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Research Report

Gynecologic oncology patient perspectives and knowledge on advance care planning: A quality improvement intervention

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ABSTRACT

Objectives: Assess and improve advance care planning (ACP) awareness and uptake among gynecologic oncology patients.

Methods: Using a quality improvement Plan-Do-Check-Act framework, we completed a single institution needs assessment and intervention. The needs assessment was a 26-question survey assessing baseline ACP knowledge and preferences of gynecologic oncology patients. We used this survey to implement an outpatient intervention in which patients were offered ACP resources (pamphlet, discussion with their gynecologic oncologist, and/or social work referral). We conducted a post-intervention survey among patients who had and had not received ACP resource(s) to assess whether our intervention increased ACP knowledge, discussions, or uptake.

Results: Among 106 patients surveyed in the needs assessment, 33 % had ACP documents, 26 % had discussed ACP with a physician, and 82 % thought discussing ACP was important. The majority preferred these conversations in the outpatient setting (52 %) with their gynecologic oncologist (80 %) instead of nurses or trainees. In the intervention, 526 patients were offered ACP resources. Compared to women who did not receive resources (n = 324), patients who received ACP resource(s) (n = 202) were more likely to have ACP discussions with their gynecologic oncologist (38 % vs 68 %, P = 0.001) and had greater proficiency regarding how to create ACP documents (median score 5/10 vs 8/10, P = 0.048), although they were no more likely to have ACP documented in their electronic medical record (27 % vs 9 %, p = 0.08). Results: Among 106 patients surveyed in the needs assessment, 33 % had ACP documents, 26 % had discussed ACP with a physician, and 82 % thought discussing ACP was important. The majority preferred these conversations in the outpatient setting (52 %) with their gynecologic oncologist (80 %) instead of nurses or trainees. In the intervention, 526 patients were offered ACP resources. Compared to women who did not receive resources (n = 324), patients who received ACP resource(s) (n = 202) were more likely to have ACP discussions with their gynecologic oncologist (38 % vs 68 %, P = 0.001) and had greater proficiency regarding how to create ACP documents (median score 5/10 vs 8/10, P = 0.048), although they were no more likely to have ACP documented in their electronic medical record (27 % vs 9 %, p = 0.08).

Conclusions: ACP uptake among gynecologic oncology patients is low, but ACP discussions with an oncologist during outpatient visits are important to patients and improve their knowledge regarding completing ACP documents.

1. Introduction

Advance care planning (ACP) allows patients to make decisions about healthcare and end-of-life preferences and document their decisions in forms such as advance directives, living wills, health care proxy forms, do-not-resuscitate orders, and physician-orders for life-sustaining treatment. Cancer patients value effective communication and information surrounding ACP (Back et al., 2008; Fallowfield and Jenkins, 1999; Emanuel et al., 1991; Kubi et al., 2020). Moreover, when ACP is addressed and implemented, outcomes include greater quality of communication, family satisfaction, concordance between patient preferences and healthcare interventions, and quality of end-of-life care (Houben et al., 2014; Matsuoka et al., 2018; Detering et al., 2010). The American Society of Clinical Oncology’s Quality Oncology Practice Improvement Program (QOPI) recommends that oncologists assess patients’ ACP status and preferences (American Society of Clinical Oncology, 2020). ACP discussions provide patients and families with the opportunity to make informed decisions about end-of-life care that align with their values and preferences. ACP discussions also facilitate communication between patients and healthcare providers, allowing for the development of a shared understanding of patient goals and preferences. Patients may value discussing ACP with their oncologist during outpatient visits, as it provides a familiar and comfortable setting for these conversations. In the intervention, 526 patients were offered ACP resources. Compared to women who did not receive resources (n = 324), patients who received ACP resource(s) (n = 202) were more likely to have ACP discussions with their gynecologic oncologist (38 % vs 68 %, P = 0.001) and had greater proficiency regarding how to create ACP documents (median score 5/10 vs 8/10, P = 0.048), although they were no more likely to have ACP documented in their electronic medical record (27 % vs 9 %, p = 0.08).

Conclusions: ACP uptake among gynecologic oncology patients is low, but ACP discussions with an oncologist during outpatient visits are important to patients and improve their knowledge regarding completing ACP documents.

