Asian Community Health Nursing Research

Asian Comm. Health Nurs. Res. 2020, 2(3), 1–7

Cancer Information Satisfaction among Indonesian Cancer Survivors

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Type of the Paper (Article)

Received: October 28, 2020; Accepted: December 12, 2020; Published: March 14, 2021

<https://doi.org/10.29253/achnr.2020.2147>

Abstract: Information for cancer patients is significant to overcome a cancer diagnosis and its treatment, affecting patients' quality of life. This study aimed to assess the level of satisfaction with the information on illness treatment among Indonesian cancer survivors, explore its association with the patients' demographic and health-related characteristics, and provide recommendations and improve the information. Sixty adult cancer survivors at the oncology unit of Panembahan Senopati Bantul Hospital of Yogyakarta, Indonesia, were recruited in a cross-sectional study design completing a demographic and health-related data form and the Satisfaction with Cancer Information Profile Questionnaire. The data were then analyzed using descriptive statistics and path analysis. Most patients were dissatisfied with the amount and content of cancer information provided by health care ranging from 12-67%, particularly on the information regarding managing unwanted-side effects of the treatment and the impact of their cancer treatment on long-term quality of life. The patients were also discontented with the detail of information, the timing, and the usefulness of information to others. Demographic and health-related characteristics directly influence the patients' satisfaction of information ($\beta = 0.461$, $p = 0.045$). Patients who were divorced, not living with their spouses, and diagnosed with cancer for a longer time (more than two years) were the significant contributors to directly influencing their satisfaction. Nurses need to enhance the detail of information, find the best time to provide and design a better way to deliver cancer patients' information.

Keywords: cancer information; cancer information needs; cancer in Indonesia; satisfaction with cancer information profile; SCIP

1. Introduction

Many studies have been conducted earlier proposing the needs for information of cancer patients were significantly high, stretched out from diagnosis of cancer to its treatments to manage cancer, which mostly was unmet (Güleser, Taşci, & Kaplan, 2012; James-Martin, Koczwara, Smith, & Miller, 2014). The most trusted source of information for cancer patients is their doctors or health professionals, followed by the internet, family, and friends, while the least trusted sources are coming from radio, newspapers, and television (Shea-Budgell, Kostaras, Myhill, & Hagen, 2014).

Healthcare providers need to supply cancer patients with needed information and ensure they are satisfied with it. This way, the patients are fulfilled with a sense of control and reassurance, which helps them decide treatment options (Husson, Thong, Mols, Oerlemans, Kaptein, & van de Poll-Franse, 2013).

As mentioned in Noguera et al. (2014), most cancer patients preferred shared decisional control. These combinations of patients' satisfaction with information and shared decision-making will generate a higher quality of life (Faller et al., 2016).

To the best of researchers' knowledge, only one study has been established exploring patients' satisfaction with information, particularly in Indonesia's breast cancer patients. This study aimed to analyze the level of satisfaction with the information on illness treatment among Indonesian cancer survivors across the type of cancer, explore its association with the patients' demographic and health-related characteristics, and provide recommendations and improve the information.

2. Method

A descriptive quantitative with a cross sectional design was applied to the study. Sixty cancer patients from the oncology unit of Panembahan Senopati Bantul Hospital of Yogyakarta, Indonesia, were recruited. The criteria were first diagnosed cancer patients, no alteration of consciousness, and communicated in the Indonesian language both written and orally.

This study was approved by the Health Research Ethical Committee of Universitas Jenderal Achmad Yani Yogyakarta. The participants filled in a demographic and health-related questionnaire and the Indonesian version of Satisfaction of Cancer Information Profile Questionnaire (SCIP) part A and part B (Iskandarsyah, de Klerk, Suardi, Soemitro, Sadarjoen, & Passchier, 2013).

The SCIP is a measurement designed to assess patients' satisfaction with cancer information composed of two subscales (Llewellyn, Horne, McGurk, & Weinman, 2006). SCIP-A is used to measure the satisfaction with the amount and content of information, which comprises 14 items responding to scales ranging from "too much", "about right", "too little", and "none wanted" information. When the participants rated "too little" or "too much", it means they are dissatisfied with the amount and content of information received, and then the items are scored 0. In contrast, when they rated "about right" or "none wanted", they are satisfied with the information and scored 1. The SCIP-B assesses satisfaction with the type and timing of the information received consists of 7 items, each rated on a 5-item response scale from "very satisfied"=5 to "very dissatisfied"=1. The total sum of each item score range from 7 to 35, with a higher score indicating a higher level of satisfaction. The participants' data were then analyzed by using descriptive statistics and path analysis to discover causal relationships between demographic and health-related variables and satisfaction with information.

