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Endometrial Cancer: The Patient Voice Is Center Stage

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INTRODUCTION

- Despite decreasing mortality rates for many cancers in the United States each year, endometrial cancer (EC) is on the rise.
  - The incidence of EC in the United States increased by approximately 20%, and the age-adjusted mortality increased by approximately 30%, between 2002 and 2022.[1,2]
- Unfortunately, EC is severely underfunded relative to its rapidly increasing mortality rate.[3,4]
- For effective coalition-building across gynecology advocacy, it is essential to quantify patient perspectives.
- Self-reported patient data can be used to establish a needs assessment for EC within the field of gynecologic oncology.
- The objectives of this study were to explore patient perspectives on the impact of treatment for EC, identify patient preferences regarding treatments, and gather insights on how patient preferences inform treatment decisions.

METHODS

- A 15-minute survey was conducted online within the United States in collaboration with The Harris Poll.

Patients

- Respondents for this survey were recruited from the patient advocacy group, Endometrial Cancer Action Network for African-Americans, sourced from their patient list (n = 21) or selected from among those who had agreed to participate in online surveys (n = 98).
- Patients with the following demographic and clinical criteria were recruited to participate:
  - ≥ 18 years of age.
  - assigned female at birth.
  - resident of the United States.
  - diagnosed by a healthcare provider with uterine, endometrial, or womb cancer.
  - ever received chemotherapy.

Survey design and analysis

- The survey was conducted between April 21 and July 7, 2025.
- Survey elements were designed to quantify the patient perspective on topics including, but not limited to, diagnosis, treatment, biomarkers, counseling, and caregiver support.
- Demographic variables were captured.
- Raw data were not weighted and are therefore only representative of the individuals who completed the survey.
- For this study, the patient sample data are accurate to within ± 8.9 percentage points using a 95% confidence level.

RESULTS

Demographic and clinical characteristics

- A participation rate of 484/571 (85%) was obtained; among these patients, 119/484 (25%) met the criteria for survey completion and subsequent data analysis.
- Select demographic and clinical characteristics are listed in **Table 1**.
  - 52 (44%) patients reported having been tested for mismatch repair (MMR) tumor status; however, among these patients, 20 (38%) were not sure of their results.
  - 46 (39%) patients reported a lack of caregiver support.
- 71 (60%) patients previously underwent surgery.

