

## **Upstream oncology: identifying social determinants of health in a gynecologic oncology population**

Anne E. Nora, MD,<sup>1</sup> Megan E. McDonald, MD,<sup>2</sup> Craig H. Syrop, MD, MHCDS,<sup>3</sup> Michael L. Haugsdal, MD<sup>3</sup>

**Keywords:** Social determinants of health, upstream, women's health, health disparities, social needs, gynecologic oncology

### **Abstract**

**Introduction:** Social determinants of health (SDoH) are the factors that affect a patient's health quality and outcomes and contribute to health disparities. Evidence suggests that clinical care contributes only 20% to patients' health outcomes, while the remainder is under the influence of upstream factors. The upstream approach to healthcare aims to address SDoH before they contribute to less ideal outcomes downstream. Several SDoH may contribute to outcomes for cancer patients. This Upstream Gynecologic Oncology Initiative seeks to identify which SDoH affect a population of patients with gynecologic malignancies.

**Hypothesis:** This study hypothesizes that women receiving care for gynecologic malignancies are affected by specific SDoH among the categories of housing, food, transportation, finances, health literacy and social support. This study aims to identify the frequency of these six social factors among the outpatient gynecologic oncology population at the University of Iowa.

**Methods:** This needs assessment is the first phase in a quality improvement project assessing the SDoH affecting women with gynecologic cancers. Two hundred twenty-two patients receiving outpatient care for gynecologic malignancies completed an anonymous needs assessment survey. Validated survey questions regarding housing, food, transportation, finances, health literacy and social support were used to identify needs. Responses were considered positive if any degree of need was reported.

**Results:** Responses demonstrated the most substantial need in the categories of social support (32%), health literacy (28%) and financial stability (24%). Less need was reported in the categories of food (11%), transportation (5%) and housing (4%). Fifty-seven percent of women reported at least one social need among the six categories screened.

**Conclusion:** Upstream SDoH, most notably social support, health literacy and financial stability are identified to be present and likely contributing to health quality, outcomes, and disparities within this gynecologic oncology

Please cite this paper as: Nora AE, McDonald ME, Syrop CH, Haugsdal ML. Upstream oncology: identifying social determinants of health in a gynecologic oncology population. *Proc Obstet Gynecol.* 2021;10(2):Article 3 [ 13 p.]. Available from: <http://ir.uiowa.edu/> Free full text article.

**Corresponding author:** Michael L. Haugsdal, MD, Department of Obstetrics and Gynecology, University of Iowa, Iowa City, IA, [michael-haugsdal@uiowa.edu](mailto:michael-haugsdal@uiowa.edu)

**Financial Disclosure:** The authors report no conflict of interest. The authors received no funding from an external source

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*patient population. Overall, these findings support the idea that SDoH should be assessed for each unique patient population - and for each patient receiving care for gynecologic cancer. While social support was the most frequently reported SDoH, many patients already received adequate help at home; suggesting that meaningful efforts should next be directed at improving health literacy in the population. Appreciation and assessment of SDoH potential to impact care and management should be used to design a routine screening tool for the study population and organize resources to address or mitigate the identified needs.*

<sup>1</sup>*University of Iowa Carver College of Medicine, Iowa City, Iowa*

<sup>2</sup>*Department of Obstetrics and Gynecology, Division of Gynecologic Oncology, University of Iowa Hospitals and Clinics, Iowa City, Iowa*

<sup>3</sup>*University of Iowa Hospitals and Clinics, Department of Obstetrics and Gynecology, Iowa City, Iowa*

## **Background**

The incidence and outcomes of gynecologic malignancies are disparate among various populations of women due in part to the influence of social determinants of health (SDoH).<sup>1</sup> While *health disparities are the differences in health quality and outcomes among patients that are related to social, economic, or environmental conditions*<sup>1</sup>; *SDoH are the actual factors* such as lifestyle, age, and environment that affect a patient's health quality and outcomes.<sup>1-4</sup> Surprisingly, evidence suggests that clinical care by providers contributes only 20% to patient health quality and outcomes, while the remaining 80% is directly related to upstream social determinants of health.<sup>2</sup> An 'upstream' approach to healthcare aims to address SDoH before they contribute to less ideal outcomes downstream.<sup>3</sup> An upstream approach to gynecologic oncology seeks to mitigate

health disparities by intervening upon the SDoH most affecting this patient population, thereby improving the delivery of cancer care.<sup>1</sup>

