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Age, patient experience and satisfaction with breast cancer care: a cohort study using linked national cancer patient experience survey and cancer registry data

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ABSTRACT

Objective To examine whether satisfaction with information provision and involvement in decision-making among people with breast cancer (BC) treated in English hospitals was associated with age and other patient characteristics.

Design Retrospective population-based cohort study, conducted as part of the National Audit of Primary Breast Cancer and the National Audit of Metastatic Breast Cancer.

Setting National Cancer Patient Experience Survey (CPES) responses linked to National Cancer Registration data for BC patients (stage 0–4) diagnosed between 2017 and 2021.

Participants 40 018 patients diagnosed with BC who responded to CPES between 2017 and 2021.

Primary and secondary outcome measures Responses to questions about overall experience of care, satisfaction with information provision, involvement in decision-making and clinical nurse specialist (CNS) contact were examined. The relationships between responses, personal, disease and clinical characteristics were analysed using multivariable Poisson regression.

Results 90% of patients rated their overall care as ≥8 out of 10 (0=very poor; 10=very good), decreasing to 82% for those aged <40 years (p<0.001). Adjusted analysis showed that stage 4 disease (incidence risk ratio (IRR) 1.19; CI 1.02 to 1.40; p<0.001), the highest deprivation (IRR 1.18; CI 1.07 to 1.30; p<0.001) and Asian (IRR 1.60; CI 1.42 to 1.82; p<0.001) or Black (IRR 1.53; CI 1.30 to 1.80; p<0.001) ethnicity were associated with a negative overall care experience. Satisfaction was high for information provision (85%) and involvement in decisions (81%), but lower among younger patients and those with advanced stage disease (both p<0.001). Fewer than 70% of patients aged <40 years felt sufficiently involved in decisions, compared with 81% >40 years (p<0.001). Patients with stage 4 disease were more likely to report dissatisfaction with involvement in decision-making (IRR 1.50: CI 1.36 to 2.67; p<0.001). Most patients (95%) had a named CNS, with 85% reporting ease of contact.

Conclusion Most patients reported high satisfaction with their BC care. Satisfaction was consistently lower among younger people and those with advanced disease; this finding might partly reflect more complex pathways but requires further exploration, ideally in partnership with patients to codesign solutions. Actionable remedial strategies are proposed.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ Novel linkage of National Cancer Patient Experience Survey (CPES) and National Cancer Registration data revealed lower satisfaction with information, involvement in decision-making and clinical nurse specialist contact among young people (18–39 years) and those with metastatic breast cancer.
⇒ Large national cohort provided sufficient power to examine associations across patient, disease and clinical characteristics, including under-represented groups.
⇒ Reliance on voluntary, self-reported data may introduce response and recall bias, particularly given declining survey response rates, which could affect generalisability.
⇒ Improved care requires hospital staff to engage with the findings of CPES and use them to implement effective improvement strategies.

INTRODUCTION

Breast cancer (BC) is the most commonly diagnosed cancer in the UK, accounting for 15% of all new cancer diagnoses, with around 55 000 cases diagnosed annually in England.[1 2] While overall 5-year BC survival is improving,[3] BC incidence in young women is increasing disproportionately with survival rates reported to have improved at a slower pace than observed in older women.[4–8] These survival disparities among young women may reflect distinct tumour biology,[9] delayed diagnosis[10] and psychosocial complexities,[11]

highlighting the need for a better understanding of their specific experiences and perceptions of care.

Patient experience is a core dimension of healthcare quality, complementing patient safety and effectiveness of care.[12] The National Health Service (NHS) recognises the importance of health services assigning equal priority to patient experience as to achieving excellent clinical outcomes and survival.[13] The 10-year plan for the NHS, published in 2025, reinforces this focus, identifying patient experience as a key measure of care quality and system performance.[14] In parallel, the National Institute for Health and Care Excellence (NICE) guidelines on patient experience provide services with a framework for operationalising this commitment, highlighting the importance of individualised care, treating patients with dignity and respect, providing continuity of care and opportunities for patient participation through information provision and shared decision-making.[15]

The National Cancer Patient Experience Survey (CPES) in England has run annually since 2010. It provides valuable insights into how patients view the quality of their cancer care and identifies areas for improvement. Eligible patients—those aged 16 and over who were admitted as an inpatient or day case for cancer-related care within a defined 3-month sampling period—are invited to complete the survey following discharge. The survey covers the entire care pathway from diagnosis to aftercare and includes (1) a global rating of overall care and (2) questions on specific elements of the care pathway as well as questions on recognised determinants of experience, including satisfaction with information provision, involvement in decision-making and support from clinical nurse specialists (CNSs).[16–18] Ease of CNS access is linked with better overall patient experience, reflecting their central role in care coordination, tailored information and psychosocial support.[18] As such, the survey is one of the few national sources of data that can provide insight into treatment decision-making and care coordination.