Table 1. Demographic and clinical characteristics

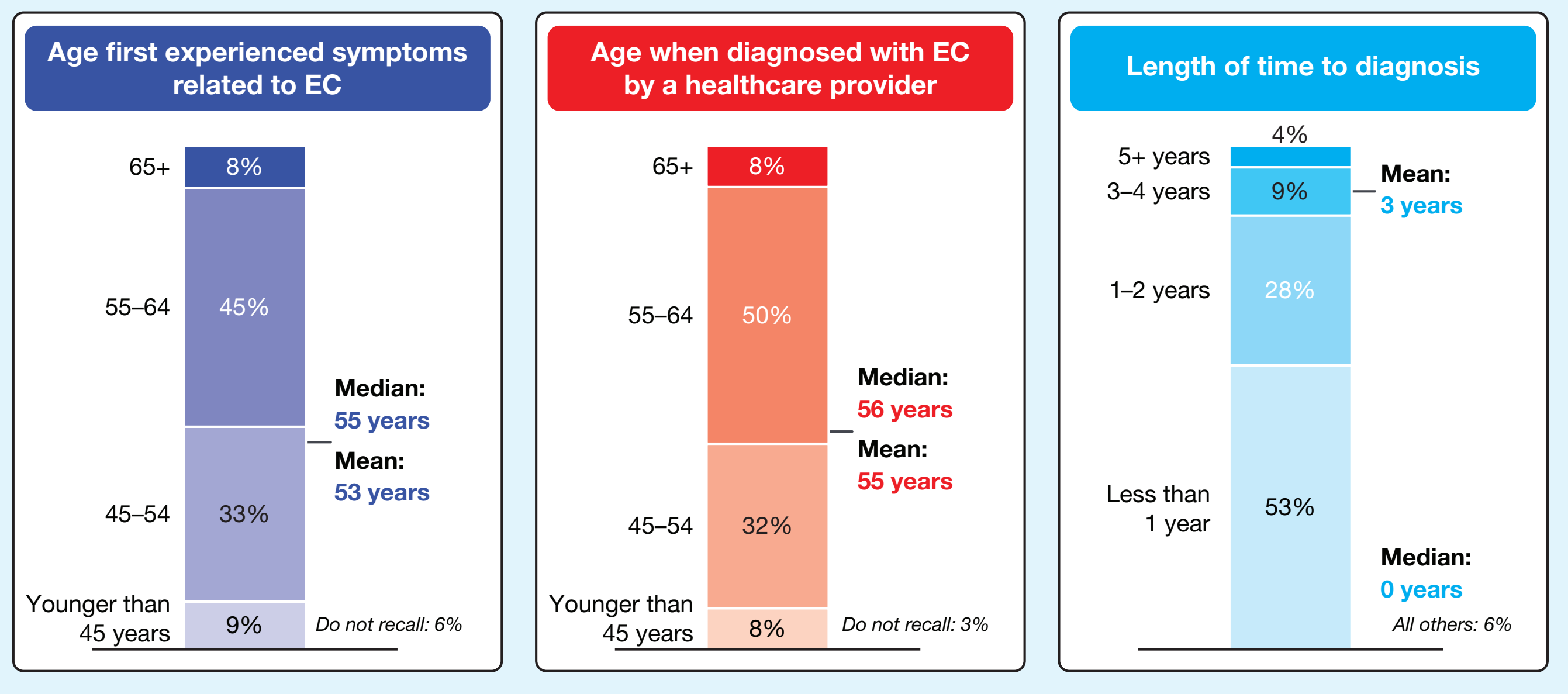
Category	Patients who completed the survey (n = 119)
Median age, years	59
Race or ethnicity, %	
White	61
Hispanic	22
Black or African American	16
Asian	1
Locale, %	
Urban / Suburban / Rural	50 / 37 / 13
Comorbidities (top 5), %	
High blood pressure	32
Arthritis	24
Anxiety	21
Diabetes	17
Depression	12
> 1 prior line of chemotherapy, %	
Yes / No	54 / 46
MMR testing and status, %	
Had test (yes / no)	44 / 56
Deficient[a]	17
Proficient[a]	44
Had the test but do not know results[a]	38
Have caregiver, %	
Yes / No	61 / 39

[a]Percentages are based on 52 patients who reported having been tested for MMR status.
MMR, mismatch repair.

RESULTS (CONTINUED)

- Patients' diagnostic path is summarized in **Figure 1**.
  - The mean age of patients when they started experiencing symptoms related to EC was 53 years.
  - The mean length of time to diagnosis was 3 years.

