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Research Report

Shared decision making for patients with breast and gynecologic malignancies undergoing chemotherapy associated with persistent alopecia

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ABSTRACT

Objective: To assess patient-perceived involvement in shared decision making among those diagnosed with breast or gynecologic malignancies undergoing chemotherapy associated with persistent chemotherapy-induced alopecia (pCIA). We also sought to identify factors that influence shared decision making.

Methods: We recruited patients from the Gynecologic Medical Oncology and Breast Medicine Services at a large academic center for this prospective cohort study. All patients were scheduled to start chemotherapy between June 1, 2017 and December 31, 2017. Following medical consultation, including discussion of the risk of pCIA, patients completed the 9-item Shared Decision Making Questionnaire (SDM-Q-9). Clinical and sociodemographic information was also collected. Univariate analysis was used to evaluate SDM-Q-9 total scores and their constituents for all variables.

Results: Sixty-one patients completed the survey. The median total SDM-Q-9 score was 95.6 (95% CI: 90–100). Most patients (n = 57, 93%) reported a high level of involvement (SDM-Q-9 total score > 66). There was no difference in total scores between patients with breast compared with gynecologic cancer ($P > .05$). By individual item, the scores for item Q1 ("*My doctor made clear that a decision needs to be made*") were significantly lower for Black patients and those with advanced disease ($P < .05$).

Conclusions: Most patients indicated they were adequately involved in shared decision making regarding chemotherapy treatment options and their risk for pCIA. Patients from underrepresented populations and those with advanced disease may benefit from additional support from their clinicians to better address the anticipated psychosocial impacts of pCIA and facilitate the provision of optimal and equitable care.

1. Introduction

Advances in chemotherapy have substantially improved survival outcomes for multiple types of malignancies. Recently, investigators have focused on addressing the negative impact of chemotherapy treatments on quality of life. (Pal et al., 2012; Wu et al., 2018) Persistent chemotherapy-induced alopecia (pCIA) is the absence or suboptimal regrowth of hair after more than 6 months following chemotherapy completion. This enduring adverse event of chemotherapy has been associated with significant disruptions to normal life. (Spaich et al., 2018; Jayde et al., 2013; Freites-Martinez et al., 2019; Dua et al., 2017; Freites-Martinez et al., 2019) Several studies have found that patients may prioritize concerns of toxicity over predicted survival benefits, especially in the advanced-disease setting. (Spaich et al., 2018; Hofheinz et al., 2016)

When formulating the optimal treatment plan for a patient diagnosed with cancer, careful consideration should be given to patient preference. A shared decision making approach in which both physician and patient

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are equally and actively involved in sharing information and reaching an agreement on how best to proceed is recommended. (Kriston et al., 2010) This approach helps facilitate value-consistent decisions, realistic expectations, effective use of coping mechanisms, increased patient satisfaction, and treatment adherence. (Oshima Lee and Emanuel, 2013; de Mik et al., 2018)

Much of the literature on shared decision making and the impact of pCIA is focused on breast cancer. (Spaich et al., 2018; Boland et al., 2020) Patients with gynecologic malignancies are frequently treated with similar alopecia-inducing cytotoxic regimens; however, knowledge surrounding patient-physician communication patterns and the burden of pCIA in the setting of gynecologic cancers is lacking. The objective of our study was to assess the shared decision making perspective of patients with breast or gynecologic cancer undergoing chemotherapy regimens that can cause pCIA. Specifically, we aimed to quantify and compare the degree of shared decision making for patients with breast compared with gynecologic cancers. We also sought to identify clinical and sociodemographic factors that may be associated with suboptimal patient-physician communication regarding the relative risks and benefits of treatment options.

2. Methods

Patient recruitment and data collection were performed at Memorial Sloan Kettering Cancer Center, a large academic cancer center, following approval by the Institutional Review Board (Protocol #14-236). Patients with a diagnosis of gynecologic or breast cancer who were scheduled to receive their first cycle of alopecia-inducing chemotherapy (taxane- or anthracycline-based) between June 1, 2017 and December 31, 2017 were invited to participate in the study. Following informed consent, the study participants completed an anonymous 9-item Shared Decision Making Questionnaire (SDM-Q-9) and a demographic questionnaire. All patients had previously undergone consultation with a medical oncologist who was familiarized with and utilized a shared decision making approach to discuss treatment options and the risk of pCIA. A counseling session with the medical oncologist lasted 30 min, which is a standard amount of time for such visits. In addition to treatment therapies, all patients were offered non-therapeutic supportive care options, which is a standard component of patient counseling at our institution. The oncologists relied on the up-to-date literature regarding the risks and benefits of chemotherapy as well as patient preferences in order to provide a balanced view of the potential cancer management options available to each patient. The study dermatologist provided additional detailed, evidence-based information, per patient request, about the risk of pCIA, its clinical aspects, and treatments options, at the time of informed consent. The session with the dermatologist lasted 15 to 30 min. Additional clinical data were extracted from electronic medical records.