The aim of this study was to examine the experience of patients with BC focusing on questions related to information provision, involvement in decision-making and contact with a CNS. In particular, it investigated whether the experience of care for patients with BC care was related to their age at diagnosis, accounting for personal, disease and clinical characteristics. The study used a dataset that linked CPES and National Cancer Registration Data (NCRD) and focused on the overall rating of experience, information provision, involvement in decision-making and contact with a CNS.

METHODS

Study design

This retrospective population-based cohort study was undertaken as part of the National Audit of Primary Breast Cancer (NAoPri) and the National Audit of Metastatic Breast Cancer (NAoMe).[19 20] The NAoPri and NAoMe are two of 10 national cancer audits delivered by the National Cancer Audit Collaborating Centre.[21] The audits evaluate the patterns of care and outcomes for people with primary and metastatic BC in England and Wales, aiming to support service improvement and enhance quality of care.

Patient and public involvement (PPI)

Members of the patient and public involvement (PPI) forums for the NAoPri and NAoMe contributed to the development of the initial scope and priorities of both audits and therefore informed the overall direction of associated research, including this study. The PPI forums were not directly involved in the conduct or analysis of this study.

National cancer patient experience survey and questions included in this analysis

The study used data from the CPES conducted between 2017 and 2021. The survey is distributed by post, with an option for online completion. Each year, NHS Trusts in England that provide adult cancer services compile a list of eligible patients—those aged 16 and over with a confirmed cancer diagnosis who have been discharged from an English NHS Trust following an inpatient episode or day-case attendance for cancer-related treatment (elective or emergency) within the April–June sampling window. The survey is not restricted to newly diagnosed individuals, meaning patients may be invited to respond in multiple survey years and at various time points following their initial BC diagnosis. Annually, a national report summarises the survey results and is published alongside tailored reports for individual NHS trusts, cancer alliances and integrated care boards.[22] Interactive online dashboards are published to facilitate data exploration.[23]

The CPES questionnaire contains around 70 multichoice questions that cover the care pathway from diagnosis to aftercare while also collecting patient demographics and clinical characteristics. This study analysed responses to six questions, covering overall experience, information provision, involvement in decision-making and aspects of contact with a CNS. The selected questions, along with their response options and any cross-year variation, are summarised in table 1. Although there were minor changes in the wording and response options of some questions across survey years, these variations were not considered impactful to cross-year analyses. In 2021, the CPES question on understanding of CNS responses was replaced with a question about the helpfulness of CNS responses, and therefore, data for this item were unavailable for that year. Most questions had categorical response options that could be grouped to reflect a positive, neutral or negative experience. An exception was the question on the overall experience of care, which used a Likert scale from 0 (very poor) to 10 (very good).

Table 1 CPES questions included in the analysis and their variations between survey years

Number in 2019 survey	Full CPES question (abbreviated reference)	Score (P/N/-)*	Question variation 2017–2021
14	Before your cancer treatment started, were your treatment options explained to you? (information provision)		1. Number 12 2017, 2018 2. Number 20 2021
	Yes, completely	P	
	Yes, to some extent	N	
	No	N	
	There was only one type of treatment that was suitable for me	N/A	
	Don't know/can't remember	N/A	
18	Were you involved as much as you wanted to be in decisions about your care and treatment? (decision-making)		1. Number 16 2017, 2018 2. Number 21 2021
	Yes, definitely	P	
	Yes, to some extent	N	
	No	N/A	
	Don't know/can't remember	N/A	
19	Did you have a main contact person within the team looking after you, such as a CNS, who would support you through your treatment? (named CNS contact)		Number 17 2017, 2018, 2021
	Yes, it was a specialist nurse	P	2017–2020 'Were you given the name of a CNS who would support you through your treatment?' (Yes, no, don't know/can't remember)
	Yes, it was another member of the team	P	
	No	N	
	Don't know/can't remember	N/A	
20	How easy or difficult has it been for you to contact your CNS? (ease of CNS contact)		Number 18 2017, 2018, 2021
	Very easy	P	
	Quite easy	P	
	Neither easy nor difficult	N	
	Quite difficult	N	
	Very difficult	N	
	I have not tried to contact my CNS	N/A	
21	When you have had important questions to ask your CNS, how often have you got answers you could understand? (understanding CNS responses)		Number 19 2017, 2018
	All or most of the time	P	2021 omitted from analysis 'Overall how helpful was the advice you received from your main contact person?'
	Some of the time	N	
	Rarely or never	N	
	I have not asked any questions	N/A	2017–2020 'No, but I would like to have been more involved', (Very helpful, quite helpful, neither helpful nor unhelpful, quite unhelpful, very unhelpful, I have not needed to ask for advice)
61	Overall, how would you rate your care? (overall experience)		Number 59 2017, 2018, 2021
	0–10 Likert scale		
	≥8	P	
	≤7	N	
	Not valid	N/A	