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Initiative recommends documenting an advance directive and/or ACP discussions by the 3rd office visit (ASCO’s Quality Oncology Practice Initiative, 2021). However, cancer patients often lack ACP knowledge and documentation, even when terminally ill (Kubi et al., 2020; Kish et al., 2000). This gap may arise from lack of patient knowledge about the prognosis or disease natural history, anxiety surrounding end-of-life issues, or poor communication between patients and providers (Back et al., 2008; Barnes et al., 2012; Heyland et al., 2013; Chandar et al., 2017). Furthermore, even patients with knowledge of ACP often lack formal ACP documents (Heyland et al., 2013; Temel et al., 2010; Brown et al., 2016). The literature specific to gynecologic oncology populations regarding ACP knowledge and uptake is limited, but suggests a gap between patient-reported importance of ACP and ACP document completion rates (Brown et al., 2016).

Before our study, our institution had no formalized pathway to screen and educate patients regarding ACP or to track ACP discussions or documentation. Patients could be referred to social work for ACP, but only if providers recognized the need to make this referral. Moreover, we did not know the magnitude of the gap between patient-perceived importance of ACP and completed ACP documents among gynecologic oncology patients at our institution. Brown et al. described gynecologic oncology patient factors associated with decreased rates of ACP completion (Brown et al., 2016) and developed a scale to gauge patient readiness to discuss ACP (Brown et al., 2017). Although research in other medical disciplines suggests that the most effective methods of increasing ACP completion include informative material, conversations during clinical visits, and assistance with ACP forms (Tamayo-Velázquez et al., 2010; Bravo et al., 2008), no such studies have been conducted specifically in gynecologic oncology.

To address these gaps, we conducted a single-institution quality improvement (QI) project, based on the Plan-Do-Check-Act (PDCA) model (Science of Improvement: Testing Changes, 2021), to assess and improve ACP discussions and documentation. First, we completed a baseline needs assessment to gauge ACP awareness among gynecologic oncology patients and identify their preferences for discussing ACP. We then used these data, along with evidence-based strategies to increase completion of ACP documents (Tamayo-Velázquez et al., 2010; Bravo et al., 2008), to develop and implement an intervention to improve patient knowledge and completion of ACP documents. Our primary outcome in the intervention was patient self-report of having discussed ACP with their gynecologic oncologist. Secondary outcomes included differences in ACP knowledge and completion of ACP documents between those who did and did not receive the intervention.

2. Materials and methods

2.1. Ethical approvals and inclusion and exclusion criteria

Before initiating the study, the Washington University Human Resource Protection Office reviewed the protocol and granted the project a Quality Improvement human subjects exemption and waived written informed consent. For the needs assessment phase, patients were eligible if they were 18 years of age or older, had a history of primary biopsy-confirmed gynecologic malignancy (cervical, endometrial, fallopian tube, ovarian, peritoneal, vaginal, or vulvar), were hospitalized on the Gynecologic Oncology service, and were established patients (defined as having one or more documented outpatient clinic visits) of the Gynecologic Oncology Division in the Washington University in St. Louis Department of Obstetrics & Gynecology. Patients were excluded if they had benign pathology, lacked English reading comprehension or fluency, were admitted for planned surgery, chemotherapy, or radiation treatment, or if they had been transferred to the service from an Intensive Care Unit. For the intervention phase of the study, patients were eligible if they met the inclusion criteria above and had not participated in the needs assessment survey and were presenting to the outpatient clinic for pre-chemotherapy, surveillance, or problem visits.

2.2. Data collection

Clinical data abstracted from the participant’s electronic medical record included age; race; religious affiliation; body mass index; medical comorbidities; tobacco use; primary cancer site; cancer histology, grade, and stage; date of cancer diagnosis; treatment(s) received (surgery, chemotherapy, radiation, hormonal therapy); disease recurrence; current treatment; prior palliative care or hospice consultations; vital status; and ACP documents uploaded into the electronic medical record (EMR). These clinical data and patients’ survey answers were all entered into Research Electronic Data Capture (REDCap), a secure web application for building and managing online data (Harris et al., 2009).

