

## Fear of Recurrence Predictors among Indonesian Gynecological Cancer Survivors

Ira Sukyati<sup>1</sup>, Yati Afiyanti<sup>2\*</sup>, Hayuni Rahmah<sup>2</sup>, Ariesta Milanti<sup>3</sup>

1. Postgraduate Programme, Universitas Indonesia, Faculty of Nursing, Universitas Indonesia, Depok 16424, Indonesia.
2. Department of Maternity Nursing, Faculty of Nursing, Universitas Indonesia, Depok 16424, Indonesia.
3. Indonesian Oncology Nurses Association, Jakarta 11420, Indonesia.

### Abstract

Fear of cancer recurrence (FCR) is the most common psychological issue amongst gynecological cancer survivors, and yet it remains unexplored, especially in developing countries such as Indonesia. Hence, this study aimed to identify the predictive factors of FCR among gynecological cancer survivors in Indonesia. A descriptive cross-sectional design was used. Women diagnosed with gynecological cancer, who had completed primary treatment were recruited from a referral hospital in Jakarta, Indonesia. Data were collected using a demographic and disease-related questionnaire and the Fear of Cancer Recurrence Inventory. Pearson's correlations test, *t*-test, and linear regression analysis were performed. A total of 114 women participated in this study. Age was the strongest predictor of FCR in the domains of severity, psychological distress, insights, and reassurance. Marital status and type of treatment strongly predicted the FCR domains of functional impairment and coping strategies, respectively ( $P < .05$ ). The findings of this study indicate the importance of patient characteristics while addressing the issue of FCR among gynecological cancer survivors. Further studies aimed at understanding FCR among gynecological cancer survivors may provide insight into the aspects of this condition that necessitate more attention.

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### Introduction

A global statistics on cancer estimated the presence of 14.1 million people with cancer, 14.7 million new cancer cases, and 8.2 million cases of cancer death in 2012.<sup>1</sup> Despite being a major cause of morbidity and mortality worldwide, the number of cancer survivors is increasing due to early detection and improved treatments.<sup>2,3</sup> However, cancer survivors commonly experience sequelae not only in their bodies but also in their psychological, social, and spiritual life.<sup>4,5</sup>

One of the most frequent psychological concerns of cancer survivors is fear of cancer recurrence (FCR).<sup>6</sup> More than one-third of cancer survivors report five or more unmet

needs at the end of the treatment period, and the most important need is dealing with FCR.<sup>7</sup> The impacts of FCR may involve various aspects including the survivors' physical functions, cognitive and emotional aspects, beliefs, and work or family.<sup>8</sup> Resultantly, FCR may negatively affect their quality of life in the long term.<sup>9,10</sup>

Studies showed that gynecological cancer survivors are likely to have up to 70% chance of cancer recurrence,<sup>9,11</sup> and the probability is higher (80%) in those with epithelial ovarian cancer.<sup>12</sup> Given the high recurrence rate, FCR is a highly pertinent issue for gynecological cancer survivors.<sup>13</sup> The study by Leeson and colleagues reported FCR as the most important issue to be addressed in gynecological cancer survivors, followed by quality of life.<sup>13</sup>

Previous research exploring factors that influence FCR in cancer survivors have yielded mixed results.<sup>14</sup> In the context of a disorder, a history of prior mental health issue is strongly associated with FCR.<sup>14</sup> Generally, FCR is likely

#### \*Corresponding author:

Yati Afiyanti  
Department of Maternity Nursing  
Faculty of Nursing, Universitas Indonesia  
Depok 16424, Indonesia  
E-mail: yatikris@ui.ac.id

to be linked with sociodemographic and disease-related factors.<sup>12,15</sup> Age and ethnicity or cultural background are frequently reported to be related to FCR.<sup>10,16-18</sup> A study among Iranian cancer survivors indicated that FCR is mostly predicted by the level of education and type of cancer,<sup>19</sup> whereas other studies have reported no association between educational level and FCR.<sup>14,20</sup> Although considerable studies have been conducted on cancer survivorship, predominantly in developed countries, very little attention has been paid to FCR.<sup>4,7</sup>

Studies regarding cancer survivorship in developing countries, including Indonesia, are limited;<sup>21</sup> moreover, to the best of our knowledge, the issue of FCR in these countries remains unexplored. Indonesia is a developing country located in Southeast Asia and has a high number of gynecological cancer cases and deaths.<sup>22</sup> Survivorship care for cancer patients is still in its initial stages of development in this country.<sup>23</sup> Therefore, the current study aimed to determine the prevalence of FCR and evaluate the factors that may account for various degrees of FCR among gynecological cancer survivors in Indonesia.

