Cancer Information Satisfaction among Indonesian Cancer Survivors

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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 | %    |
|---------------------------------|------------------------|------|
| **Age**                         | 57.65 ±13.19           |      |
| **Marital status**              |                        |      |
| Single                          | 1                      | 1.7  |
| Married                         | 55                     | 91.7 |
| Divorced                        | 4                      | 6.7  |
| **Gender**                      |                        |      |
| Female                          | 47                     | 78.3 |
| Male                            | 13                     | 21.7 |
| **Living with a partner**       |                        |      |
| Yes                             | 56                     | 93.3 |
| No                              | 4                      | 6.7  |
| **Education (highest)**         |                        |      |
| 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  |
| **Tumor location**              |                        |      |
| 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  |
| **Time since diagnosis**        |                        |      |
| 1-6 months                      | 19                     | 31.7 |
| >6-12 months                    | 16                     | 26.7 |
| >12-24 months                   | 14                     | 23.3 |
| >24 months                      | 11                     | 18.3 |
| **Metastasis**                  |                        |      |
| No                              | 58                     | 96.7 |
| Yes                             | 2                      | 3.3  |
| **Health insurance**            |                        |      |
| No                              | 0                      | 0.0  |
| Yes                             | 60                     | 100.0|
| **Amount of treatment modalities** |                      |      |
| 1 therapy                       | 27                     | 45.0 |
| 2 therapies                     | 22                     | 36.7 |
| 3 therapies                     | 11                     | 18.3 |
| **Family history of cancer diagnosis** |                |      |
| 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 | %   |
|-------------|--------------------|-----|
| Subscale 1: Unwanted effects | | |
| 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 |
| Subscale 2: Long-term effects | | |
| 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 |
| Subscale 3: Social/financial support | | |
| 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 ≤ 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                              | $\beta$ | 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.

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