Original Article

# Unmet Supportive Care Needs Survey among Male Partners of Gynecological Cancer Survivors in Indonesia

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ABSTRACT

**Objective:** The number of gynecological cancer survivors is increasing in Indonesia, and these women often require physical and emotional support from their male partners as primary caregivers. However, the male caregiver's need for biological, psychological, and social support is often neglected. This study aims to assess the demographic and clinical determinants affecting the unmet supportive care needs of the gynecological cancer survivors' husbands in Indonesia. **Methods:** This cross-sectional survey involved 152 husbands of survivors who were recruited by a consecutive sampling method in two national referral hospitals. A self-administered Cancer Survivors' Partners Unmet Needs Questionnaire was used for data collection. Multiple linear regression was performed to analyze the data. **Results:** The majority of participants (97.4%) reported at least one unmet need. The primary unmet needs were legal services (71.1%), financial support (70.4%), cancer recurrence concerns (69.7%), and ongoing health support (66.4%). These needs were significantly associated with the wife's radio-chemotherapy and lower household income ($P < 0.01$) and also related to the husband's education level, duration of caregiving, and wife's cancer stage. **Conclusions:** Husbands of gynecological cancer survivors in Indonesia reported a need for legal, financial, and health-care information and assistance. Multidisciplinary professionals should be involved in developing policy and interventions which facilitate the social-economic protection of survivors and their husbands, as well as comprehensive care needs to enhance the women's survival rate.

**Key words:** Gynecological cancer, supportive care needs, survivorship

## Introduction

Following the merits of early cancer screening and treatments, the number of gynecological cancer survivors has been increasing worldwide.[1] The World Health Organization estimated that the number of gynecological cancer (cervix uteri and ovary) in Indonesia increased from 31,166 cases in 2014 to 52,857 cases in 2020, and these cancers constituted 24.2% of new cancer cases in females.[2,3] These women need support for their

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biological, psychological, social, and spiritual lives after the gynecological cancer diagnosis.[4,5] Recent studies reported that most of the survivors experienced uncertainty, despair, anxiety, and depression because of cancer recurrence risk, decreasing the women's quality of life.[6-8] The distress of cancer diagnosis and treatment affects the ability of the women and their partners to adjust to the disease.[9]

The definition of cancer survivorship in the National Comprehensive Cancer Network Clinical Practice Guidelines in Oncology has been currently upgraded to include the family members and caregivers impacted by the survivorship experience.[10] The process of cancer treatment and rehabilitation can create biological, psychological, and social tensions for both gynecological cancer survivors and their male partners.[9,11] The profound impact of the disease and its treatment results in physical and psychosocial burdens on the survivor's partners, particularly when they are the main caregivers.[12,13] These men play crucial roles in their partner's basic care, treatment, and emotional well-being, and their stressful experience can impact their partner's psychological condition and adjustment ability.[9] However, since the major attention during cancer treatment is on the patient, the partner's needs are often neglected.[14,15]

To date, studies indicate that multifaceted issues affect the male partner's role and physical-emotional aspects in taking care of female cancer survivors including lack of information, shortage of social time, and deprivation of sexual activity.[15,16] Cancer survivors' partners experience challenges in meeting the women's needs, as their own needs for information, role adjustment, and emotional supports are undernoticed by health-care providers.[12] The lack of investigation and management of the needs of the survivors' partners may become the barriers for health-care providers to provide optimal care and treatment for the gynecological cancer survivors. By understanding and supporting the needs of the survivor's partner, providers are expected to help them adjust to the new roles and support them to be better caregivers.[9]

Supportive care assessment is not a routine practice for cancer patients in Indonesia. The country has not yet implemented a standard of oncology nursing practice in general and leaves behind the needs of survivors' husbands. There has been no research exploring the unmet needs of the survivors' husbands in Indonesia. This present study fills such a research gap. It aims to assess the demographic and clinical determinants affecting the unmet supportive care needs of the survivors' husbands in Indonesia, which, it is expected, will enable them to improve their support of the survivors. This research is part of a larger research project that focuses on developing gynecological cancer survivorship guidelines for clinical practice in Indonesia.