### Materials and methods

Patients presenting at the oncology outpatient unit at the Indonesian Army Central Hospital in Jakarta, Indonesia, were included in this cross-sectional, descriptive analytical study. The inclusion criteria were as follows: at least 18 years old; a diagnosis of gynecological cancer; have undergone at least one primary cancer treatment; ability to communicate in Bahasa Indonesia; and ability to give consent to participate in the study. The participants were selected using the consecutive sampling method during May-June 2017. Our calculation of the sample size with a significance level of 5% and a statistical test power of 80% yielded a minimum number of 130. However, only 114 eligible patients out of 124 patients who agreed to participate in our study were finally selected in the current study.

A sociodemographic and cancer-related questionnaire and the Fear of Cancer Recurrence Inventory (FCRI) were used in this study. FCRI consists of 42 question items divided into seven domains as follows: (1)

cancer-related triggers; (2) severity; (3) psychological distress; (4) coping strategies; (5) functioning impairments; (6) insight; and (7) reassurance.<sup>24,25</sup> The FCRI is considered as a valid and reliable test with good psychometric properties.<sup>25-27</sup> In the current study, FCRI was translated into the Indonesian language, subjected to readability and linearity tests by a panel of experts at the University of Indonesia, and piloted among cancer patients in different setting.

All data were analyzed using the Statistical Package for Social Sciences (SPSS) software (version 17, SPSS Inc., Chicago, IL, USA). The *P* value was set at <.05. Data were initially screened for normality using the Kolmogorov-Smirnov test. Sociodemographic and disease-related characteristics as well as the FCR were calculated for the descriptive analysis. The survivors' characteristics were analyzed using Pearson's correlation test and independent *t*-test. Analysis of variance test was performed to examine the relationship between background characteristics and FCR. Multivariate analysis with linear regression was performed to determine the factors that accounted for the increased levels of FCR in gynecological cancer survivors in Indonesia.

Ethical approval was obtained from the Ethics Committee of the Faculty of Nursing, University of Indonesia. All participants had signed an informed consent to voluntarily participate in this study. The ethical principles for conducting studies with human subjects were in accordance with the guidelines of the Declaration of Helsinki throughout the study process. We ensured fairness and privacy along with maximum benefit and minimum harm in any form for all participants. Formal permission and access for this study was granted by the hospital after reviewing our ethical approval and study proposal.

### Results

As shown in Table 1, the majority of the 114 participants (mean age, 52 years) in this study was married (90.4%) and diagnosed with early stage gynecological cancer (73.3%). Over half of the participants had high school education or higher (57.9%) and worked as housewives (57.9%). Fifty percent of the participants had a diagnosis of cervical cancer, and 61.1% had undergone single cancer treatment (Table 1).

The mean FCR was 78.25 (standard deviation [SD], 26.75; 95% confidence interval), and the median was 75. The FCR questionnaire has seven domains including trigger, severity, psychological distress, functional impairments, insight, reassurance, and coping strategy. The highest mean score was in the domain of coping strategies (29.50), followed by other domains as outlined in Table 2. The lowest mean score was the domain of insight of FCR (3.14 ± 3.64).

Category	Frequency	Percentage (%)
Age		
Mean ± SD (range)	52.35 ± 11.735	(25–78)
Education		
High school and above	66	57.9
Nine-year primary school	48	42.1
Occupational status		
Employed	24	21.1
Housewife	90	78.9
Marital status		
Married	10.3	90.4
Single/notmarried	11	9.6
Cancer stage		
Early	60	73.3
End	54	26.7
Cancer type		
Cervical cancer	63	55.3
Ovary cancer	48	42.1
Other	3	2.6
Treatment		
Single	68	55.3
Double	48	42.1

**Table 1.** Characteristics of the gynecological cancer survivors (N= 114). SD= standard deviation.

Variable	Mean	SD	95% CI
<b>FCR</b>	78.25	26.75	73.21–84.42
Trigger	13.23	9.56	11.44–15.49
Severity	13.52	7.94	11.59–14.91
Psychological distress	5.02	4.56	3.78–5.52
Functional impairments	6.61	6.40	5.43–8.13
Insight	3.14	3.64	2.42–3.95
Reassurance	7.19	4.71	6.45–8.20
Coping strategy	29.50	6.45	28.78–31.48

**Table 2.** Fear of recurrence among gynecological cancer survivors (N= 114). SD= standard deviation; CI= confidence interval

Following bivariate selection, variables with *P*-value < .05 were included in the multivariate modeling. Four domains of the FCR were predicted by the age of the gynecological cancer survivors in this study: severity, psychological distress, insight, and self-reassurance. Alternatively, marital status and type of treatment were linked with functional impairment and coping strategy (Table 3).

