

# Perceived Healthcare Team Support and Emotional Health Among Gynecologic Cancer Survivors

Megan Olson, Ashley Stenzel, PhD, Katherine Brown, BS, Patricia Jewett, PhD, Rachel Vogel, PhD

## Abstract

Gynecologic oncology survivors face many challenges during and after their cancer treatment. Emotional and social support can help mitigate the potential negative effects on quality of life and can improve patients' mental health. Our objective for this study was to assess whether patients' satisfaction with the support received from their healthcare team was associated with less anxiety, depression, or distress. Individuals with a previous gynecologic cancer diagnosis treated at the University of Minnesota completed a cross-sectional survey regarding their satisfaction with support provided by various members of their healthcare team: physicians, nurses, and other support staff. Participants of this study were on average 60.6±10.6 years old, with 45.0% diagnosed with endometrial cancer and 37.2% diagnosed with ovarian cancer. The overwhelming majority (82.9%) of respondents were highly satisfied with the care they received and valued this support. Overall, this study found that gynecologic oncology patients receiving care at the University of Minnesota are satisfied with the emotional support they are receiving from their healthcare team. Our conclusion does not address our initial aim due to subject's high level of and little variation in satisfaction with support received. Future research gathering longitudinal data from diagnosis through treatment and beyond would provide further insight into gynecologic oncology patient's emotional health as it relates to emotional support satisfaction.

## Introduction

As the number of cancer survivors increases, the long-term negative effects of treatment as well as the disease itself have become a substantial public health concern. Morbidity can be high depending on the specific disease, and can cause multiple physical and emotional symptoms, which may

become chronic. Quality of life is important to cancer patients, with evidence showing it matters equally, if not more than, length of life. While emotional health and distress and their relationship with patient quality of life have been studied, 2, 3, 4, 5, 6 few studies have looked at how support from healthcare providers can impact emotional health. 7,8



Satisfaction with someone's healthcare team is a complex issue dependent on many factors: expectations, results of treatment, cost, convenience, pain, and setting. When a patient is not satisfied with their cancer care they may become distressed, which can negatively impact health outcomes. Furthermore, few studies have investigated patient-reported healthcare team support in gynecologic oncology; those that have focused on patient's satisfaction with the support given by nurses.

To address gaps in the literature, we investigated satisfaction with support given by different members of the healthcare team among individuals with gynecologic cancers. In this study, we sought to describe the association between perceived satisfaction of emotional support provided by different members of the healthcare team and patients' emotional health in an ongoing cohort study of gynecologic cancer patients at the University of Minnesota. We hypothesized that gynecologic cancer survivors who reported feeling unsupported by their healthcare team would have poorer quality of life and emotional health, including symptoms of distress, anxiety, and depression.

## Methods

Study Design and Population

This cross-sectional survey was part of an ongoing prospective cohort study with recruitment from 2017 until 2020. The GOLD study was approved by the University of Minnesota Institutional Review Board (No. 1612S01581). Eligibility criteria included being 18 years or older, having a previous diagnosis of gynecologic cancer that was treated at the

University of Minnesota, and being able to read/write in English. Potential participants were identified using electronic medical records. Participants provided informed consent and Health Insurance Portability Accountability Act (HIPAA) forms allowing the research team to access their medical record.

Recruitment and Data Collection
Individuals participating in the cohort study were invited to participate in a follow-up cross-sectional survey in July 2020.
Participants stated their preference of completing an online REDCap or paper (mailed) survey at study entry. Clinical records were reviewed for pertinent data relating to cancer type and treatment received.

Measures

Survey information collected included: demographics, emotional health measures, and questions about satisfaction with each of the different members of their healthcare team (doctors, nurses, and support staff). Subjects reported their satisfaction with support on a 0-10 scale, with 0 reflecting "Not at all Satisfied" and 10 representing "Extremely Satisfied." The primary outcome of this study was the satisfaction of subjects with the support given by the nurses, doctors, and other support staff throughout their gynecologic oncology treatment at the University of Minnesota.