2.3. Baseline ACP knowledge and needs assessment

Eligible patients admitted to the Gynecologic Oncology service between June 2017 and February 2018, were approached and asked to complete a 26-question needs assessment survey (Fig. 1), which included the following: whether the patient had current ACP documents and whether they had given a copy to their healthcare provider; self-rating of their current state of health; true/false and multiple choice questions regarding baseline ACP knowledge; yes/no and multiple-choice questions regarding awareness of and prior discussions with healthcare providers about ACP; importance of discussing ACP (on a Likert scale of 0–5); preferences for discussing ACP (multiple choice); and whether completing the survey changed their willingness to discuss ACP. If patients reported they did not have ACP documents, they were asked to describe why. The survey was designed with input from the Gynecologic Oncology Division to assess the prespecified study outcomes, with questions about ACP knowledge based on our institutional ACP informational pamphlet entitled “Advance Directives” (BJC Creative Services, Bender printing) (Supplemental 1).

2.4. ACP intervention

To implement and assess our intervention, we used the Plan-Do-Check-Act (PDCA) framework. We designed an intervention to address ACP and offer ACP resources (“plan”), offered this intervention to all patients at their outpatient gynecologic oncology visit (“do”), and conducted a post-intervention survey to determine whether patient ACP knowledge or behavior differed between those who did and did not receive ACP resources (“check”). We are now using the resulting data to change procedures in the division and plan future PDCA cycles (“act”). (Science of Improvement: Testing Changes, 2021).

The intervention was implemented between March and May 2019, (Fig. 1) and was based on two systematic reviews which identified the success of clinical discussions, written materials, and assistance with ACP forms as successful means to increase ACP completion. (Tamayo-Velázquez et al., 2010; Bravo et al., 2008) The intervention was as follows. First, at the time of check-in for their outpatient appointments in our gynecologic oncology clinic, all eligible patients were given a four-item questionnaire asking whether they had completed ACP documents and which, if any, of three ACP resources they desired at their appointment: discussion about ACP with their primary gynecologic oncologist, an ACP informational pamphlet entitled “Advance Directives” (BJC Creative Services, Bender printing), or social work referral. Second, the patient’s primary gynecologic oncologist reviewed the questionnaire and offered the preferred ACP resource(s) during the appointment. ACP resources were offered to any patient who requested it, regardless of whether or not they already had ACP documents. Third, providers documented on the questionnaire which resources, if any, had been provided during the visit.

Between August and October 2019, patients who had participated in the intervention phase were mailed a letter asking them to complete an enclosed post-intervention survey and return it in a provided self-addressed and stamped envelope. Patients’ answers on the
The post-intervention survey contained 23 questions regarding: whether the patient had current ACP documents and if they had given a copy to their healthcare provider; self-rating of their current state of health; true/false and multiple choice questions regarding ACP knowledge; yes/no and multiple-choice questions regarding awareness of and prior discussions with healthcare providers about ACP; and three questions to rate their self-reported understanding of ACP and how to complete ACP documents on a 10-point Likert scale (0 = unsure, 10 = fully understand). The ACP uptake rate was calculated as the number of patients who self-reported attainment of ACP documents between the outpatient intervention visit and post-intervention survey divided by the total number of patients who lacked ACP at their outpatient visit.
2.5. Statistical analysis

Descriptive statistics were used to summarize demographic and clinical characteristics and to compare groups. Continuous variables are reported as medians with interquartile ranges or means with standard deviations. Qualitative variables are summarized by counts and percentages. Pearson’s chi-square or Fisher’s exact tests were used as appropriate. Student’s t-tests or Mann-Whitney U tests were used for continuous variables as appropriate. In the needs assessment, responses were compared between patients with and without pre-existing ACP documents. A multivariate analysis (covariates included age, body mass index, race, religion, cancer site, cancer stage, current treatment, and recurrent disease) was used to assess patients predictors of readiness, ACP knowledge, and preferences in discussing ACP. In the intervention, we compared responses between patients who did and did not receive ACP resources. We used logistic regression models to identify patients at risk for not having ACP as well as those who desired ACP resources. SAS software was used for all analyses and P < 0.05 was considered significant. This manuscript was written according to the Revised Standards for Quality Improvement Reporting Excellence (SQUIRE 2.0) guidelines (Ogrinc et al., 2015).