Model	Standardized Coefficients	Coefficients (Beta)	<i>P</i> value	R square (R <sup>2</sup> )
Severity				
Age	0.245	4.552	.000	0.039
Psychological distress				
Age	0.188	2.004	.040	0.035
Functional impairment				
Marital Status	-0.187	-4.049	.046	0.039
Insight				
Age	0.258	2.134	.000	0.067
Self-reassurance				
Age	0.894	2.125	.019	0.048
Coping strategy				
Treatment	0.186	2.901	.047	0.035

**Table 3.** Linear regression analysis of the FCR predictive factors.

## Discussion

Moderate levels of FCR (mean, 78.25; median, 75; range, 20–152) were noted among the Indonesian gynecological cancer survivors in the present study. Low to moderate FCR levels have been reported previously among survivors of breast<sup>8</sup> and mixed types of cancer.<sup>25</sup> In another longitudinal study on patients with mixed cancers undergoing surgery, the patients had high FCR levels during the perioperative period, which was significantly decreased 2 months later, but persisted until 18 months post-surgery.<sup>28</sup> Furthermore, the levels of FCR at baseline during the perioperative period in some patients tended to remain high during the remainder of the study period. A prospective study measuring FCR among head and neck cancer survivors at three different time points on 1 year after cancer rehabilitation reported that the majority of the survivors had moderate levels of FCR that remained stable over time; moreover, time since diagnosis was not significantly associated with FCR.<sup>29</sup> However, since there are no established criteria to determine a clinically significant FCR in terms of duration, severity, or frequency, the descriptive

statistics in this study might be of limited clinical relevance.

Age has been associated with FCR in patients with gynecological,<sup>10</sup> breast,<sup>30-33</sup> head, and neck cancer.<sup>34</sup> In the current study, age was found to be the most important predictor of increased FCR and accounted for the variance of FCR in the domains of severity, psychological distress, insight, and self-reassurance. This finding adds to the cumulative findings of a previous systematic review, which suggested that age is one of the major predictors of FCR.<sup>15</sup> Young patients tend to respond to the disease with more stress, uncertainty, and fear.<sup>35</sup> However, a systematic review focusing on FCR among ovarian cancer patients demonstrated that both older and younger women presented with significant levels of FCR.<sup>36</sup>

Single or unmarried participants had a greater degree of FCR in the functional impairment domain. Former studies have yielded different findings on the relationships between marital status and FCR level.<sup>15,16,25,37</sup> The diagnosis and treatment of cancer can disrupt the functioning abilities of a female, and the presence of a spouse as a caregiver may act as a significant source of support for the woman.

The coping strategies pertinent to FCR can be determined by the type of treatment as indicated in our study findings. Evaluations of the association between type of cancer treatment and FCR have yielded mixed results among survivors of cancer at different sites.<sup>15,18,20</sup> A qualitative study in Australia revealed that some women who had brachytherapy expressed more fear and concern because they found the treatment to be more daunting and less familiar when compared with other cancer treatments.<sup>38</sup>

Among the FCR domains, coping strategy was found to have the highest average score, contributing to the increased levels of FCR in this study. Coping mechanisms are the individual's response to the cancer experience.<sup>39</sup> When a gynecological cancer survivor is increasingly aware of the risk of cancer recurrence, she may demonstrate certain behaviors such as performing more self-examinations, seeking medical attention and support, and developing anxiety.<sup>40</sup> Therefore,

FCR can be adaptive to cancer rehabilitation unless it becomes persistent and excessive.<sup>14</sup>

Constant FCR can have negative impacts on the survivors' quality of life.<sup>10</sup> Studies have consistently shown that it tends to persist over time;<sup>14</sup> hence, this issue should be addressed early in the course of cancer treatment.

### Limitations of the study

This study used a cross-sectional design that can only capture a one-time situation of FCR with limited generalizability. We did not examine the effects of time since cancer diagnosis and treatment that may contribute to variations in FCR levels. Another limitation of this study was sample bias; the participants were mostly married to Indonesian army personnel since we had conducted our study at the army hospital. Studies with a bigger population at multiple settings may provide a wider picture of the FCR issue among gynecological cancer survivors.

### Conclusions

Indonesian gynecological cancer survivors in the present study had moderate levels of FCR, which was mainly predicted by age in the FCR domains of severity, psychological distress, insight, and self-reassurance. Marital status and type of treatment also accounted for the degree of FCR experienced by the survivors. Nursing care to address FCR should consider the individual background of the patient or survivor as it may contribute to the variations in FCR levels. Younger survivors may need more attention to cope with their FCR concerns. It is important to be sensitive while exploring the needs of cancer survivors with regard to FCR and initiating discussions on how to manage the issue. Further studies aimed at understanding the experience of FCR among gynecological cancer survivors may shed more light on the aspects of FCR that necessitate more attention.

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## Declaration of Interest

The authors report no conflict of interest.

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