Prior work has found that chronic diseases, including cancer, are affected by the SDoH including housing and food security, transportation means, personal financial stability, health literacy, and social support.<sup>1, 4-9</sup> In many conditions a vicious, negative feedback loop exists in which SDoH negatively affect chronic disease and the disease contributes to persistence of the social needs.<sup>5, 10</sup> This is not surprising as cancer care is complex and many patients struggle to appreciate all the information provided to them. Early diagnosis and timely adherence to treatment optimizes prognosis; while delayed or interrupted management is associated with increased morbidity and mortality.<sup>11</sup> For patients to comply with treatment they must be able to meet social needs that include adequate housing and nutrition, transportation to attend healthcare visits, knowledge or resources to help them understand their diagnosis and treatment options, an ability to afford the expenses of their care, and access to social support systems. While extensive research has been done on SDoH for various types of cancer (colorectal, cervical, breast) less has been done to study specific SDoH in women receiving care for all types of gynecologic malignancies.<sup>4,6,8,25</sup> The upstream approach maintains that the first step of mitigating negative effects of SDoH, is to identify which social factors are present in this patient population.

### Food Security

Food security is defined as having “access at all times to enough food for an active healthy life”, and includes “the ready availability of nutritionally adequate and safe foods, as well as assured ability to acquire acceptable foods in socially acceptable ways”.<sup>17</sup> In 2019, 10.5% of U.S. households were food insecure at least at some point during the year.<sup>35</sup> Food insecurity increases the likelihood of poorer health and limited access to healthcare.<sup>5,18</sup> Malnutrition is directly associated with increased postoperative complications, hospital readmissions, returns to the operating room, ICU admissions, and cancer recurrence.<sup>34</sup> Cancer—a chronic condition—is also known to increase the likelihood of food insecurity among patients.<sup>5</sup> Several additional factors are known to be associated with a higher incidence of food insecurity among cancer survivors including female gender, lower education, and characteristics including female reproductive cancer.<sup>20</sup>

### Financial Stability

Oncologic care has become increasingly expensive in recent decades due to advanced treatments options requiring more frequent follow-up appointments and longer, overall survival trends.<sup>21</sup> Out-of-pocket payments for cancer care are also increasing, even for patients with health insurance.<sup>22</sup> All too often, the financial strain precipitated by cancer treatment (even if curative) may require the patient to choose between paying for medical care or paying for food or other social needs, thus contributing to the vicious cycle of socioeconomic

driven health disparities.

### Health Literacy

Health literacy is described as the cognitive and social abilities that contribute to the capacity of a patient to understand and promote their own health.<sup>7,13-14</sup> Health literacy allows patients to be actively engaged in oncologic treatment decisions and optimize potential outcomes.<sup>6</sup> Without proficient health literacy, patients generally have difficulty navigating the complex healthcare system and cannot fully participate in managing their health. This has been associated with increased hospitalization rates, less frequent cancer screening and disproportionately higher rates of disease and mortality.<sup>27</sup> Adequate health literacy has also been linked to health-related empowerment and patient perceived self-efficacy, which has been shown to be important in compliance with colorectal cancer screening.<sup>26</sup>

### Social Support

Social support can be described as advice or assistance accessed through a social network with benefit to the individual.<sup>4</sup> Adequate social support in patients with a cancer diagnosis is associated with both psychosocial and physical benefits.<sup>29</sup> Poor social support, on the other hand, is associated with increased morbidity and mortality.<sup>4,9,12</sup> Many studies suggest that psychological states resultant to a lack of social support are associated with increased incidence and progression of cancer.<sup>4,9,12</sup>

### Housing

Housing instability is a SDoH that encompasses a number of challenges, such as difficulty paying rent, overcrowding, moving frequently, staying with relatives, or spending the bulk of household income on housing.<sup>30</sup> These circumstances can make it more difficult for patients to access healthcare and may lead to less ideal health outcomes.<sup>30</sup> Specifically, housing instability affects a patient's ability to undergo timely cancer screening and care.<sup>1, 4-9</sup>

### Transportation

Barriers in transportation often lead to rescheduled or missed appointments, delayed care, and missed or delayed medication use.<sup>32</sup> Difficulty with transportation is particularly important for those with lower incomes and those who are under- or uninsured.<sup>32</sup> Geography plays an important role in access to care as transit options are more limited in rural areas. Rural patients generally report more problems with transportation and travel distance to healthcare providers than do urban residents.<sup>33</sup> Cancer care requires clinician visits, medication access, and flexibility in dynamic treatment plans; however, without transportation delays in treatment are likely to occur.<sup>32</sup>

Screening gynecologic oncology patient populations for their specific SDoH needs is the first step to better

understanding how these factors may affect their clinical care and ultimate health outcomes. It also establishes a starting point for identifying what *upstream* interventions providers might implement to mitigate the poor outcomes and eliminate health disparities.<sup>1,6-8,14</sup> This study seeks to begin an investigation into the social determinants of health that may be contributing to the health quality and outcomes among the gynecologic oncology patient population served at a single, midwest academic medical center. The first stage aims to identify the incidence of need among common social factors: food security, financial stability, health literacy, social support, housing security, and transportation means.