Figure 1. Path to endometrial cancer diagnosis

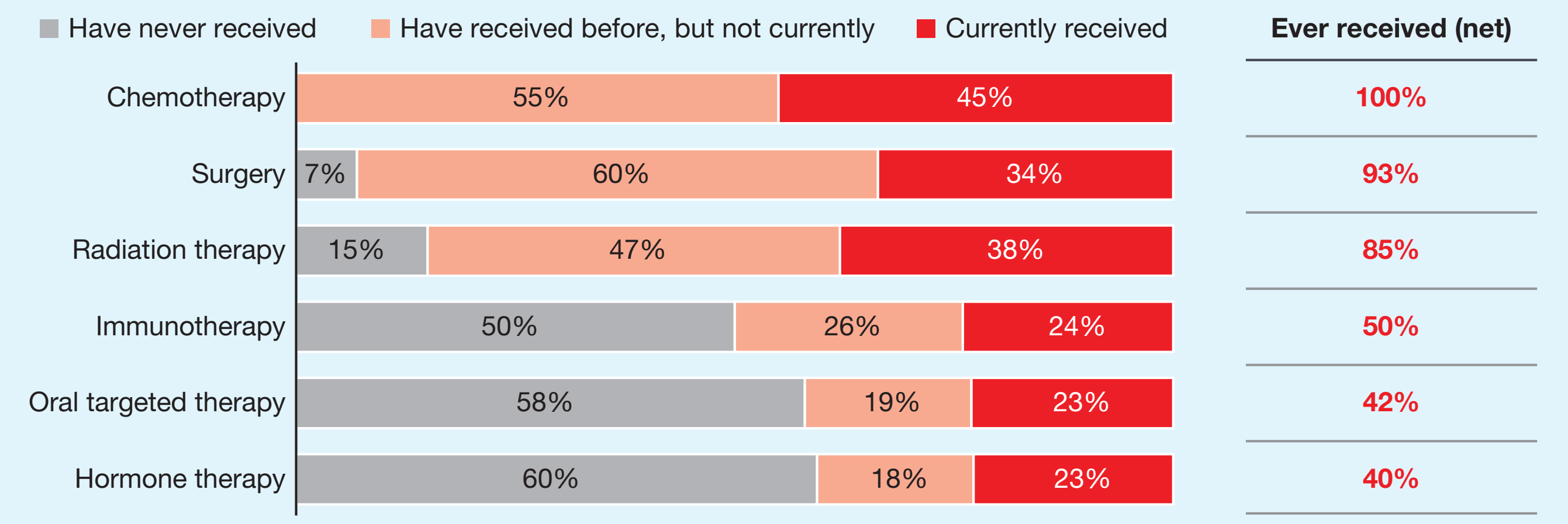


Percentages may not add to 100 due to rounding.
EC, endometrial cancer.

Treatment experience and perception

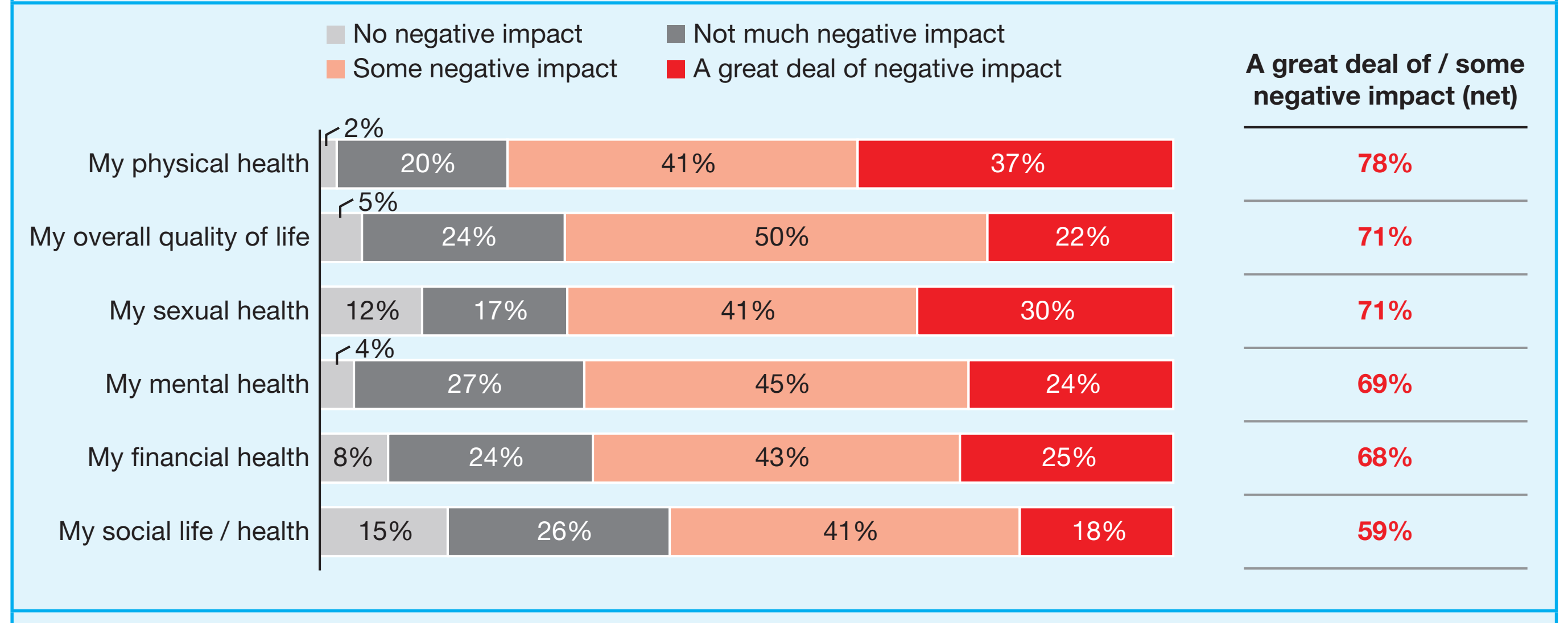
- Treatment history is shown in **Figure 2**.
  - More than 2 in 5 patients had tried or were currently receiving the following treatments: immunotherapy (50%), oral targeted therapy (42%), or hormonal therapy (40%).
- Among patient considerations regarding treatment choices, impact of side-effects on quality of life (61%), potential for long-term side effects (57%), and the ability to slow cancer progression (56%) were the most commonly reported.
- The negative impacts of living with EC on physical, mental, financial, and social aspects of life are summarized in **Figure 3**.
  - More than half of respondents reported some or a great deal of negative impact across the domains studied (ranging from 59% to 78% of patients).
  - The majority (71%) of patients reported a negative impact on their overall quality of life.