*Scoring (positive, negative or not applicable) follows the approach outlined in the 2019 CPES technical document.[28]
CNS, clinical nurse specialist; CPES, Cancer Patient Experience Survey; N, negative; N/A, not applicable; P, positive.

Study cohort, data sources and linkage

The study cohort included women and men aged 18 years or older, newly diagnosed with BC (International Classification of Diseases, 10th Revision (ICD-10) diagnosis codes: C50 and D05), Tumour, Node, Metastasis (TNM) stages 0–4, in England between 1 January 2017 and 31 December 2021, who returned a response to the CPES during the same period. A flow diagram outlining the derivation of the study cohort is presented in online supplemental figure 1. The cohort was derived from pseudonymised patient and tumour-level data provided by the National Cancer Registration and Analysis Service, linked at the individual level to CPES response data from survey years 2017–2021. Inclusion was based on the date of diagnosis. Patients who responded to CPES between 2017 and 2021 but were diagnosed prior to 2017 were excluded. For individuals with multiple CPES responses across survey years, only the earliest response was included; this typically corresponded to the year of diagnosis. Further information on inclusion criteria for the NAoPri and NAoMe can be found in the State of the Nation Reports and associated methodology documents.[24 25]

The study used the NCRD as the primary source of information about personal and disease characteristics.[26] This was combined with data from multiple national sources, including the Cancer Outcomes and Services Dataset, the Systemic Anti-Cancer Therapy (SACT) dataset, the Radiotherapy Dataset (RTDS) and Hospital Episode Statistics (HES). Variables used in this study included: age at diagnosis, gender, ethnicity, performance status (PS), socioeconomic deprivation (Index of Multiple Deprivation (IMD) quintiles), route to diagnosis and date of diagnosis. The Charlson Comorbidity Index (CCI) scores were calculated using secondary diagnoses (ICD-10 codes) from HES-Admitted Patient Care records within 24 months prior to BC diagnosis.[27]

Treatment details were derived from HES (surgery), RTDS (radiotherapy) and SACT (chemotherapy). Surgical variables were defined as mastectomy (with or without reconstruction) or breast-conserving surgery (BCS) within 12 months of diagnosis. Adjuvant radiotherapy was defined as radiotherapy initiated within 6 months following surgery. Receipt of neoadjuvant or adjuvant chemotherapy was combined to assess the impact of any chemotherapy. Six treatment categories were analysed: (1) no treatment, (2) mastectomy, (3) mastectomy and radiotherapy, (4) BCS, (5) BCS and radiotherapy and (6) multimodal treatment, incorporating surgery and chemotherapy (with or without radiotherapy). These categories were chosen to reflect the level of treatment detail consistently available in national data. No endocrine treatment details were included in this study. For patients recorded having received radiotherapy only (n=129), this was assumed to reflect a data recording error, with surgery possibly performed in a private setting and not captured in the dataset. These individuals were classified as having received BCS plus radiotherapy. As the BCS plus radiotherapy group was larger than the mastectomy plus radiotherapy group, any potential misclassification was expected to have a minimal impact on the results.

Statistical analysis

Descriptive statistics were used to summarise personal, disease and clinical characteristics of the study cohort. Responses to each of the six selected survey questions were recoded as binary variables (positive or negative), following the approach outlined in the 2019 CPES technical document (table 1).[28] Responses classified by CPES as 'not applicable', such as 'don't know/can't remember' or, for CNS-related questions, cases where no contact had been attempted, were excluded from the analysis. For the question 'Overall, how would you rate your care?', a positive rating was defined as a response of 8 or higher on the Likert scale (0–10). For the descriptive analysis, age at diagnosis was categorised into 10-year increments, with the exception of the end categories (18–39 years, 90+ years).