### **Hypothesis**

This study hypothesizes that patients receiving care for gynecologic malignancies are affected by unique and specific constellations of SDoH among the categories of housing and food security, transportation means, personal financial stability, health literacy, and social support. These factors in turn likely affect the health quality and outcomes of these patients. This study aims to identify the frequency of these six social factors within the gynecologic oncology patient population at the University of Iowa. This will inform planning for future interventions to mitigate these needs among this specific population.

**ANONYMOUS SURVEY**  
Identifying Upstream Social Determinants of Health Among Gynecologic Oncology Patients

Instructions: Please read each of the following questions and select the single response that best applies to your current personal situation. Do not include your name or other identifying information.

1. What is your housing situation today?

- I do not have housing (I am staying with others, in a hotel, in a shelter, living outside on the street, in a car or abandoned building, etc.)
- I have housing today, but I am worried about losing housing in the future
- I have housing

2. Within the past 12 months, I worried that our food would run out before I got money to buy more.

- Often True
- Sometimes True
- Never True

3. In the past 12 months, a lack of transportation has kept me from medical appointments, meetings, work or from getting food or medicine.

- Yes, it has kept me from medical appointments or getting medications
- Yes, it has kept me from non-medical meetings, appointments or getting the things that I need
- No

4. How hard is it for you to pay for the very basics like food, housing, medical care, and heating?

- Very hard
- Somewhat hard
- Not hard at all

5. How often do you have problems learning about your medical condition because of difficulty understanding written information?

- Always
- Often
- Sometimes
- Occasionally
- Never

6. If for any reason you need help with day-to-day activities such as bathing, preparing meals, shopping, managing finances, etc., do you get the help you need?

- I don't need any help
- I get all the help I need
- I could use a little more help
- I need a lot more help

**Figure 1. Upstream Gynecologic Oncology Screening Questionnaire**

## **Methods**

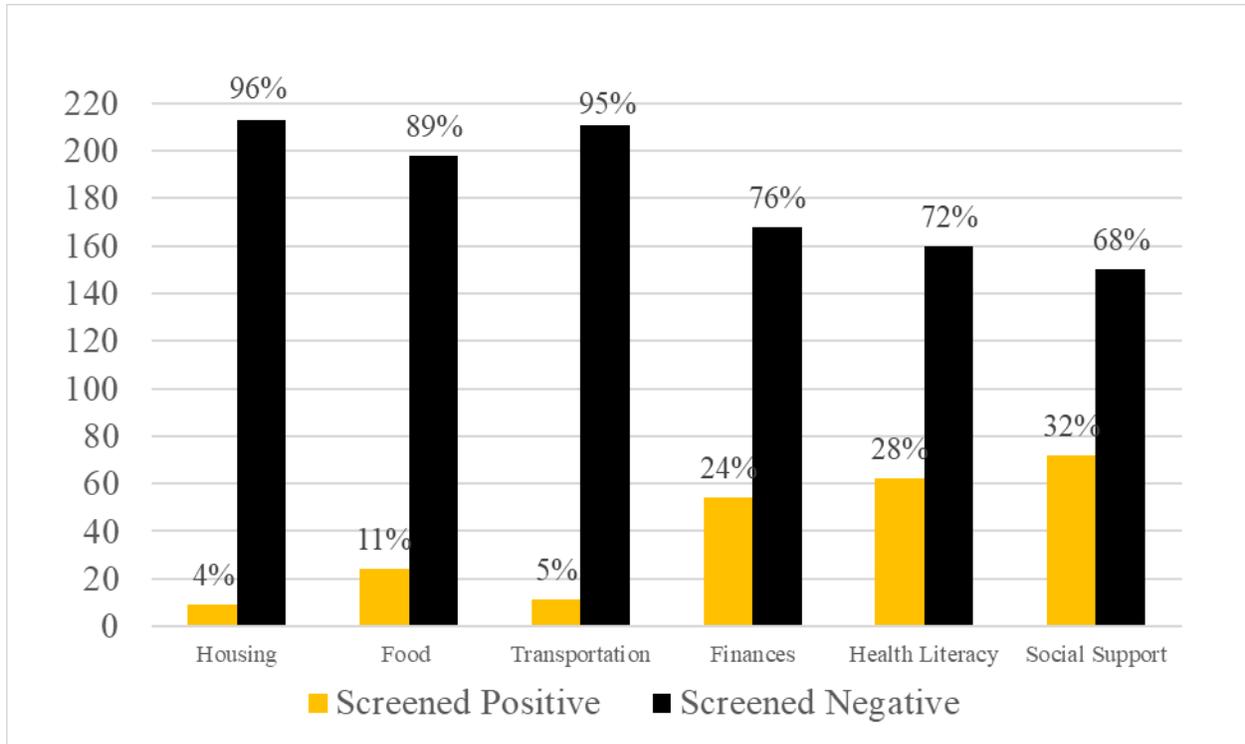
IRB approval (University of Iowa Human Subjects Office: #201912408) was obtained to administer an anonymous, needs assessment survey to a convenience sample of patients receiving outpatient care within the University of Iowa Hospitals and Clinics Holden Comprehensive Cancer Center's Gynecologic Oncology Clinic. This particular population was selected for sampling because the outpatient clinic serves as the entrance to gynecologic care for the majority of patients, thus it was deemed to provide the most representative sample of the local population in question. While rooming patients in the clinic, clinical staff provided patients with paper surveys with attached invitation and instructions. Patients were asked to place the completed, or not completed, survey in a secure box at the end of their visit. The assessment was used to identify social needs within the categories of housing and food security, transportation means, personal financial stability, health literacy, and social support.<sup>14-16</sup> The survey contained six validated questions taken from prior studies. (Figure 1) Five of the six validated questions (regarding housing, food insecurity, transportation, financial stability, and social support) were taken from the Centers for Medicare & Medicaid Services *Accountable Health Communities Health-Related Social Needs Screening Tool*.<sup>24</sup> One question