# Methods

## *Design, sample, and setting*

We conducted a cross-sectional survey at the oncology outpatient units of the Sardjito General Hospital Yogyakarta in Central Java Province and the Soetomo General Hospital in East Java Province from June to September 2018. Men whose wives had been diagnosed with gynecological cancer for at least 1 year were recruited using a consecutive sampling method. From 160 husbands of survivors invited to take part in this study, 152 agreed to participate, indicating a 95% response rate. The inclusion criteria of the participants were as follows: in a married relationship with a gynecological cancer survivor, 20–70 years old, the wife having completed primary cancer treatment, and living with no severe accompanying illness or mental disorder. Men whose wives were receiving intensive palliative care or experiencing cancer recurrence were excluded from the study.

## *Data collection*

The survey data were collected using a self-administered questionnaire which was delivered by research assistants who worked as nurse or midwife in the appointed hospitals and were recognized by the participants. Before the data collection, the research assistants provided the eligible participants with information about the study purposes, methods, and data collection process. Written informed consent was obtained from all individual participants involved in this survey study. The husbands of survivors were recruited in the inpatient or outpatient wards during their visit to the hospital for their wife's treatment or last cycle of cancer therapy. Although they were recruited by hospital staff, all participants were provided with the option to decline involvement or to withdraw from their participation in this research.

## *Measures*

A demographic survey was conducted to collect participants' demographic determinants, which consisted of socioeconomic characteristics (educational background, employment status, and personal income) and wife's clinical history (length of time husband caregiving the cancer survivor, cancer stages, and treatment details). Meanwhile, the main variable in this study, the male partner's unmet supportive care needs, was measured using the Cancer Survivors' Partners Unmet Needs-Indonesia (CaSPUN-I) Questionnaire.[17] This study adopted 35 items in CaSPUN-I to assess and identify the unmet supportive care needs of participants. Each item was scored as 0 for "no/met need" and 1 for "unmet need." The items were rated similarly to the CaSPUN-I to measure the unique needs of gynecological cancer survivors for supportive care and services. Then,

all unmet needs were classified into five discrete domains: comprehensive cancer care (15 items), partner impact (10 items), emotional support (5 items), protections (3 items), and relationships (2 items). The CaSPUN-I tool was modified from the Australian CaSPUN research instrument by Hodgkinson *et al.*, adjusted to the Indonesian cultural values related to some specific terminologies.[18] It has demonstrated good internal consistency, validity, and reliability among survivors' partners in Indonesia (Cronbach's alpha 0.97).[17] Permission for use was granted to the authors. The Indonesian version of the questionnaire was used to collect the data in this research.

### Statistical analysis

Data analyses were performed using IBM SPSS Statistics Base version 22 manufactured in Armonk, NY, US. Descriptive statistics including frequency, percentage, and mean score were used to analyze the demographic characteristics and unmet needs of the participants. Afterward, multiple linear regression was used to compare the score of unmet needs with the demographic characteristics of the participants.

### Ethical approval

The ethical approval for this study (Approval No. 28/UN2.F12.D/HKP. 02.04/2018) was obtained from the Faculty of Nursing, Universitas Indonesia, while research permits were obtained from each hospital in which the study was conducted.

## Results

### Participants' demographics and wives' clinical determinants

The mean age of the participant was 52 years old (ranging from 23 to 74 years), while the mean age of their wives was 48 years old (ranging from 20 to 68). The majority of the participants completed at least middle school (71.7%), worked (87.5%), had family monthly income ≤IDR 2,000,000/month (72.4%), and had been caring for their wives for at least 1 year (66.4%). Most of the participants' wives were diagnosed with Stage III gynecological cancers, i.e. ovarium, cervical, and endometrium cancer (40.1%) and had received chemotherapy (49.3%) [Table 1]. However, 11,8% participants were unaware of their wife's cancer staging, while wife's medical record does not show it as well.

### Participants' unmet needs for supportive care

The present study found that total mean score of the unmet supportive care needs reported by the participants was 17 (ranging from 0 to 35). Of the 152 participants, 97.4% reported at least one unmet supportive care need. The highest percentages of specific unmet needs were aligned under the protection and comprehensive cancer care domains, particularly related to legal services to protect them, as caregiver, from malpractice (71.1%), financial assistance from the government or other funding agency (70.4%), support to mitigate the fear of cancer recurrence (69.7%), and easy access to health-care providers who can be contacted whenever necessary (66.4%) [Table 2].