3. Results

3.1. Demographic and clinical characteristics

The mean age of participants was 57.7 years (SD=13.2, range=23 – 87), the majority were female (78.3%), living with a partner (78.3%), and the highest education was an elementary school (33.3%). Most of them were having a tumor in the breast (43.3%) and blood (33.3%) and were newly diagnosed with cancer within six months (31.7%) with no metastasis (96.7%). Most participants received a single treatment modality of cancer (45%) and a combination of 2 treatments (36.7%). All of them were covered by health insurance, and 85% did not have a family history of a cancer diagnosis. Demographic and clinical characteristics are summarized in Table 1.

3.2. Patients' satisfaction with information

Satisfaction with the amount and content of information scores ranging from 2 to 12 with the mean score of 7.03 ± 2.71 whereas the patients' satisfaction with the type and timing of information extent from 17 to 26 with the mean score of 21.4 ± 2.26 as seen in Table 2.

Table 1. Demographic and clinical characteristics of study participants.

Variable	Number of participants	%
<i>Age</i>	57.65 ±13.19	
<i>Marital status</i>		
Single	1	1.7
Married	55	91.7
Divorced	4	6.7
<i>Gender</i>		
Female	47	78.3
Male	13	21.7
<i>Living with a partner</i>		
Yes	56	93.3
No	4	6.7
<i>Education (highest)</i>		
None	3	5.0
Elementary school	20	33.3
Junior high school	16	26.7
High school	16	26.7
College or university	5	8.3
<i>Tumor location</i>		
Breast	26	43.3
Digestive	6	10.0
Male genital	1	1.7
Blood	20	33.3
Lung	5	8.3
Mouth	1	1.7
Female genital	1	1.7
<i>Time since diagnosis</i>		
1 -6 months	19	31.7
>6 - 12 months	16	26.7
>12 - 24 months	14	23.3
>24 months	11	18.3
<i>Metastasis</i>		
No	58	96.7
Yes	2	3.3
<i>Health insurance</i>		
No	0	0.0
Yes	60	100.0
<i>Amount of treatment modalities</i>		
1 therapy	27	45.0
2 therapies	22	36.7
3 therapies	11	18.3
<i>Family history of cancer diagnosis</i>		
None	51	85.0
Yes	9	15.0

Table 2. Means, standard deviations, and range of SCIP.

Measure	Mean	SD	Min-Max
Satisfaction with the amount and content of information	7.03	2.71	2 -12
Satisfaction with the type and timing of information	21.40	2.26	17 -26

Twelve to sixty-seven percent of participants stated were not satisfied with the amount and content of information they received from health care providers ranging for each item of the SCIP-A questionnaire. Table 3 displays specific aspects of the insufficient information, particularly on the information of action to do when the patients experience unwanted side-effects (67%), the impact of the treatment on patients' quality of life over the next year (62%), and the long-term impact of treatment on functioning in daily basis (57%).

Table 3. Proportion of patients who reported to have received too little information on the SCIP-A.

SCIP-A item	Number of patients	%
<i>Subscale 1: Unwanted effects</i>		
Whether the treatment has any unwanted side-effects	7	12
What the risks of your experiencing side-effects are	28	47
What the risks of your experiencing complication are	32	53
What you should do if you experience unwanted side-effects	40	67
Whether your treatment interferes with other medicines you may be taking	26	43
<i>Subscale 2: Long-term effects</i>		
How you may expect to feel immediately after treatment	27	45
Whether you may need further treatment in the future	33	55
The effects of treatment on your appearance	33	55
The long-term impact of treatment on functioning (daily activities)	34	57
How long you expect the recovery to take	30	50
How your treatment may impact on your quality of life over the next year	37	62
<i>Subscale 3: Social/financial support</i>		
The effects of treatment on your ability to work	31	52
Who to ask/where to go for possible financial support	31	52
Patient support groups for you and your partner	29	48

Regarding the patients' satisfaction with the type and timing of information ($SCIP-B \leq 3$) as presented in Table 4, the patients were mostly dissatisfied with the detail of information (90%), the timing (83%), and the usefulness of the information to their partner and family (83%). The mean scores of the timing of supplying information, its detail, and the understandable information were also highlighted as the dissatisfaction domain.

Table 4. Means and standard deviations of SCIP-B item scores.

SCIP-B item	Number of participants scored 0 - 3	%	Mean	SD
The usefulness of the information to you	6	10.0	3.90	0.30
The usefulness of the information to partner/family	50	83.3	3.17	0.38
The amount of written information supplied	47	78.3	3.00	0.66
The amount of verbal information supplied	39	65.0	3.23	0.65
The timing which you received information	50	83.3	2.92	0.65
The detail of the information given to you	54	90.0	2.37	0.76
How understandable the information was to you	49	81.7	2.82	0.79

As seen in Table 5, the demographic and clinical characteristics of the patients showed significant causal relation to the satisfaction with cancer information ($\beta = .461$, $p = .045$) where marital status, living with a partner, and time since diagnosis were the significant sub-variables which had a direct influence on the satisfaction with cancer information.