(regarding health literacy) was taken from *Brief Questions to Identify Patients With Inadequate Health Literacy* by Chew et al.<sup>14</sup>

During January and February 2020, a total of two-hundred fifty adult female patients attending an outpatient clinic encounter at the UIHC Gynecologic Oncology Clinic were invited to complete the survey. Data included survey responses which were analyzed for frequency and proportion of responses screened positive or screened negative. Responses for each question were considered positive if any degree of need was reported.

## **Results**

Of the 250 patients approached, 222 surveys were completed (response rate = 88%). The remaining 28 distributed surveys were not completed. One-hundred and twenty-six (57%) women reported at least one social need, while 96 (43%) women reported no social needs. Responses demonstrated the most substantial need in the categories of social support (N=72, 32%), health literacy (N=62, 28%), and personal financial stability (N=54, 24%). Relatively less need was reported in the categories of food (24, 11%), transportation (11, 5%), and housing (9, 4%). (Figure 2)



**Figure 2. Frequency of Gynecologic Oncology Patients Who Screened Positive for SDoH**

Table 1 shows individual response frequency (%). Although social support was the most frequently reported need (N=72, 32%), of those who screened positive, 56 (25.23%) reported that “I get all the help I need”, 14 (6.31%) reported

“I could use a little more help”, and 2 (0.9%) reported “I need a lot more help.” Although 32% of women screened positive for social support, only 7% of women reported that social support was an unmet need. (Table 1)

**Table 1. Response Frequency of Survey Questions**

	Number of patients	Frequency of patients	Total patients
<b>What is your housing situation today?</b>			222
I have housing	213	95.95%	
I have housing today, but am worried about losing future housing	4	1.80%	
I do not have housing	5	2.25%	

<b>Within the past 12 months, I worried that our food would run out before I got money to buy more.</b>			222
Never True	198	89.19%	
Sometimes True	21	9.46%	
Often True	3	1.35%	
<b>In the past 12 months, a lack of transportation has kept me from medical appointments, meetings, work, or from getting food or medicine.</b>			222
No	211	95.05%	
Yes, it has kept me from non-medical meetings, appointments or getting the things that I need	5	2.25%	
Yes, it has kept me from medical appointments or getting medications	6	2.70%	
<b>How hard is it for you to pay for the very basics like food, housing, medical care, and heating?</b>			222
Not hard at all	168	75.68%	
Somewhat hard	50	22.52%	
Very hard	4	1.80%	
<b>How often do you have problems learning about your medical condition because of difficulty understanding written information?</b>			222
Never	160	72.07%	
Occasionally	50	22.52%	
Sometimes	11	4.95%	
Often	0	0%	
Always	1	0.45%	
<b>If for any reason you need help with day-to-day activities such as bathing, preparing meals, shopping, managing finances, etc, do you get the help you need?</b>			222
I don't need any help	150	67.57%	
I get all the help I need	56	25.23%	
I could use a little more help	14	6.31%	
I need a lot more help	2	0.90%	