The mean scores of specific unmet needs varied according to the participants' demographics and clinical determinants. Nearly 11.8% of participants with the highest education level (completing academy or university) had the lowest unmet needs (score 14.9/35). Regarding occupation, the lowest mean score of unmet needs was found among unemployed men (score 12.1/35), while employed participants had higher mean unmet care needs (score 17.7/35) [Table 1].

Participants with the lowest monthly income experienced the highest mean score of unmet supportive care needs (score 19.3/35). The higher the income, the less unmet supportive needs occurred [Table 1]. However, the linear regression analysis of this study indicated that the household monthly income is not significantly associated with the participants' unmet needs [$P < 0.05$; Table 3]. The fact that some working partners could not participate in this study might affect the significant association of income to the score of the unmet needs. These results were also explained by the specific unmet concerns presented in Table 2, which shows that most participants (70.4%) need information on obtaining financial support.

The clinical history of the wife also influenced the unmet need for supportive care of these gynecological cancer survivors' husbands. When the husbands had taken care of their wife for a longer time, their unmet needs for supportive care decreased. Of 152 participants, the mean score of participants' unmet needs was high in the 1st and 2nd years of caregiving (17.7/35 and 19.4/35) but declined afterward. Nearly 15.1% of participants, who had been caregiving for more than 2 years, reported the lowest need for supportive care (score 10.8/35). Last, participants whose wives had received only radiotherapy or combined radiochemotherapy treatment showed the most severe need of supportive care (score > 22/53) of all determinants. This indicates that a husband whose wife received combined radio-chemotherapy or single radiotherapy had the highest unmet care needs [Table 1]. Regression analysis in the present study indicated that the unmet supportive care needs of the survivors' husbands were associated significantly with the type of cancer therapy, particularly radiochemotherapy ($P < 0.002$) and radiotherapy [$P < 0.029$; Table 3]. In line with this finding,

**Table 1: Participants' demographics and mean score of unmet supportive care needs ($n$=152)**

| Variables | *n* (%) | Mean score | SD score | Significant |
|---|---|---|---|---|
| Education level | | | | |
| Primary school | 43 (28.3) | 16.6 | 12.5 | 0.675 |
| Middle school | 34 (22.4) | 18.8 | 11.5 | |
| High school | 57 (37.5) | 16.8 | 11.2 | |
| Academy/university | 18 (11.8) | 14.9 | 9.0 | |
| Occupation | | | | |
| Employed | 133 (87.5) | 17.7 | 11.3 | 0.044* |
| Unemployed | 19 (12.5) | 12.1 | 10.7 | |
| Household monthly income (IDR) | | | | |
| <1,000,000 | 58 (38.2) | 19.3 | 11.7 | 0.138 |
| 1,000,000-2,000,000 | 52 (34.2) | 15.2 | 11.7 | |
| >2,000,000 | 42 (27.6) | 16.0 | 10.2 | |
| Duration of survivors' caregiving (years) | | | | |
| <1 | 101 (66.4) | 17.7 | 11.1 | 0.014* |
| 1-2 | 28 (18.4) | 19.4 | 12.6 | |
| >2 | 23 (15.1) | 10.8 | 9.1 | |
| Survivor's cancer stage | | | | |
| Do not know*** | 18 (11.8) | 14.6 | 9.4 | 0.039* |
| 1 | 26 (17.1) | 12.6 | 9.4 | |
| 2 | 40 (26.3) | 19.2 | 12.3 | |
| 3 | 61 (40.1) | 18.8 | 11.7 | |
| 4 | 7 (4.6) | 10.6 | 8.1 | |
| Type of survivors' cancer therapy | | | | |
| Chemotherapy | 75 (49.3) | 14.2 | 10.3 | <0.001** |
| Radiation | 25 (16.4) | 22.2 | 10.5 | |
| Radio-chemotherapy | 27 (17.8) | 24.9 | 11.5 | |
| Surgery or other combined treatments | 25 (16.4) | 11.4 | 8.6 | |

*$P$<0.05, **$P$<0.01. ***Participants did not know their wife cancer stage and the stage was not stated in survivors' medical record. SD: Standard deviation

66.4% sought easy access to health-care providers and 57.9% sought help to manage ongoing side effects and/or complications that their wife experienced because of the treatment [Table 2].