Cancer-related distress was measured using the National Comprehensive Cancer Network Distress Thermometer, version 2.2016; with higher scores indicating greater distress 10. Depression was measured using the Patient Health Questionnaire-8 (PHQ-8) score; where higher scores indicate more depression

symptoms<sup>11</sup>. Generalized anxiety was measured using the General Anxiety Disorder-7 (GAD-7), with higher scores indicating greater anxiety severity<sup>12</sup>.

Clinically relevant information extracted from medical records included date of cancer diagnosis, location of primary cancer, cancer stage, comorbidities, and treatment. Statistical Analysis

Frequency distributions were measured to examine dispersal of responses with respect to satisfaction with support by various health team members, satisfaction with receipt of medical information, demographic (i.e. race, education, marital status, income, employment, residence) and clinical characteristics (i.e. cancer type, disease stage, surgical/chemotherapeutic/radiation interventions). The perceived support measures were consistently high with minimal variability, therefore limiting our ability to conduct statistical analyses. Data were analyzed using SAS 9.4 (Cary, NC).

# Results

Among the 338 active study participants invited to the cross-sectional survey, 234 (69.2%) completed the survey and were included in this analysis. All participants who completed this survey self-identified as female. The mean age of respondents was 60.6 ±10.6 years and participants were on average of 2.2±0.09 years from their cancer diagnosis (Table 1). The majority of women in this study were white (98.7%), had no college degree (57.6%), and were in a relationship (63.4%). The most common cancer types were endometrial/uterine cancer (45.0%) and ovarian/fallopian tube/primary peritoneal

cancer (37.2%). The cancers listed are grouped together due to the fact they are treated similarly, even though the cancers themselves are different. Most respondents had early stage disease (63.0%); almost all participants had surgery as part of their treatment plan (93.5%), most had chemotherapy (62.8%); and some received radiation (30.3%).

The majority of respondents reported that feeling supported by their provider was extremely important (Table 2). Across all members of the healthcare team, the overwhelming majority of respondents were highly satisfied with the support received: oncology healthcare team (median 10, mean 8.88±1.73), gynecology or primary care physician (median 10, mean 8.65±2.06), and gynecology or primary care support staff (median 9.5, mean 8.68±1.81). The overwhelming majority of respondents also believed that their providers were concerned about their patient's emotional and that it was important to receive understandable medical information.

Due to the vast majority of respondents feeling satisfied with their support received, no further analyses could be performed to investigate the associations between satisfaction with support and potential emotional health impacts since there was little variability with regards to satisfaction with support, with only a small number of individuals who were not satisfied with their supportive care.

## Discussion

Gynecologic oncology patients participating in this study reported high satisfaction with the support provided by the healthcare team. These data are consistent with patient satisfaction surveys of all patients receiving care within the MHealth Gynecologic Oncology Clinic surveys. These surveys also report that the majority of patients receiving care at the University of Minnesota are satisfied with the support received<sup>13</sup>. This finding is also consistent with self-reported satisfaction with gynecologic oncology care at other accredited cancer institutes (for example, Johns Hopkins: (https://www.hopkinsmedicine.org/gynecolo gy\_obstetrics/specialty\_areas/gynecologic\_o ncology/research\_safety\_and\_quality/patient satisfaction.html)<sup>14</sup>. These data suggest that National Comprehensive Cancer Network (NCCN) guidelines on supportive care may have been met among participants in this study $^{15}$ .

Mattsson et al. (2018) investigated distress in cancer patients and their need for support services based on the perceived adequacy of the support received5. The authors concluded that most gynecologic patients who experienced more distress were in need of more support services. They also investigated reasons why patients did not seek out support services. One of the reasons many patients did not seek support was because they did not know who to turn to. Mattson et al (2018) recommended that patients who are not satisfied with their results need to be referred to more support services in order to decrease their distress levels. While this study was not able to investigate distress levels of those who were not satisfied, an important next step is to describe patient's utilization and satisfaction with offered support services outside from their primary and oncologic medical teams.