The SDM-Q-9 is a validated scale used to evaluate patients' perceived involvement in decision making; it has shown good acceptance, reliability, and feasibility in multiple medical settings, including oncology. (Kriston et al., 2010; Wu et al., 2019; Geessink et al., 2018; Calderon et al., 2018) The questionnaire consists of 9 self-administered questions, each of which represents one step in the decision making process. Each item is scored from 0 ("completely disagree") to 5 ("completely agree") on a 5-point Likert scale. Item Q4, "*My doctor precisely explained the advantages and disadvantages of the treatment options,*" had additional content specific to the risk of developing pCIA —"*My doctor explained that hair loss may persist even after 6 months of last chemotherapy cycle (seen in less than 30% of patients), characterized by a diffuse hair loss and hair thinning, mostly involving the crown area, and that some topical dermatologic therapies may help in this condition.*" The score for each item and the total scores were linearly transformed to a scale between 0 and 100. (Kriston et al., 2010) Based on previous research, the following categories were used to classify the patients' perceived level of involvement in decision making: a total SDM-Q-9 score of 0–33 suggested a low level of perceived involvement, a total score of 34–66 suggested an intermediate level, and a total score of 67–100 suggested a high level. (Hahlweg et al., 2020) Each item of the SDM-Q-9 was analyzed on the respective Likert-scale using frequency distribution.

Statistical analysis was performed using R 4.1.0 (R foundation, Vienna, Austria). Univariate analyses were performed for comparison of non-parametric data using the Kruskal-Wallis or Wilcoxon rank sum tests of significance. A significance level of $P < .05$ was used to identify patient characteristics that predicted a low level of perceived involvement in shared decision making.

3. Results

Thirty-one patients with breast cancer and 30 patients with gynecologic cancer participated in the study. Of the 30 patients with gynecologic cancer, 17 had uterine cancer, 8 had ovarian cancer, 3 had cervical cancer, and 2 had vaginal cancer. Demographic information and the mean total SDM-Q-9 scores are presented in Table 1. The median age of patients was 59 years (95% CI: 54–65; range: 25–85 years). The median total SDM-Q-9 score was 95.6 (95% CI: 90–100). Most patients (n = 57, 93%) reported they felt highly involved in shared decision making, while 5% (n = 3, 2 patients with breast and 1 with gynecologic cancer) and 2% (1 patient with gynecologic cancer) reported an intermediate and a low level of perceived involvement in shared decision making, respectively. There was no significant difference in the total SDM-Q-9 scores between patients with breast compared with gynecologic cancer. Similarly, when the total SDM-Q-9 scores were stratified by other clinical and sociodemographic characteristics, there were no significant differences in perceived involvement in shared decision making ($P > .05$; Table 1).

Fig. 1 illustrates the scores per SDM-Q-9 item. The scores for each item were also stratified by patient characteristics and compared using univariate analyses (Supplemental Table S1). For the self-reported race variable, we compared the itemized scores for Black and White patients.

Table 1
Median SDM-Q-9 scores based on sociodemographic and clinical characteristics.