## Discussion

In understanding the husbands' needs as a caregiver for gynecological cancer survivors in Indonesia, this present study examined the primary unmet supportive care needs of survivors' husbands and the intertwined determinants affecting their needs. The majority of these husbands (more than 70%) indicated a high demand for social protection and comprehensive cancer care including legal, financial, and psychological services, and on-demand health-care assistance and information to support them in nurturing their wives adequately. Consistent with these results, a systematic review of six countries exploring the family experience in caregiving gynecological cancer survivors[13] suggests that as a caregiver, male partners felt an increasing life burden because of their caring responsibilities, working instability, and financial difficulties during survivors' therapy, while the quality of their social life and interpersonal relationship with the survivor degraded. Studies in low-, middle-, and high-income countries noted that many of the caregivers of cancer survivors felt exhausted, anxious, and depressed, sometimes to a greater degree than experienced by the survivors, while health-care providers overlooked their well-being and ignored inquiries of support.[13,14,19] The financial issues and fear of recurrence experienced by the partners were in line with the survivors' distress.[7,9,20] National health policy is urgently needed to consolidate the legal and economic burdens faced by the gynecological cancer survivors and their caregivers.[21]

This study highlights that the major unmet needs of the gynecological cancer survivors' husbands, in which the CaSPUN mean scores were the highest, are highly influenced by the wife's treatment of radiochemotherapy or radiotherapy only ($P$ < 0.001). The cancer treatments may yield short- and long-term effects on the physical and psychosocial well-being of both gynecological cancer survivors and their partners.[8,16] Radiotherapy can create scarring of vaginal tissue that obstructs male penetration as the vagina becomes shortened and stenosed, while chemotherapy may cause body image and sexual identity disturbance.[22,23] Consistent with this result, other literature suggests that, although radiotherapy is highly recommended for Stage I and II gynecological cancer patients, as it relates to a higher survival rate, the treatment often results in more

**Table 2: Proportions of unmet needs for supportive care reported by the husband of gynecological cancer survivors in Indonesia ($n$=152)**

| Number | CaSPUN-I items | $n$ (%) | Domain |
|---|---|---|---|
| 17 | Need help to get legal protection | 108 (71.1) | Protection |
| 15 | Need information how to get financial support | 107 (70.4) | Protection |
| 18 | Need help on concerns of cancer recurrence | 106 (69.7) | Comprehensive cancer care |
| 11 | Easy to reach health care providers for partners | 101 (66.4) | Comprehensive cancer care |
| 3 | Need understandable information | 91 (59.9) | Comprehensive cancer care |
| 4 | Need information about local health services | 90 (59.2) | Comprehensive cancer care |
| 2 | Need information as a partner | 89 (58.6) | Comprehensive cancer care |
| 9 | Need help to manage treatment's side effects of partner | 88 (57.9) | Comprehensive cancer care |
| 8 | Need help to reduce stress in partner's life | 86 (56.6) | Comprehensive cancer care |
| 10 | Need help for own health | 86 (56.6) | Comprehensive cancer care |
| 7 | Need that complaints be addressed | 80 (52.6) | Comprehensive cancer care |
| 1 | Need update information about partner's condition | 78 (52.0) | Comprehensive cancer care |
| 19 | Need emotional support | 76 (50.0) | Comprehensive cancer care |
| 26 | Need help to deal with the life changes | 75 (49.3) | Partner impact |
| 31 | Need help so partner can move on | 71 (48.7) | Partner impact |
| 5 | Manage partner's health with health care provider team | 73 (48.0) | Comprehensive cancer care |
| 16 | Need information how to get health insurance | 72 (47.4) | Protection |
| 21 | Help how to support partner | 71 (46.7) | Comprehensive cancer care |
| 14 | Need help to deal with the impact on my working life | 70 (46.1) | Emotional support |
| 35 | Need help to make my life count | 69 (45.4) | Partner impact |
| 28 | Need help to adapt with physical changes of my partner | 68 (44.7) | Partner impact |
| 32 | Need help to deal with other that do not understand the change life | 70 (46.1) | Partner impact |
| 20 | Need help to communicate with others | 69 (45.4) | Comprehensive cancer care |
| 6 | Need to know that the health care team works together for his partner | 68 (44.7) | Comprehensive cancer care |
| 33 | Need help to deal with uncertainty | 67 (44.1) | Partner impact |
| 20 | Need help to communicate with others | 67 (44.1) | Comprehensive cancer care |
| 6 | Need to know that the health care team works together for his partner | 66 (43.4) | Comprehensive cancer care |
| 33 | Need help to deal with uncertainty | 65 (42.8) | Partner impact |
| 27 | Need help to cope with the impact on relationship | 65 (42.8) | Partner impact |
| 12 | Need accessible hospital parking area | 64 (42.1) | Emotional support |
| 22 | Need support for loved ones | 63 (41.4) | Emotional support |
| 25 | Need help with additional responsibilities | 61 (40.1) | Partner impact |
| 29 | Help to deal with intimacy | 60 (39.5) | Relationship |
| 23 | Need help to talk with other who have same situation | 58 (38.2) | Partner impact |
| 13 | Need help to deal with partner's life changes | 54 (35.5) | Emotional support |
| 24 | Need help to explain partner's condition to other | 49 (32.2) | Emotional support |
| 34 | Need help on spiritual belief | 48 (31.6) | Partner impact |
| 30 | Help to get children | 31 (20.4) | Relationship |