Patients in this study were seen at the

University of Minnesota, which is one of two National Cancer Institute (NCI)-designated comprehensive cancer centers in the state. To obtain this NCI status, cancer care facilities are required to offer ongoing top-effort basic, translational, and clinical research portfolios, active leadership promoting NCI-designated efforts, community outreach, and extensive resources for patients living with cancer 16. As such, it is plausible that patients seen for their cancer treatment at the University of Minnesota receive on average more support and resources than other clinics. In a study examining ovarian cancer, being treated at an NCI-designated cancer institute was found to be directly associated with adherence to treatment guidelines and was associated with improved cancer survival when compared to those treated at alternative institutes <sup>17</sup>. Another study identified that greater distance of patient residence with respect to NCIdesignated comprehensive cancer centers was associated with worse cervical cancer outcomes 18. Similar findings have been found for other cancer sites, even when adjusting for socioeconomic and other demographic variables <sup>19, 20</sup>. The impact of the high standards of care and resources associated with care at an NCI-designated center may play a role in the satisfaction with care among patients at the University of Minnesota. Future studies examining patient reported satisfaction and outcomes associated with delivery of care by center status should be explored.

#### Limitations

This study has limitations. Crosssectional surveys only offer information at one point in time. Our study is limited by a relatively small homogenous sample of primarily white and non-college educated individuals who reported a high rate of satisfaction with care. Social desirability bias may be playing a role as participants may feel obligated to answer positively after the physicians and their staff treated them for cancer. In addition, more detailed questions may have allowed us to observe nuanced differences in satisfaction with care.

## **Conclusion and Future Research**

The aim of this study evolved throughout the course of data analysis. Since the overwhelming majority of our respondents were highly satisfied with the care they received at the University of Minnesota Gynecologic Oncology clinics, we were not able to run any analyses of anxiety, depression, or distress on those who were not satisfied. In the future, it would be important to identify patients who were not satisfied with the support services offered at the University of Minnesota during their cancer treatment and investigate whether these negative feelings impacted their mental health in terms of anxiety, depression, or distress.

To conclude, this study found that gynecologic oncology patients receiving care at the University of Minnesota are satisfied with the support they are receiving from all aspects of their healthcare team. It is important to monitor support satisfaction among patients over time to ensure care is remaining satisfactory throughout and beyond treatment. Additional research is needed to further understand the associations between support provided by the healthcare team and emotional health among cancer survivors.

Table 1. Participant demographic and clinical characteristics.

Characteristic	Mean (SD)
Age, years	60.6 (10.6)
Time since diagnosis, years	2.2 (0.9)
	n (%)
Race	
White, Non-Hispanic	227 (98.7%)
Other	3 (1.3%)
Education	
No college degree	129 (57.6%)
At least one college degree	95 (42.4%)
Income	
<\$50,000	77 (34.7%)
\$50,000-\$99,999	75 (33.8%)
≥\$100,000	50 (22.5%)
Prefer not to say	20 (9%)
Relationship status	
Not in a relationship	81 (36.7%)
In a relationship	140 (63.4%)
Disease stage	
Early (I/II)	143 (63%)
Advanced (III/IV)	84 (37%)
Disease site	
Ovarian/Fallopian tube/Primary peritoneal	86 (37.2%)
Cervical cancer	24 (10.4%)
Endometrial/uterine cancer	104 (45%)
Vaginal cancer	4 (1.7%)
Vulvar cancer	10 (4.3%)
Other	3 (1.3%)
Receipt of surgery	
No	15 (6.5%)
Yes	216 (93.5%)
Receipt of chemotherapy	
No	86 (37.2%)
Yes	145 (62.8%)
Receipt of radiation	
No	161 (69.7%)
Yes	70 (30.3%)

Table 2. Reported support by healthcare providers.

