. Due to the global aging, cancer prevalence and the number of people treated for cancer will increase even if its incidence rates remain constant or decrease. In the United States, costs are also likely to increase as new, more advanced, and more expensive treatments are adopted as standards of cancer care [36]. In Indonesia, the five domains of non-communicable disease/NCDs (cardiovascular disease, cancer, chronic obstructive pulmonary disease, diabetes mellitus, and mental illness) will cost \$4.47 trillion (or \$17,863 per capita) from 2012 through 2030, and this health expenditure is higher compared to India and China [37].

Social contacts with the loved ones can be a balm, and represent sources of support, validation, and information, and personal relationships can serve as venues for distraction, enjoyment, and pleasure in the context of cancer [30]. Social wellbeing contributed to significant quality of life improvement in cancer survivors as it is being one of the domains. This study reveals that women living with cervical cancer are those more in need of social support compared to those with breast cancer. Multidisciplinary intervention needs to be developed in the near future to address this need.

#### 4. CONCLUSION

Averagely, women living with breast and cervical cancer have sufficient social wellbeing and receive high social support. Social wellbeing was better in those with breast cancer. Women living with cervical cancer are those who more in need of social support and multidisciplinary intervention for increasing their social wellbeing. Social wellbeing differs significantly between women living with breast and cervical cancer, which influenced by various aspects, such as: family stress, work life, home activities, worryness, social support, personal relation, sexuality, social isolation, and financial burden. Home activities were the best predictor of social wellbeing in both cases with more influences on cervical cancer; therefore this aspect requires special attention from health care professionals.

#### ACKNOWLEDGEMENTS

This study was funded by the Center of Food and Nutritional Research, Institute of Research and Community Service, Widya Mandala Catholic University Surabaya, by Grant number: 077a/WM01.5.2/N/2018. This publication was supported by Faculty of Nursing, Widya Mandala Catholic University Surabaya.

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