CaSPUN-I: Cancer Survivors' Partners Unmet Needs-Indonesia

negative impacts, particularly to the social, emotional, and sexual burden of the gynecological cancer survivors.[6,23,24] A systematic review of 14 quantitative studies by Tsatsou *et al*. (2019) highlights that sexual dysfunction, including decreased libido, vaginal dryness, and dyspareunia, were still present in the long term after radiotherapy of cervical cancer and were strongly related to survivors' depression.[25] Long-term life impacts of treatment to gynecological cancer survivors increase the male partners' care needs to maintain a healthy sexual relationship, as in the Asian cultural context, many are reluctant to talk about psychosexual issues with their partner and to obtain sexual care.[26-28] Couple psychosexual interventions, such as private counseling and education, may assist the survivors and their partners in meeting their sexual needs and maintaining their relationships following cancer treatment.[29]

Contrary to studies in high-income countries, in which family caregivers were appraised as a health-care system saver,[4,12,30] our study indicated that the highest proportions of husbands' unmet needs were legal protection and financial assistance information. Cancer treatment creates a harmful financial burden for cancer survivors in Indonesia as the national health coverage only pays the cancer treatment inside health-care facilities and no caregiving funds can be accessed by cancer survivors or their caregivers.[31] Developing a comprehensive cancer

**Table 3: The results of the multiple regression score of unmet supportive care needs ($n$=152)**

| Variables | $B$ | SE | $t$ | Significant |
|---|---|---|---|---|
| Intercept | 3.70 | 5.47 | 0.68 | 0.500 |
| Education level | | | | |
| Primary school | −2.11 | 3.65 | −0.58 | 0.564 |
| Middle school | −0.55 | 3.73 | −0.15 | 0.884 |
| High school | 0.85 | 3.07 | 0.28 | 0.783 |
| Academy/university (reference) | | | | |
| Occupation | | | | |
| Employed | 4.70 | 2.65 | 1.78 | 0.078 |
| Unemployed (reference) | | | | |
| Household monthly income (IDR) | | | | |
| <1,000,000 | 3.08 | 2.70 | 1.14 | 0.256 |
| 1,000,000-2,000,000 | 0.12 | 2.47 | 0.05 | 0.962 |
| >2,000,000 (reference) | | | | |
| Duration of survivors' caregiving (years) | | | | |
| <1 | 3.64 | 2.61 | 1.40 | 0.165 |
| 1-2 | 4.06 | 3.10 | 1.31 | 0.192 |
| >2 (reference) | | | | |
| Survivor's cancer stage | | | | |
| Unknown*** | 1.00 | 4.78 | 0.21 | 0.835 |
| 1 | −0.57 | 4.60 | −0.12 | 0.901 |
| 2 | 2.37 | 4.46 | 0.53 | 0.597 |
| 3 | 2.55 | 4.35 | 0.59 | 0.558 |
| 4 (reference) | | | | |
| Type of survivors' cancer therapy | | | | |
| Chemotherapy | 0.89 | 2.65 | 0.33 | 0.738 |
| Radiation | 7.55 | 3.42 | 2.21 | 0.029** |
| Radio-chemotherapy | 10.17 | 3.27 | 3.11 | 0.002* |
| Surgery or other combined treatments (reference) | | | | |