Variable	n (%)
Importance of feeling supported by provider 0 (Not important at all) 1 2 3 4 5 6 7 8 9 10 (Extremely important)	2 (0.9%) 1 (0.4%) 1 (0.4%) 1 (0.4%) 2 (0.9%) 6 (2.6%) 8 (3.5%) 14 (6%) 29 (12.5%) 22 (9.5%) 146 (62.9%)
Satisfied with Oncology Healthcare team 0 (Not at all satisfied) 1 2 3 4 5 6 7 8 9 10 (Extremely satisfied)	0 (0%) 1 (0.4%) 1 (0.4%) 3 (1.3%) 3 (1.3%) 10 (4.3%) 3 (1.3%) 13 (5.6%) 32 (13.4%) 40 (17.2%) 126 (54.3%)
Satisfied with Gynecology or Primary Care Physician 0 (Not at all satisfied) 1 2 3 4 5 6 7 8 9 10 (Extremely satisfied)	1 (0.4%) 2 (0.9%) 0 (0%) 7 (3%) 4 (1.7%) 13 (5.7%) 4 (1.7%) 13 (5.7%) 25 (10.9%) 40 (17.4%) 121 (52.6%)
Satisfied with Gynecology or Primary Care Support Nurses/Support Staff 0 (Not at all satisfied) 1	0 (0%) 0 (0%) 1 (0.4%)

2 3 4 5 6 7 8 9 10 (Extremely satisfied)	3 (1.3%) 4 (1.7%) 16 (7%) 6 (2.6%) 13 (5.7%) 36 (15.7%) 36 (15.7%) 115 (50%)
Feel patient support concern of Oncology Healthcare Team No Yes Unsure	8 (3.4%) 197 (84.6%) 28 (12%)
Feel patient support concern of Gynecology or Primary Care Physician No Yes Unsure	10 (4.3%) 188 (81%) 34 (14.7%)
Feel patient support concern of Gynecology or Primary Care Nurses/Support Staff No Yes Unsure	6 (2.6%) 193 (82.8%) 34 (14.6%)
Important to receive understandable medical information Not important at all Somewhat important Very important	1 (0.4%) 20 (8.6%) 212 (91%)
Received medical information in understandable way No Yes	3 (1.3%) 228 (98.7%)

# References

- [1] Hodgkinson, K., Butow, P., Fuchs, A., Hunt, G. E., Stenlake, A., Hobbs, K. M., Brand, A., Wain, G. (2007). Long-term survival from gynecologic cancer: Psychosocial outcomes, supportive care needs and positive outcomes. *Gynecologic Oncology*, 104(2), 381–389. https://doi.org/10.1016/j.ygyno.2006.08.036
- [2] Fitch, M. I. (2003). Psychosocial management of patients with recurrent ovarian cancer: Treating the whole patient to improve quality of life. *Seminars in Oncology Nursing*, 19(SUPPL. 1), 40–53. https://doi.org/10.1016/S0749-2081(03)00060-3
- [3] Steele, R., & Fitch, M.I. (2008). Supportive Care Needs of Women With Gynecologic Cancer. *Cancer Nursing*, *31*(4), 284-291. doi: 10.1097/01.ncc.0000305743.64452.30
- [4] Cassedy, H. F., Tucker, C., Hynan, L. S., Phillips, R., Adams, C., Zimmerman, M. R., ...Stringer, C. A. (2018). Frequency of psychological distress in gynecologic cancer patients seen in a large urban medical center. *Baylor University Medical Center Proceedings*, 31(2), 161–164. https://doi.org/10.1080/08998280.2018.1440857
- [5] Mattsson, E., Einhorn, K., Ljungman, L., Sundström-Poromaa, I., Stålberg, K., & Wikman, A. (2018). Women treated for gynaecological cancer during young adulthood A mixed-methods study of perceived psychological distress and experiences of support from health care following end-of-treatment. *Gynecologic Oncology*, 149(3), 464–469. https://doi.org/10.1016/j.ygyno.2018.03.055
- [6] Johnson, C., George, M., & Fader, A. (2017). Distress Screening: Evaluating a Protocol for Gynecologic Cancer Survivors. Clinical Journal of Oncology Nursing, 21(3). 353-361. doi: 10.1188/17.cjon.353-361
- [7] Power, J., Brown, L., & Ritvo, P. (2008). A qualitative study examining psychosocial distress, coping, and social support across the stages and phases of epithelial ovarian cancer. *Health Care for Women International*, 29(4), 366–383. https://doi.org/10.1080/07399330701876521
- [8] Lutgendorf, S. K., Sood, A. K., Anderson, B., McGinn, S., Maiseri, H., Dao, M., ...