3. Results

3.1. Baseline ACP knowledge and needs assessment

Of 175 gynecologic oncology patients approached, 106 (61 %) completed the needs assessment survey. The majority were white (81 %), had a religious preference (72 %), and had recurrent disease (58 %). Patients had a variety of primary cancer sites and stages and performance status values (Table 1).

Most patients (82 %) thought discussing ACP was somewhat or very important. However, only 33 % of patients had existing ACP documents, 49 % did not know how to obtain ACP documents, only 18 % reported having ever discussed ACP during an office visit, and only 26 % had ever shared their end-of-life care preferences with their gynecologic oncologist. Patients with recurrent disease were more likely than those without recurrent disease to have discussed end-of-life care (85 % vs 64 %, P = 0.001) or whether they would want to receive cardiopulmonary resuscitation or be placed on a mechanical ventilator (80 % vs 50 %, P = 0.001).

Patients felt more comfortable discussing ACP with their gynecologic oncologist (80 %) than with a resident or fellow (32 %) or a nurse (50 %). The majority (52 %) of patients expressed that the outpatient office was the best setting for discussing ACP. Compared to patients without existing ACP documents, those with ACP documents were more likely to correctly answer the question: “the power of attorney is next of kin unless designated otherwise” (64 % vs 85 %, P = 0.027). We found no other significant differences in ACP knowledge between patients with and without ACP documents. At the end of the survey, 80 % of patients felt it would be helpful to talk with their gynecologic oncologist about advance directives, 38 % asked for more information, and 55 % reported that participating in the survey changed their willingness to discuss ACP.

3.2. ACP intervention

Of the 543 gynecologic oncology patients who were offered the outpatient intervention, 526 (97 %) met inclusion criteria (Fig. 1) and were included in analysis. Two hundred eighteen (41 %) self-reported having existing ACP documents and 308 (59 %) either did not have or were unsure whether they had ACP documents. Compared to women with ACP documents, those without ACP documents were younger (median age 68 vs 62, P < 0.0001) and were more likely to have non-Stage IV disease (75 % vs 81 %, P = 0.003), non-recurrent disease (67 % vs 77 %, P = 0.006), no religious preference (33 % vs 44 %, P = 0.002), and cervical cancer (6 % vs 17 %, P = 0.002) (Table 2).

### Table 1
Baseline advance care planning knowledge and needs assessment patient characteristics (N = 106).

<table>
<thead>
<tr>
<th>Variable</th>
<th>Current ACP documents (n = 218)</th>
<th>No current ACP documents (n = 308)</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, median (IQR*)</td>
<td>61 (53-70)</td>
<td>75 (63-75)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Religious preference, n (%)</td>
<td>147 (67.4)</td>
<td>179 (81.0)</td>
<td>0.03</td>
</tr>
<tr>
<td>Primary cancer site, n (%)</td>
<td>84 (38.4)</td>
<td>93 (30.3)</td>
<td>0.001</td>
</tr>
<tr>
<td>Endometrial</td>
<td>105 (47.9)</td>
<td>136 (44.3)</td>
<td>0.001</td>
</tr>
<tr>
<td>Cervical</td>
<td>12 (5.5)</td>
<td>54 (17.5)</td>
<td>0.01</td>
</tr>
<tr>
<td>Vulvar/vaginal/other</td>
<td>17 (7.8)</td>
<td>25 (8.1)</td>
<td>0.01</td>
</tr>
<tr>
<td>Stage, n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I</td>
<td>93 (42.5)</td>
<td>139 (45.3)</td>
<td>0.01</td>
</tr>
<tr>
<td>II</td>
<td>11 (5.0)</td>
<td>23 (7.5)</td>
<td></td>
</tr>
<tr>
<td>III</td>
<td>60 (27.4)</td>
<td>90 (29.3)</td>
<td>0.01</td>
</tr>
<tr>
<td>IV</td>
<td>36 (16.5)</td>
<td>25 (8.1)</td>
<td></td>
</tr>
<tr>
<td>Current treatment, n (%)</td>
<td>76 (34.7)</td>
<td>87 (28.3)</td>
<td>0.12</td>
</tr>
<tr>
<td>Recurrent disease, n (%)</td>
<td>74 (33.8)</td>
<td>70 (22.8)</td>
<td>0.005</td>
</tr>
<tr>
<td>Interested in ACP resources, n (%)</td>
<td>43 (19.7)</td>
<td>97 (31.5)</td>
<td>0.003</td>
</tr>
<tr>
<td>Discussion with provider</td>
<td>11 (5.0)</td>
<td>25 (8.1)</td>
<td>0.16</td>
</tr>
<tr>
<td>ACP pamphlet</td>
<td>41 (18.8)</td>
<td>90 (29.2)</td>
<td>0.01</td>
</tr>
<tr>
<td>Social work referral</td>
<td>16 (7.7)</td>
<td>39 (12.7)</td>
<td>0.09</td>
</tr>
</tbody>
</table>