The relationship between question responses and personal and disease characteristics was analysed using Poisson regression models with robust standard errors. Multivariable regression models were used to derive incidence risk ratios (IRRs) for the likelihood of a negative experience for age, gender, stage of disease, socioeconomic deprivation, ethnicity, prepandemic status (2017–2019) or postpandemic status (2020–2021) and treatment received. A model was fitted to each question individually using all available complete observations. Not every patient in the study population answered each of the six selected survey questions, and responses for each question were analysed independently. All statistical tests were two-sided, and p values <0.001 were considered to demonstrate statistical significance.

Missing data were handled as follows: stage of disease (5.5%), ethnicity (4.1%) and CCI (0.1%) were assigned to an 'unknown' category and included in the regression analysis. This approach was chosen to retain representation of all patient groups and minimise data loss. PS was frequently missing (38.1%) and was reported only in the descriptive analysis. All statistical analyses were conducted using Stata V.17.

RESULTS

The study cohort comprised 40 018 patients diagnosed with BC who responded to CPES between 2017 and 2021. Most respondents (99.5%) were female, with a median age at diagnosis of 61 years (range 18–99). CPES responses were unevenly distributed across survey years. Table 2 presents the CPES response year alongside the personal, disease and clinical characteristics of the study cohort.

Reported experience of BC care

The percentage of respondents who reported a positive experience was generally high between 2017 and 2021,

Table 2 Personal, disease and clinical characteristics of people with BC responding to the Cancer Patient Experience Survey 2017–2021

Characteristic	Number of people n=40 018	Per cent of total number	Characteristic	Number of people n=40 018	Per cent of total number
CPES year			Stage		
2017	5796	14.5	Stage 0	2228	5.6
2018	10 632	26.6	Stage 1–3 a	32 625	81.5
2019	10 409	26.0	Stage 3b, 3c	1624	4.1
2020	3080	7.7	Stage 4	1327	3.3
2021	10 101	25.2	Unknown	2214	5.5
Gender			Screen detected		
Female	39 798	99.5	Yes	12 077	30.2
Age (years)			Performance status		
18–39	1824	4.6	0	21 659	54.1
40–49	5740	14.3	1	2521	6.3
50–59	10 752	26.9	2+	604	1.5
60–69	11 671	29.2	Unknown	15 234	38.1
70–79	7796	19.5			
80–89	2235	5.6			
IMD deprivation quintile			Co-morbidity (Charlson index)		
Least deprived—1	10 106	25.3	0	36 131	90.3
2	9586	24.0	1	2844	7.1
3	8546	21.4	2+	1014	2.5
4	6862	17.1	Unknown	29	0.1
Most deprived—5	4918	12.3			
Ethnicity			Treatment pathway		
White	35 478	88.7	No treatment	1747	4.4
Asian or Asian British	1279	3.2	Mastectomy	2966	7.4
Black or Black British	746	1.9	Mastectomy+RT	1535	3.8
Mixed	231	0.6	BCS	2412	6.0
Other ethnic group	648	1.6	BCS+RT	11 999	30.0
Unknown	1636	4.1	Multimodal	19 359	48.4

BCS, breast conserving surgery; CPES, Cancer Patient Experience Survey; IMD, Index of Multiple Deprivation; RT, radiotherapy.

with 89.5% rating their overall experience as 8 or above (Q61). The proportions who reported being satisfied with information provision (Q14) and with involvement in decision-making (Q18) were slightly lower at 85.3% and 80.9%, respectively. 95.3% of respondents reported having a named CNS (Q19), and 85.0% reported being able to contact them easily (Q20). Levels of comprehension of CNS responses (Q21) were also high at 88.1%. There was some variation in the proportions each year (table 3 and online supplemental figure 2), with respondents during the years of the COVID-19 pandemic (2020 and 2021) reporting slightly lower values.

Online supplemental table 1 presents the results of Poisson regression analyses examining the association between personal, disease and clinical characteristics and responses to each of the six selected CPES questions from 2017 to 2021.

Relationship between CPES respondent characteristics and overall experience of BC care

Rating of overall experience varied by personal, disease and clinical characteristics (figure 1A). The likelihood of reporting a negative experience increased as patient age decreased. The youngest respondents were most likely to rate their care with a score ≤7 (18–39 years IRR 1.77; CI 1.57 to 1.99; p<0.001).