Characteristic	No. of patients (%)	Median SDM-Q-9 scores (95% CI)	*P* value*
Cancer diagnosis			
Gynecologic	30 (49.2)	96.5 (82.2–100)	0.65
Breast	31 (50.8)	95.0 (86.7–100)	
Age (median, 59 years; 95% CI: 54–65)			
<60 years	31 (50.8)	95.6 (88.9–100)	0.52
≥60 years	30 (49.2)	98.8 (82.2–100)	
Self-reported race			
Asian	3 (4.9)	100	0.32
Black	14 (23.0)	90 (71.1–100)	
White	44 (72.1)	95.6 (90–100)	
Education			
High school or less	13 (21.3)	97.8 (66.7–100)	0.90
College or higher	48 (78.7)	95.6 (88.9–100)	
Marital status			
Married	43 (70.5)	97.5 (82.2–100)	0.68
Single or divorced	18 (29.5)	92.2 (86.7–100)	
Stage at diagnosis			
I and II	30 (49.2)	96.7 (90–100)	0.51
III and IV	31 (50.8)	91.1 (82.2–100)	
Chemotherapy setting			
Neoadjuvant	36 (59.0)	97.6 (91.1–100)	0.30
Adjuvant	25 (41.0)	90. (82.2–100)	
Prior chemotherapy			
Yes	10 (16.4)	97.8 (77.8–100)	0.41
No	51 (83.6)	95.6 (88.9–100)	
Number of anticancer therapy options discussed			
One	22 (36.1)	100 (86.7–100)	0.27
Multiple	39 (63.9)	95.0 (80.0–100)	

*No significant differences were present within each subgroup ($P > .05$).
SDM-Q-9: 9-item Shared Decision-Making Questionnaire.

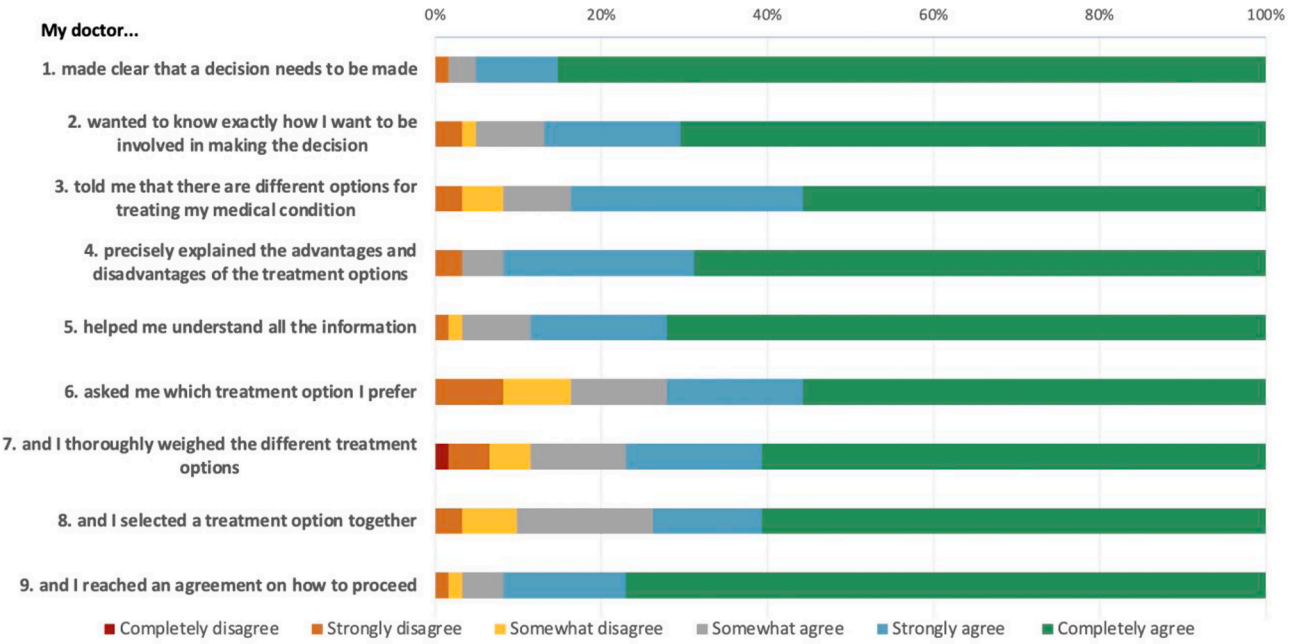

Fig. 1. SDM-Q-9 items evaluating stepwise patient perceptions of shared decision making SDM-Q-9: 9-Item Shared Decision-Making Questionnaire.

Patients who identified as Asian (n = 3) were excluded from this analysis because they responded "completely agree" to almost all of the questions. The scores for item Q1, "*My doctor made clear that a decision needs to be made,*" were significantly lower for Black patients compared to White patients ($P < .05$). Patients with advanced-stage disease also gave significantly lower scores to this question, compared to patients with stage I or II disease ($P < .05$). Furthermore, for some clinical and sociodemographic variables (ie, the number of anticancer therapy options discussed, level of education obtained, chemotherapy setting, and prior chemotherapy), there were differences in the itemized scores that did not reach statistical significance, which is likely due to the small sample size (Supplemental Table S1).