*Intertquartile range #Patients who answered “No” or “ Unsure”; Significant results in bold text.
One hundred forty patients (27 %) desired 1 or more ACP resources, including 97 patients among 308 (32 %) without ACP documents and 43 patients among 218 (20 %) with ACP documents. Of those without ACP documents who desired ACP resources, 25 (26 %) wanted to discuss ACP with their oncology provider, 89 (92 %) wanted an ACP pamphlet, and 38 (39 %) desired a social work referral (Table 2). Among patients who lacked ACP documents, factors associated with desiring ACP resources included older age (median age 64 vs 61, P = 0.01), religious preference (67 % vs 52 %, P = 0.01), and current cancer treatment (38 % vs 23 %, P = 0.007). Compared to patients who declined ACP resource(s), those who desired ACP resource(s) were more likely to be undergoing current cancer treatment (28 % vs 39 %, P = 0.01). All other variables were similar between the two groups.

3.3. Post-intervention survey

Among 202 subjects who received ACP resources during the intervention, 107 were randomly contacted for post-intervention survey, and 50 (25 %) completed the survey. Among 324 subjects who did not receive ACP resources, 118 were randomly contacted for post-intervention survey and 48 (15 %) completed the survey, meeting our prespecified convenience samples (Fig. 1). Compared to controls, those who received ACP resource(s) were more likely to have stage IV disease (6 % vs 30 %, P = 0.02). The two groups were otherwise balanced in sociodemographic and clinical characteristics (Supplemental Table 2).

Patients who received ACP resources during the intervention were significantly more likely than controls to have had ACP discussion(s) with their gynecologic oncologist (68 % vs 38 %, P = 0.001). In both groups, the majority of patients considered ACP discussions with their gynecologic oncologist to be somewhat or very important (92 % who received ACP vs 88 % of controls, P = 0.67). Patients who received ACP resources were more likely than controls to know how to create an ACP document (median self-reported proficiency 8/10 vs 5/10, P = 0.048). Otherwise, there were no differences between the two groups in ACP discussions (Table 3) or knowledge (Supplemental 3). Patients who reported discussing ACP or end-of-life care with their gynecologic oncologist were more likely than controls to have ACP documents recorded in their EMR, but the difference was not significant (27 % vs 9 %, P = 0.08). Overall, patients who received ACP resources were no more likely than controls to have ACP documents recorded in their electronic medical record.

<table>
<thead>
<tr>
<th>Question</th>
<th>Received ACP resources (n = 50)</th>
<th>Did not receive ACP resources (n = 48)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge of how to make ACP document (1–10*)</td>
<td>8 (4–10)</td>
<td>5 (0–10)</td>
<td>0.048</td>
</tr>
<tr>
<td>Discussed ACP with a gynecologic oncologist, n (%)</td>
<td>34 (68.0)</td>
<td>18 (37.5)</td>
<td>0.001</td>
</tr>
<tr>
<td>Discussed ACP with ANY health care provider, n (%)</td>
<td>46 (92.0)</td>
<td>39 (81.3)</td>
<td>0.12</td>
</tr>
<tr>
<td>Discussed end-of-life care with a gynecologic oncologist, n (%)</td>
<td>4 (8.0)</td>
<td>3 (6.3)</td>
<td>1.00</td>
</tr>
<tr>
<td>Discussed end-of-life care with ANY health care provider, n (%)</td>
<td>18 (36.0)</td>
<td>13 (27.1)</td>
<td>0.34</td>
</tr>
<tr>
<td>Discussed end-of-life care with a friend/family member, n (%)</td>
<td>45 (90.0)</td>
<td>41 (85.4)</td>
<td>0.49</td>
</tr>
</tbody>
</table>

*Patient self-report of understanding using Likert scale: ‘0 = unsure and 10 = fully understand’; Significant results in bold text.