*$P$<0.05; **$P$<0.01. ***Participants did not know their wife cancer stage and the stage was not stated in survivors' medical record.

care program in Indonesia will require multidisciplinary approaches, including legal and funding bodies, to optimally provide for the survivors' health rights and the husbands' needs in caregiving for their wives.

Although no significant association was found, those from the lowest income group (<IDR 1,000,000 or 71 USD) reported the highest unmet needs. Other specific demographic groups which reported high unmet needs scores for the husband, but not showing correlation, were those who were employed and those who had no academy or university degree. Consistent with these findings, a systematic review by Teskereci and Kulakac[13] and Zuo *et al*.[23] reported that the caregivers' new roles lowered their quality of life and that the negative impact was even worse when the caregivers had low education, low income, and unstable jobs. A qualitative study of family caregivers in Indonesia described that caregivers experienced financial and employment disturbance during their home-based palliative care for cancer patients.[32]

On the other hand, some husbands in the present study demonstrated low scores of unmet needs according to their sociodemographics and wife's clinical status. Although no significant association was found, the husbands who had a longer period of caregiving (more than 2 years) and a wife with cancer Stage of I or IV had lower scores of unmet care needs. A scoping review by Petricone-Westwood and Lebel postulates that the well-being and life quality of ovarian cancer caregivers changed over time and tended to decline.[15] Recent studies reported that the survivors' cancer stage was highly related to the type of therapy received, which might cause different complications for the women and increase the supportive care needs of the caregivers, particularly regarding cancer care information.[6,8,33]

### Limitations

Several limitations are noted in the present study. First, our study has a small sample size and was not randomized because some of the gynecological cancer survivors were accompanied by family members other than their husbands, who were working. Meanwhile, some other survivors did not have a husband. We anticipated this limitation using consecutive sampling and collected the data from two different public hospitals in two different provinces. Data collection was conducted in public hospitals and did not capture the unmet needs of caregivers of survivors who sought medical services in private hospitals. This is

noteworthy as the type of hospital may represent different socioeconomic groups. Thus, our sample generalizability is reduced. A qualitative study to explore the need for supportive care among caregivers of gynecological cancer survivors, and the social-cultural factors influencing their needs, is recommended for future research.

# Conclusions

The male partners (husbands) of gynecological cancer survivors in Indonesia reported various unmet needs of supportive care, which were significantly affected by the husbands' socioeconomic and the survivors' clinical determinants. The highest support needed by the survivors' husbands was related to legal, financial, and health-care information and assistance. Radiation-related therapy, lower socioeconomic status, and shorter duration of caregiving led to higher unmet care needs. Health-care interventions for the gynecological cancer survivors should be designed not only to address the survivors' supportive care needs but also their husband's needs of legal, financial, and health-care information. Health education and counseling should be provided to the survivors and their husbands before and after the radiation-related therapy. Interdisciplinary and key stakeholder collaborations are urgently required in developing health-care strategies that address the supportive care needs of gynecological cancer survivors and their husbands. Addressing the biological, psychological, and social needs of these couples is expected to improve their well-being across the survivorship continuum.


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## *Conflicts of interest*

The corresponding author, Prof. Yati Afiyanti, is an editorial board member of *Asia-Pacific Journal of Oncology Nursing*. The article was subject to the journal's standard procedures, with peer review handled independently of Prof. Afiyanti and their research groups.


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