**Discussion**

The results of this needs assessment survey demonstrate the unique SDoH context for the population of gynecologic patients receiving outpatient cancer care at the University of Iowa Holden

Comprehensive Cancer Center. Response rates for each of the six categories explored were sometimes similar and at times different from trends published by other teams studying other populations of cancer patients. This supports the idea that SDoH should be

assessed for each unique patient population—and likely for each individual patient.<sup>1,8,14</sup> The need to screen all patients for SDoH is further illustrated by a study performed in 2019 which assessed the impact of food insecurity among women receiving high-risk obstetrics care at the healthcare institution serving as the setting for this study.<sup>19</sup> Nearly one quarter of patients with high-risk pregnancies screened positive for food insecurity at some point in their pregnancy, while in this current study only 11% of gynecologic oncology patients screened positive for food insecurity which is similar to the general population in the state of Iowa and the U.S.<sup>8,17,19,35</sup> Again, emphasizing the need to standardize screening for SDoH in each patient population.

More than half of the women reported at least one social need during their visit to the gynecologic oncology outpatient clinic. Health literacy and personal financial stability were the most frequently reported needs and this was similar to other studies, particularly populations of patients with breast cancer.<sup>4,6</sup>

A study performed by the U.S. Department of Education in 2003 found that only 12% of Americans were considered to be proficient in their health literacy skills and approximately 36% had only basic or low basic health literacy skills.<sup>27</sup> The lower rate of inadequate health literacy (28%) in this study may be due to self-report biases. Future steps should be taken to assess patients' health literacy with a validated health literacy questionnaire in order to prevent reporter biases. However, such questionnaires are often lengthy, and

currently there are no validated questionnaires specific to gynecologic oncology. Therefore, future steps should include validating an efficient health literacy assessment tool specific to gynecologic cancer.

This study found that 24% of patients reported financial distress, consistent with other studies which show that between 22% and 64% of patients with cancer report stress or worry about paying bills.<sup>36</sup> Importantly, more financial distress in cancer patients is associated with increased psychologic distress such as anxiety and depression.<sup>36</sup> The findings of this study suggest future attention should be paid to better understanding the relationship between mental health and financial strain in this patient population.

This study has several limitations. First, the survey used in this study contained six questions which were validated separately. The fact that this combination of questions has never been used together as a needs assessment tool may limit its validity; however, five of the six questions were validated together and therefore the addition of one new question likely has limited impact on the overall validity of the survey. Second, the study was performed for a limited duration using convenience sampling of a specific, local patient population. This prevents the results from being applied to other geographical regions as well as parallel patient populations in the same institution. Third, the study was anonymous and did not obtain demographic data, nor information regarding the specific type of disease, disease stage, or treatment phase. This

prevents the study from inferring specific conclusions regarding relationships between SDoH and unique clinical contexts of gynecologic malignancies. That is to say, the study provides a general perspective for this local population; but it is a perspective that sets the course for the next phase. As race and ethnicity were not queried but SDoH are influenced by race, results may not be representative of the general composition of the clinic as a whole or the population of Iowa. Furthermore, capture of participants required attendance to outpatient appointments and this in itself is influenced by SDoH. This is to say, selection bias may exist by not including patients who missed their appointments. Fourth, this study sampled the outpatient population rather than the inpatient population who are often hospitalized for complications of treatment or management of advanced disease. Therefore, the trends cannot be reliably applied beyond patients receiving outpatient care for their disease. Finally, although it is anonymous the survey does rely on self-reported data which may be affected by reporting bias on the part of the patients.

## **Conclusion**

Health literacy and personal financial stability represent the most frequently reported unmet SDoH needs in the outpatient gynecologic oncology clinic at the University of Iowa. The general similarities and differences in these findings relative to other studies emphasize the need to assess each patient population for a unique constellation of SDoH, and likely each specific patient. Next, if each patients' need can be matched with a meaningful

*upstream* intervention there could be substantial potential to improve the delivery of gynecologic cancer care beyond the clinical setting.

Future studies should aim to assess these SDoH within the inpatient gynecologic oncology patient population in order to more accurately account for patients with potentially more advanced, complicated disease. Health literacy was the most frequently reported unmet social need, therefore future work should look to assess individual health literacy and its relationship to type of gynecologic cancer and downstream health outcomes. Specifically, the investigators plan to look deeper into health literacy and its effects through the use of patient focus groups. This will help guide future interventions such as decision making guides, illustrations or interactive videos of pathophysiology, cancer care-coordinators, or improved physician-patient communication.

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