4. Discussion

This study provides valuable information regarding gynecologic oncology patients’ attitudes toward ACP and can be used to improve uptake of ACP documentation. First, we found that patients desire ACP discussions and prefer to have these discussions in the outpatient setting with their gynecologic oncologist. Second, offering ACP resources in the outpatient setting is feasible. Third, receipt of ACP resources improved patient-centered outcomes including increased ACP discussions with their gynecologic oncology provider and improved proficiency regarding how to complete an ACP document. However, our intervention did not increase overall ACP documentation, indicating that more research is needed to test behavioral interventions that assess and promote patient readiness to bridge the gap between expressed interest in ACP and actual documentation.

Potential reasons that our study intervention did not increase uptake or ACP documentation may be related to patient factors such as insight into their anxiety surrounding end-of-life issues, unstable social support to discuss ACP, and even lack of motivation to prioritize ACP documentation over more pressing unmet social and mental health needs. Nevertheless, as we discuss below, other considerations related to our actual study design, implementation, and length of follow-up, may have also contributed to not finding a direct association between patient expressed interest in ACP and actual uptake and documentation.

Consistent with work in other patient populations, we found that gynecologic oncology patients value ACP, but often do not discuss the topic with their providers. Additionally, patients often lack access to ACP documents and do not fill them out (Brown et al., 2016; Yadav et al., 2017). Despite widespread support for ACP (Emanuel et al., 1991; Brown et al., 2017; Tamayo-Velázquez et al., 2010; Brinkman-Stoppeenburg et al., 2014; Gaeta and Price, 2010; Oczkowski et al., 2016), there is no consensus on the most effective intervention to improve ACP document access and completion (Bravo et al., 2008; Waldrop and Meeker, 2012). Given the paucity of ACP data specific to gynecologic oncology patients (Nicolay et al., 2012), our QI project may serve as an example of how to design and test an ACP intervention that is tailored to patients’ needs and implemented within their cancer care team (Davidoff et al., 2015).

Although patients who received ACP resources during our intervention did not have greater ACP knowledge or document completion than did controls, they were more likely to have ACP discussions with their provider, which was our primary outcome. Moreover, when patients reported having these discussions, they were more likely to complete ACP forms. Although this effect was not statistically significant, it is consistent with multiple studies suggesting that ACP discussions alone can lead to completion of ACP documents (Houben et al., 2014; Sinclair et al., 2017; Morrison et al., 2005; Reilly et al., 1995). Future studies should reveal whether a longer follow-up time than we used (3–6 months post-intervention) or a larger sample size could yield a statistically significant difference in ACP document completion.

Because our intervention occurred in the outpatient setting, it captured patients in different stages of their cancer care, including diagnosis, active treatment, surveillance, and recurrence, but before deterioration, which is when many oncologists may first broach the subject of ACP (Keating et al., 2010). Including such a heterogeneous group allowed us to capture meaningful differences in patients’ needs and preferences regarding ACP resources. Among patients in the intervention phase, undergoing active treatment was predictive of desiring ACP resource(s), although disease recurrence did not correlate with ACP needs. Notably, 80 % of patients in our needs assessment phase, but only 30 % of those in the intervention phase desired ACP resources. This may have been because our needs assessment was conducted with inpatients, who may be more attuned to their goals of care than outpatients, similar to the findings of Goswami et al. (2020). It could also have been due to unacceptability of the intervention to our patients, since the intervention was designed based on prior studies, but not patient input. Relevant
to our subspecialty, ACP planning may be especially beneficial in young patients who have no religious preference, have cervical cancer, have early stage disease, or have non-recurrent disease, as these populations were least likely to have completed ACP documents.