Figure 2. Treatment types received



Percentages may not add to 100 due to rounding.

Figure 3. Negative impact of living with/managing endometrial cancer on aspects of life



Percentages may not add to 100 due to rounding.

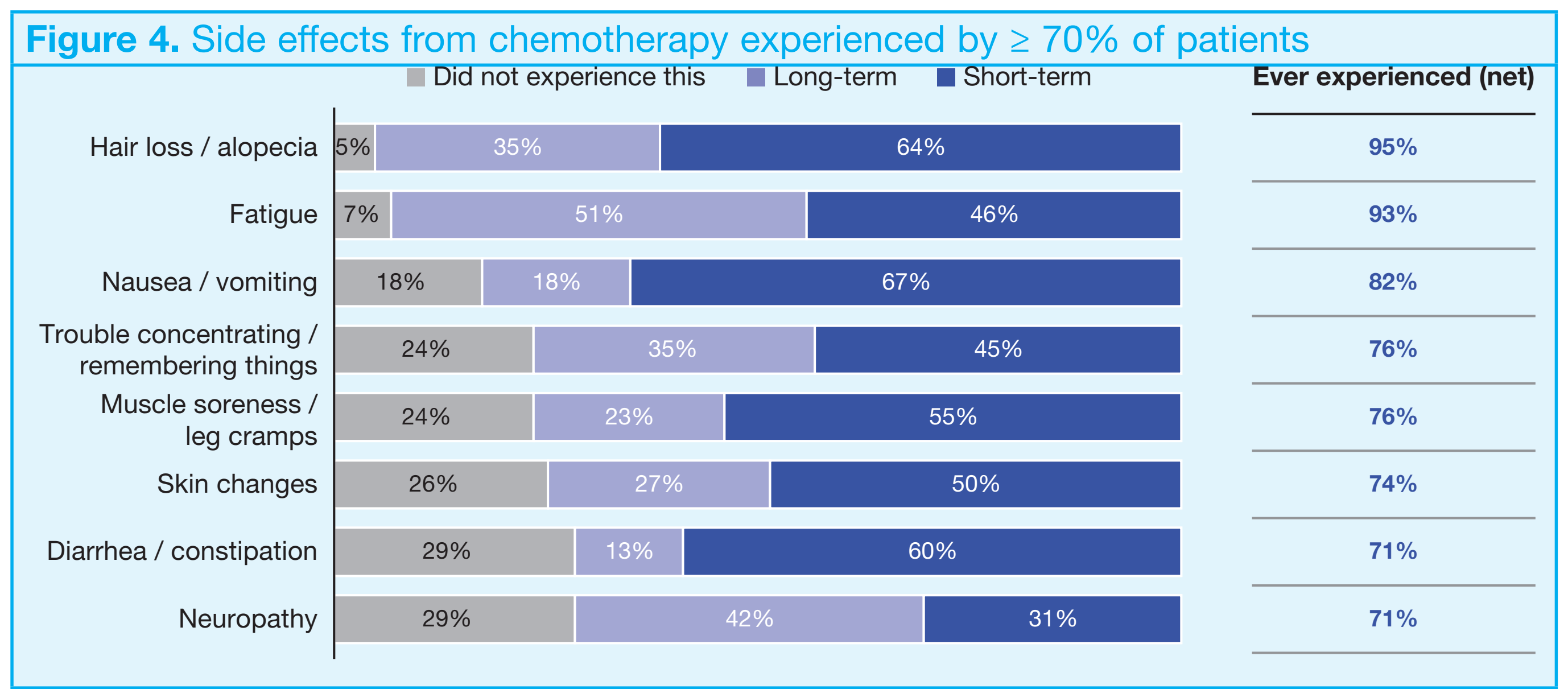
- The most common (> 70%) patient-reported side effects of chemotherapy are reported in **Figure 4**.
- **41%** of patients who received more than 1 line of chemotherapy reported that their second-line chemotherapy was worse than the first, and **69%** reported that they often feel/felt like they were missing out on life with how much time they spent in chemotherapy treatments.
- **70%** of patients agreed that the burden of chemotherapy treatment was almost as much as the burden of the disease itself, and **71%** of patients reported that they would prefer not to use chemotherapy again in the future.