4. Discussion

Our findings show no difference in perceived involvement in shared decision making regarding chemotherapy treatment options and the risk of pCIA among patients with breast compared with gynecologic cancers, with most patients self-reporting adequate involvement. Our results suggest that models from the breast cancer literature regarding patient preference and perceived involvement in cancer treatment may also be applicable to patients with gynecologic cancers. Our analysis also showed that Black race and advanced-stage disease were associated with lower itemized SDM-Q-9 scores, suggesting these and other clinical and sociodemographic factors may contribute to communication challenges between patients and physicians. Awareness of these risk factors may facilitate the provision of more optimal and equitable support for patients undergoing chemotherapy.

Taxanes (eg, docetaxel, paclitaxel), anthracyclines (eg, doxorubicin, daunorubicin), and alkylating agents (eg, cyclophosphamide, cisplatin) are associated with severe hair loss. (Freites-Martinez et al., 2019; Palamaras et al., 2011) At least 60% of patients who receive these regimens experience chemotherapy-induced alopecia (CIA), and up to 30% develop pCIA. (Zielinski et al., 2005; Sibaud et al., 2016; Chan et al., 2021) The prevalence and patterns of pCIA vary according to the specific chemotherapy regimen administered. For example, 23.3% of patients receiving docetaxel reported pCIA compared to 10.1% of patients treated with paclitaxel ($P < .01$). (Munzone et al., 2019) Additionally, the dose, treatment schedule, combination of cytotoxic agents, and subsequent adjuvant or maintenance therapies (eg, endocrine therapies or PARP inhibitors) may also contribute to the increased risk of pCIA. (Slaught et al., 2021; Shah et al., 2018)

There are two automated scalp cooling devices approved by the US Food and Drug Administration for all patients with solid tumors receiving alopecia-inducing chemotherapy regimens. (Martín et al., 2018) The efficacy of these devices is variable and dependent upon the type of chemotherapy regimen, with significantly less hair preservation in patients receiving anthracyclines compared to those receiving non-anthracycline-based regimens. While scalp cooling may help mitigate pCIA, data are limited. (Hoffer et al., 2021)

Hair loss, especially scalp alopecia, may be more traumatic for women than for men. (Hesketh et al., 2004) Women may associate alopecia with a loss of femininity, sexuality, vitality, and strength. (Choi et al., 2014; McGarvey et al., 2001) CIA can lead to profound psychosocial distress, including depression, anxiety, a reduced sense of well-being, and lower self-esteem. Patients frequently consider hair loss as the most traumatic aspect of chemotherapy, and up to 8% of patients reject chemotherapy to avoid CIA. (Spaich et al., 2018; Siegel et al., 2022) The distressing impacts of CIA have been extensively studied in breast cancer, which is the most common cancer in women and typically presents at a relatively young age. (McGarvey et al., 2001; Chua et al., 2020) Effective screening and treatment options have led to a dramatic increase in the number of breast cancer survivors, many of whom express concerns about the persistent body changes after breast cancer treatments (SEER).

The management of gynecologic cancers usually involves cytoreductive surgery and taxane-based chemotherapy, which results in CIA in most patients. In the United States, the incidence of gynecologic cancers is rising; in 2022, there will be an estimated 65,950 newly diagnosed cases of uterine cancer, 19,880 cases of ovarian cancer, and 14,100 cases of cervical cancer. (Chua et al., 2020) Based on data from 2012 to 2018, the relative 5-year survival rates range from 49.7% for ovarian cancer to 81.3% for uterine cancer. (Shen et al., 2018) Compared to other cancers, significantly less research has been done to explore the impact of CIA in patients with gynecologic cancers undergoing cytotoxic treatment—a population that is often greatly impacted by treatment-related side effects. (Boland et al., 2020) A qualitative study examining CIA in women with ovarian cancer demonstrated that hair loss was a major concern, with some women describing it as being more traumatic than their ovarian cancer diagnosis. (Jayde et al., 2013) While both breast and

gynecologic cancers predominantly affect women and are psychosocially linked to womanhood, there are distinct differences between these cancers. Breast cancer is associated with better survival outcomes. (Shen et al., 2018) Screening, treatment, post-surgery recovery, and recurrence rates are specific to cancer type, and thus, it is possible these factors may differentially affect the impact of pCIA on women with these cancers.