Two institution-wide changes that occurred during our study period may have affected our results. Our department moved to new inpatient floors and moved our outpatient offices to a new physical location on the medical campus. Thus, there was a 12-month time lapse between our needs assessment and the intervention phase. Additionally, our electronic medical records were converted to a new system between our needs assessment and intervention. During inpatient admissions, nursing staff are now prompted to document ACP records and any do-not-resuscitate order. It is possible that documentation of ACP documents in medical records improved during our study period because of these factors.

We note several additional limitations of our study. First, although we designed our intervention to assess a random convenience sample of patients who accepted or declined the ACP intervention, our post-intervention survey cohort was small. Second, the control group was exposed to questions about ACP and were offered ACP resources at the time of their outpatient visit. Thus, some control patients may have felt encouraged to think about or pursue ACP at a later time, which may have biased our results towards the null. Third, our study has recall bias because we asked patients questions in the post-intervention setting. For example, in 11 cases, the physician documented an ACP discussion, but the patient did not recall this conversation when asked during the post-intervention survey. Fourth, it is possible that physicians inaccurately perceived or documented patients’ acceptance or declination of ACP resources. Fifth, although our groups were clinically heterogeneous, we excluded patients without English reading comprehension or speaking fluency. Thus, we may have missed important perspectives of patients with limited health literacy, or those who are non-English speaking, which limits the generalizability of our results. Finally, we did not analyze our data by patients’ race, which may affect end-of-life communication and resource utilization (Pollak et al., 2010; Loggers et al., 2009).

Our institution is taking several steps to improve care of cancer patients. For example, we are developing an outpatient palliative care clinic. In addition, we plan to capitalize on informatics available in our new electronic medical record system to identify patients that are lacking ACP documentation and use electronic functions such as pop-up alerts to implement universal screening and documentation of ACP. Other steps could include obtaining patient input to design more acceptable interventions, increasing ACP discussions through dedicated appointments or telemedicine visits, and expanding ACP discussions to the inpatient setting. In gynecologic oncology, our goal is to have documented ACP documents for ≥ 50% of patients and documented ACP discussions for ≥ 80% of patients.

In summary, this QI project adds to the small body of literature regarding ACP among gynecologic oncology patients. Consistent with studies in patients with other cancer types (Brown et al., 2016; Brown et al., 2017; Vogel et al., 2013), we find that although gynecologic oncology patients value ACP, few patients have documented ACP forms in their medical records. We show that patients value supplemental resources such as an ACP pamphlet, ACP discussions, and/or social work referral. However, the most effective intervention appears to be discussion of ACP prompted by a gynecologic oncologist.

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CRediT authorship contribution statement

Sarah P. Huepenbecker: Conceptualization, Methodology, Validation, Investigation, Writing – original draft. Sophia Lewis: Investigation, Data curation, Writing – review & editing. Mark C. Valentine: Investigation, Writing – review & editing. Marguerite L. Palsoul: Conceptualization, Methodology, Writing – review & editing. Premal H. Thaker: Writing – review & editing. Andrea R. Hagemann: Writing – review & editing. Carolyn K. McCourt: Writing – review & editing. Katherine C. Fuh: Writing – review & editing. Matthew A. Powell: Writing – review & editing. David G. Mutch: Writing – review & editing. Lindsay M. Kuroki: Conceptualization, Methodology, Formal analysis, Resources, Writing – review & editing, Supervision, Project administration.

Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Dr. Fuh reports participation on advisory boards for Aravive and Myriad, grants from Merck, and patents/royalties from Stanford University, outside the submitted work. Dr. Kuroki reports grants from National Center for Advancing Translational Sciences of the NIH (KL2TR002346) and Doris Duke Fund to Retain Clinical Scientists, a patent from the GOG Foundation, and a leadership role as a Junior Board Member of the ASSCP, outside the submitted work. Dr. Powell reports advisory board participation for Merck, GSK/Tesaro, AstraZeneca, Eisai, SeaGen, and Clovis Oncology, outside the submitted work. Dr. Mutch reports leadership roles in the Foundation for Women’s Cancer, NCI Gynecologic Cancer Steering committee, and NCCN Committee for Cervix and Corpus, outside the submitted work. Dr. McCourt reports royalties from UpToDate, outside the submitted work. Dr. Palisoul reports consulting fees from Medtronic, outside the submitted work. There were no other reported conflicts of interest.

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Appendix A. Supplementary material

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References