Table 5. The influence of demographic and clinical characteristics on satisfaction with cancer information (SCIP).

Variable	β	SE	t	p-value
Demographic and clinical characteristics	0.461	0.48	1.27	0.045
Age	0.286	0.49	0.59	0.057
Gender	0.283	0.37	0.77	0.534
Marital status	0.594	0.33	1.79	0.046*
Living with partner status	0.581	0.35	1.66	0.040*
Education	-0.043	0.44	0.10	0.425
Tumor location	0.380	0.50	0.76	0.240
Time since diagnosis	0.708	0.36	1.95	0.021*
Metastatic status	-0.126	0.22	0.56	0.387
Number of treatment modalities	0.014	0.46	0.03	0.493
Family history of cancer	-0.072	0.39	0.18	0.920

4. Discussion

Regarding the satisfaction of the participants' information, the amount and content of information were only counted around 50% of patients' needs, which was showed by the mean score of 7.03 ± 2.71 while the maximum score of the questionnaire is 14. On the other hand, the mean score of patients' satisfactions to the type and timing of provided information was 21.4 ± 2.26 , which still did not quite meet the range of satisfaction criteria (SCIP-B item score > 3 or the range of total score of 7 questions is > 21 to 35). It is in accord with findings from Iskandarsyah, de Klerk, Suardi, Soemitro, Sadarjoen, & Passchier (2013) stating that Indonesian breast cancer patients were also dissatisfied with the information provided by health care providers, a study in Chinese breast cancer population in Hong Kong also supports the result of low satisfaction rates coming from the information provided by health care professionals (Li, So, Fong, Lui, Lo, & Lau, 2011). The findings of the current study are in opposition to the previous study in a western country where the majority of the cancer patients felt well or quite informed about their condition expanding from diagnosis, the chance of cure/recovery, the probable course of the disease, treatment options along with their risks and side effects (Faller et al., 2016).

Further, in terms of satisfaction with the amount and content of information (SCIP-A), there was an interesting finding where the most satisfying information for the patients was regarding whether the treatment has any side-effects (88%), which was rated extremely high as compared to other domains.

However, in contrast, the most dissatisfying information was on what to do when they experienced the treatment's unwanted side effects. It means the health care providers had provided information to the patients but did not detail enough to fulfill their needs, as seen on the result of SCIP-B, where the detail of information given to patients only satisfied 10% of patients. Furthermore, the patients were also dissatisfied with the timing of receiving information (mean = 2.92) and the understandability of information to them (mean = 2.82). Different findings are coming from Iskandarsyah, de Klerk, Suardi, Soemitro, Sadarjoen, & Passchier (2013), which portrayed patients' satisfaction on the type and timing of information provided for cancer patients mostly on each subdomain except on the amount of written information supplied (mean = 2.77).

The results from path analysis showed marital status, living with a partner, and time since diagnosis were the significant sub-variables, which directly influenced cancer information satisfaction with a positive causal relation. Other demographic and health-related characteristics did not have direct causal attribution to the satisfaction with cancer information. Therefore, patients who were married, living with a partner, and newly diagnosed (1 to 6 months) with cancer were patients with a higher demand for cancer information. Similar to a study from Matsuyama, Kuhn, Molisani, & Wilson (2013), which mentioned that married cancer patients were associated with higher information needs over time and the highest information needs are highest near diagnosis time and change across the treatment process. Hsieh, Chou, & Guo (2018) mentioned that disease-related information and physical care-related information were the most needed for cancer patients at initial diagnosis.

In contrast with findings from Iskandarsyah, de Klerk, Suardi, Soemitro, Sadarjoen, & Passchier (2013), who conducted a study in Indonesian breast cancer patients, which revealed none of the demographic and clinical characteristics were significantly associated with SCIP scores. Faller et al. (2016) reported no correlation between time since diagnosis with patients' satisfaction of information irrespective of gender in 4020 cancer patients in Germany. They also found that patients living with a partner and those with higher education were more satisfied with the provided information.

5. Conclusion

Our findings suggest that many Indonesian cancer survivors were dissatisfied with cancer information provided by health care providers, particularly on the management of unwanted side-effects of treatments and their impact on functioning daily and with patients' long-term quality of life. The health care providers need to detail information, specify the timing, and design information to be easier to comprehend by patients. Cancer patients who are married, living with a partner, and newly diagnosed need extra attention to their information satisfaction needs.

Acknowledgment

The researchers would like to express gratitude to the Ministry of Research and Technology/National Research and Innovation Agency of Republic Indonesia for funding this research project.

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