Given the known burden of hair loss, patient preference and participation in treatment decisions are critical. The results of our study show that following the discussion of treatment options for breast or gynecologic cancer with a medical oncologist, most patients felt adequately involved in shared decision making. There was no difference observed in total SDM-Q-9 scores between patients with breast cancer compared with gynecologic cancer. Univariate analysis of the itemized SDM-Q-9 scores showed that compared to patients with breast cancer, patients with gynecologic cancer may find it more challenging to understand the proposed treatment options and associated side effects, although the difference was not statistically significant (item Q5, $P = .13$).

Analysis of the itemized SDM-Q-9 scores also showed that compared to White and Asian women, Black women reported more challenges making treatment decisions with their medical oncologist (item Q1, $P = .02$). For all questions, the mean itemized scores were lower for Black patients; however, the difference did not reach statistical significance, so it may be attributable to the small sample size. Because the medical oncologists in this study were White females, patient-physician racial discordance may have played a role in lower patient-perceived involvement among the Black patients. This is consistent with abundant emerging research supporting that racial concordance is associated with a higher quality of communication between patients and physicians. (Ku and Vichare, 2022; Austin et al., 2015)

Patients with advanced-stage disease also reported significantly lower scores to item Q1, "*My doctor made clear that a decision needs to be made*" ($P = .01$). Previous research suggests that it can be more challenging to engage patients with serious illness in complex health care decisions. (Stacey et al., 2010) When patients were stratified by the number of anticancer therapies discussed, patients gave higher scores when only one therapy, compared to many therapies, was discussed, although the difference was not statistically significant (total SDM-Q-9 score, $P = .27$). In contrast, Stacey et al found that patients were more satisfied with and active in decision making when they were offered choices for cancer treatment. (Kutner et al., 2006) Of note, some understanding of medical information is required for participation in decision making. Health literacy varies directly with the level of education attained. (Wallace et al., 2016) Based on the results from the 2003 National Assessment of Adult Literacy, greater than 75% of adults with less than a high school diploma were at or below the basic level of health literacy. To account for confounding bias, we stratified the subgroups of patients with a lower and higher education level based on whether one or multiple chemotherapy options were discussed. Interestingly, patients with a higher level of education (college degree or higher) gave lower SDM-Q-9 scores when more than one anticancer therapy was discussed (n = 33; median score, 93.3; 95% CI: 77.8–97.8) compared to only one (n = 15; median score, 100; 95% CI: 88.9–100; $P = .06$), which did not reach statistical significance, likely due to a small sample size. From this, we infer that more educated patients may be overwhelmed by choice to a greater degree while participating in decision making compared to patients with a lower level of education.

Univariate analyses of the itemized SDM-Q-9 scores showed that several other clinical and sociodemographic factors, including a lower education level, neoadjuvant settings, and receiving chemotherapy for the first time, may impact a patient's ability to understand new medical information, communicate with their physicians, and make an informed decision regarding chemotherapy treatment and side effects.

There were two outliers in our study who gave significantly lower scores compared with other participants. A very low SDM-Q-9 score of 20 was given by a patient with stage IV undifferentiated endometrial carcinoma, who identified herself as Black and who was starting treatment with paclitaxel and carboplatin. The second patient gave a low SDM-Q-9 score of 40, self-identified as White and had stage Ia pT1bN0 triple-negative moderately differentiated invasive ductal carcinoma of the left breast. She elected to proceed with doxorubicin and cyclophosphamide. Both patients had high school or less as their highest level of schooling.