Treatment considerations and patient education

- The importance of different aspects when selecting a treatment is summarized in **Figure 5**.
  - Accessibility, insurance coverage, and healthcare provider recommendation were reported as the most important aspects of treatment decisions (**Figure 5**).
- Regarding treatment preferences, 92% of patients prioritized a personalized treatment plan, and 82% of patients preferred a treatment option that does not cause as much hair loss/alopecia as chemotherapy.

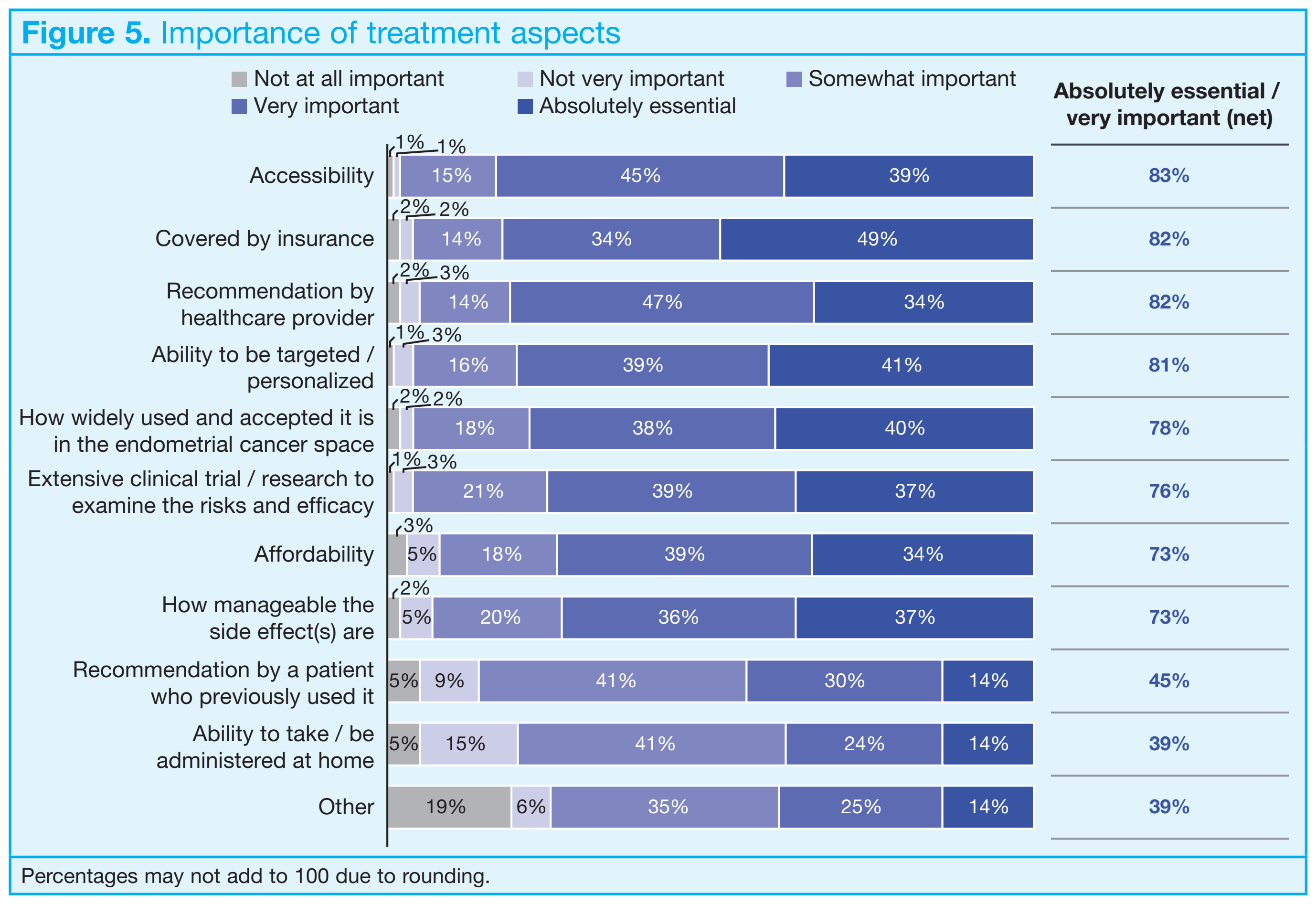
- Most patients strongly agreed or somewhat agreed with the following statements:
  - **"I wish my healthcare provider and I spent more time discussing what matters to me regarding my EC treatment(s)"** (79% of patients).
  - **"I feel informed about various EC treatments"** (72% of patients).
- 91% of patients agreed that they would like to know about different treatment options for EC besides chemotherapy.
- 62% of patients who self-identified as a person of color reported feeling informed about various treatment options (versus 79% of those who did not self-identify as a person of color), though results were based on extremely small samples and should be interpreted as qualitative.

Figure 4. Side effects from chemotherapy experienced by ≥ 70% of patients



Note: Question was presented as a multiple select grid (respondents could select both 'long-term' and/or 'short-term' for each side effect), therefore rows may add to over 100%, and long-term and short-term values cannot be added to determine the patients who ever experienced a side effect.

Figure 5. Importance of treatment aspects



Percentages may not add to 100 due to rounding.

CONCLUSIONS

- Patients with EC place high value on individualized treatment planning and shared decision-making.
  - However, 38% of patients who were tested for MMR status were uncertain of their results, 39% of patients reported a lack of caregiver support, and patients waited an average of 3 years for a diagnosis, highlighting significant unmet needs.
- Chemotherapy often comes with steep personal burdens that deepen with multiple lines of therapy; as such, non-chemotherapy options are in high demand and should be considered and prioritized when appropriate.
  - 91% of patients agreed that they would like to know about treatment options besides chemotherapy.
- Given time constraints in oncology practice, innovative strategies to enhance educational outreach, individualized treatment planning, and collaborative care are critical within the EC community, especially for patients of color and those navigating later lines of treatment.

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Infographic

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