  Lubaroff, D. M. (2005). Social support, psychological distress, and natural killer cell activity in ovarian cancer. *Journal of Clinical Oncology*, https://doi.org/10.1200/JCO.2005.10.015

  23(28), 7105–7113.

- [9] Graham, B. (2016). Defining and Measuring Patient Satisfaction. *Journal of Hand Surgery*, 41(9), A2-e329.
- [10] NCCN Managing Stress and Distress. Available at: https://www.nccn.org/patients/resources/life\_with\_cancer/distress.aspx. (Accessed: 29th March 2020)
- [11] Kroenke, K., Spitzer, R. L. & Williams, J. B. W. The PHQ-9: Validity of a brief depression severity measure. *J. Gen. Intern. Med.* **16**, 606–613 (2001).
- [12] Spitzer, R. L., Kroenke, K., Williams, J. B. W. & Löwe, B. A brief measure for assessing generalized anxiety disorder: The GAD-7. *Arch. Intern. Med.* **166**, 1092–1097 (2006).
- [13] Discover Our Difference. (n.d.). Retrieved December 31, 2020, from https://www.mhealth.org/discover-our-difference/adult-patient-experience
- [14] Patient Satisfaction and Quality. (2017, August 11). Retrieved December 31, 2020, from <a href="https://www.hopkinsmedicine.org/gynecology\_obstetrics/specialty\_areas/gynecologic\_oncology/research\_safety\_and\_quality/patient-satisfaction.html">https://www.hopkinsmedicine.org/gynecology\_obstetrics/specialty\_areas/gynecologic\_oncology/research\_safety\_and\_quality/patient-satisfaction.html</a>
- [15] National Comprehensive Cancer Network. (n.d.). Retrieved December 31, 2020, from https://www.nccn.org/professionals/physician\_gls/default.aspx
- [16] NCI-Designated Cancer Centers. (n.d.). Retrieved December 31, 2020, from https://www.cancer.gov/research/infrastructure/cancer-centers
- [17] Bristow, R., Chang, J., Ziogas, A., Campos, B., Chavez, L., & Anton-Culver, H. (2015). Impact of NCI Comprehensive Cancer Centers on ovarian cancer treatment and survival. *Gynecologic Oncology*, *138*, 2-3. doi:10.1016/j.ygyno.2015.04.020
- [18] Barrington, D. A., Dilley, S. E., Landers, E. E., Thomas, E. D., Boone, J. D., Straughn, J. M., . . . Leath, C. A. (2016). Distance from a Comprehensive Cancer Center: A proxy for poor cervical cancer outcomes? *Gynecologic Oncology*, 143(3), 617-621. doi:10.1016/j.ygyno.2016.10.004
- [19] Wolfson, J. A., Sun, C., Wyatt, L. P., Hurria, A., & Bhatia, S. (2015). Impact of care at comprehensive cancer centers on outcome: Results from a population-based study. *Cancer*, *121*(21), 3885-3893. doi:10.1002/cncr.29576
- [20] Birkmeyer, N. J., Goodney, P. P., Stukel, T. A., Hillner, B. E., & Birkmeyer, J. D. (2005). Do cancer centers designated by the National Cancer Institute have better surgical outcomes? *Cancer*, *103*(3), 435-441. doi:10.1002/cncr.20785