There are several limitations to our study. The study was conducted at a single cancer center, which may limit the generalizability of our findings. Next, contemporary evidence-based data regarding the risk of pCIA associated with a specific chemotherapy regimen was incorporated into patient counseling, which could have introduced some variation into the information that each patient was provided during the consultation. Of note, standard institutional dosing guidelines were used for chemotherapy administration. Furthermore, in addition to a consultation with their medical oncologist, patients were also approached by a dermatologist, who discussed dermatologic chemotherapy-associated side effects while consenting them to the study. This differs from routine practice, as dermatologists do not usually meet with patients prior to chemotherapy. This study also had a small sample size; thus, it was underpowered to optimally detect all of the differences in the SDM-Q-9 scores. Future studies with larger sample sizes are warranted. In addition, the acceptance rate of chemotherapy at our institution was high, and we were unable to identify any patients who declined chemotherapy. It would have been preferable to have included perspectives of patients who chose not to proceed with chemotherapy. Based on population data from the National Cancer Data Base (NCDB), a 1.8% chemotherapy refusal rate has been reported among patients with ovarian cancer (147,713 patients; from 1998 to 2011), 11.4% for endometrial cancer (60,187 patients; from 2004 to 2016), and 14.1% for invasive breast cancer (2,058,568 patients; from 2004 to 2016). (Barrington et al., 2022; Moya et al., 2021; Wallace et al., 2016) Of note, the study participants were well informed of the risk of developing pCIA with the selected cytotoxic chemotherapy by their treating medical oncologist and the study dermatologist. Furthermore, the oncologists used a shared decision making approach but were not provided with a specific script to guide the conversation; thus, some degree of variation is possible. As study participants self-selected to participate, self-selection bias may have influenced our findings. The future direction of this project should include exploration of the perspectives of patients who perceive less involvement in shared decision making and those who decline chemotherapy after being counseled. Additionally, it would be informative to assess whether the study outcomes would have differed if the discussions surrounding pCIA had been conducted solely by the treating oncologist, as an additional consultation with a dermatologist prior to chemotherapy is not routine practice.

Despite these limitations, this is the first study to assess how perceived involvement in shared decision making among patients with breast cancer compares to that of patients with gynecologic cancer when considering the risks and benefits of chemotherapy and potential for pCIA. Given the body of published literature on shared decision making and the extent of distress caused by CIA among patients with breast cancer, (Spaich et al., 2018; Boland et al., 2020) our results suggest that this knowledge can be extrapolated to patients with gynecologic cancer. Shared decision making and patient-centered care will be especially important in the future as new anticancer therapies emerge and improved survival outcomes lead to more cancer survivors at risk for pCIA. Furthermore, patients undergoing chemotherapy may benefit from support from clinicians to prevent and manage dermatologic adverse events. Our hope is that the oncologists who treat patients with gynecologic cancers will be able to integrate the perspectives of dermatologists who are frequently only consulted after the development of pCIA in order to facilitate early discussions regarding the potential risks of permanent hair loss as part of a shared decision making process. Finally, our study presents evidence that some sociodemographic and clinical factors may pose challenges in patient-physician

communication.

5. Conclusions

Clinicians treating patients with gynecologic and breast cancers must be aware of the benefits of shared decision making and the need to effectively communicate the risks of pCIA. A better understanding of the sociodemographic and clinical factors associated with perceived inadequate patient involvement in shared decision making may present opportunities to provide more equitable care for patients undergoing chemotherapy and dealing with its adverse events.

Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Dr. Freites-Martinez reports consulting fees from Galderma, Leo Pharma, Pierre Fabre, and to the SHB law firm, which represents Sanofi Aventis U.S. Dr. O'Cearbhaill reports honoraria from GSK, Bayer, Regeneron, SeaGen, R-Pharm, GOG Foundation, Fresenius Kabi, Immunogen, MJH Life Sciences and Curio. Dr. Goldfarb reports grants from Paxman Coolers Ltd and Sprout Pharmaceuticals Inc paid to the institution; consulting from NanOlogy and Spectrum Pharmaceuticals; and participation in an advisory board for Sermonix Pharmaceuticals LLC, Revision Skincare, and Ms. Medicine. Dr. Lacouture reports grants, consulting fees, and honoraria from Johnson & Johnson, Novocure, QED, Bicara, Janssen, Novartis, F. Hoffmann-La Roche AG, EMD Serono, Astrazeneca, Innovaderm, Deciphera, DFB, Azitra, Kintara, RBC/La Roche Posay, Trifecta, Varsona, Genentech, Loxo, Seattle Genetics, Lutris, OnQuality, Azitra, Roche, Oncoderm, NCODA, and Apricity, as well as receives research funding from Lutris, Paxman, Novocure, Johnson & Johnson, US Biotest, OQL, Novartis and AstraZeneca; royalties from Harborside Press; and leadership fees from Hoth, Lutris. Dr. Friedman reports grants paid to the institution from Daiichi, Merck, Bristol-Myers Squibb, AstraZeneca, Genentech/Roche, and Mersana; consulting fees from Bristol-Myers Squibb, Seagen; honoraria from OncLive and Aptitude Health; uncompensated participation in advisory boards for Genentech/Roche for MyPathway and Merck for LYNK-002; and drugs from Genentech/Roche. All other authors have no potential conflicts of interest to disclose.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.gore.2022.101095.

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