Higher disease stage was associated with a negative overall experience (stage 4 IRR 1.19; CI 1.02 to 1.40; p<0.001), this pattern was consistent across all age groups, with the difference most pronounced in younger patients (figure 2A). Other characteristics associated with

Table 3 Summary of positive responses on selected CPES questions among people with breast cancer, by CPES year

Question	Total responses	Average positive responses 2017–2021 (%)	Total responses by CPES year (% positive)				
			2017	2018	2019	2020	2021
Q61—Overall experience	38 802	89.5	5154 (90.9)	9216 (89.5)	9037 (89.6)	2623 (87.5)	8709 (89.4)
Q14 —satisfaction with information provision	36 920	85.3	4568 (86.3)	8318 (86.0)	8220 (86.4)	2350 (83.2)	8038 (83.6)
Q18—involvement in decision-making	39 291	80.9	4629 (81.8)	8356 (80.3)	8472 (82.8)	2401 (78.9)	7908 (79.5)
Q19—named CNS	38 803	95.3	5482 (96.8)	9891 (96.0)	9596 (95.7)	2790 (94.0)	9217 (93.8)
Q20—ease of CNS contact	33 512	85.0	4263 (86.9)	7558 (85.3)	7263 (84.3)	2166 (83.5)	7244 (84.8)
Q21—understanding CNS responses	24 322	88.1	4306 (89.7)	7632 (88.5)	7351 (87.6)	2137 (85.5)	*

NB: for positive response definition, see table 1.
*No data are available for 2021.
CNS, clinical nurse specialist; CPES, Cancer Patient Experience Survey.

a negative overall experience were being in the most deprived socioeconomic quintile (IRR 1.18; CI 1.07 to 1.30; p<0.001) and being of Black/Black British (IRR 1.53; CI 1.30 to 1.80; p<0.001) or Asian/Asian British (IRR 1.60; CI 1.42 to 1.82; p<0.001) ethnicity. Among the different care pathways, those least likely to report a negative overall experience of care were patients who had BCS and radiotherapy (IRR 0.63; CI 0.54 to 0.73; p<0.001) and patients who had multimodal treatment (IRR 0.73; CI 0.64 to 0.84; p<0.001).

Relationship between CPES respondent characteristics satisfaction with information provision prior to cancer treatment

85.3% of CPES respondents reported satisfaction with the information provided to them. However, as with overall experience, levels of dissatisfaction were greater among younger patients (18–39 years IRR 1.67; CI 1.50 to 1.85; p<0.001) and those with stage 4 disease (IRR 1.43; CI 1.27 to 1.62; p<0.001) (figure 1B). This gradient of increasing likelihood of dissatisfaction with advancing stage was most pronounced among the youngest patients (figure 2B).

Socioeconomic deprivation was inversely associated with dissatisfaction, with respondents from the most deprived quintile (IMD 5) least likely to report dissatisfaction (IRR 0.79; CI 0.72 to 0.86; p<0.001). Asian/Asian British responders were 18% more likely (IRR 1.18; CI 1.05 to 1.33; p=0.023) and Black/Black British responders 20% more likely (IRR 1.20; CI 1.03 to 1.41; p=0.023) to report dissatisfaction than White British responders.

Relationship between CPES respondent characteristics and satisfaction with involvement in decision-making about their cancer care

80.9% of CPES respondents reported satisfaction with their involvement in decision-making. Again, we observed greater levels of dissatisfaction among those of younger age (18–39 years IRR 1.59; CI 1.46 to 1.73; p<0.001) and higher stage (stage 4 disease IRR 1.50; CI 1.36 to 1.67; p<0.001) (figure 1C). The impact of late-stage disease was most pronounced in younger respondents (figure 2C).

Dissatisfaction was more likely in Asian/Asian British respondents (IRR 1.13; CI 1.02 to 1.25; p<0.001) and Black/Black British respondents (IRR 1.33; CI 1.18 to 1.50; p<0.001) compared with White British respondents. After adjusting for other factors, those receiving BCS and RT were least likely to report dissatisfaction with involvement in decision-making (IRR 0.77; CI 0.69 to 0.86; p<0.001).

Relationship between CPES respondent characteristics and interactions with CNS

Overall, 95.3% of CPES respondents reported having a named CNS, and there was minimal observed association with age or disease stage (figures 1D and 2D). However, denying having a named CNS was less common for patients in the most deprived socioeconomic quintiles (IMD 5 IRR 0.72; CI 0.61 to 0.84; p<0.001) and in those from a Black/Black British ethnic background (IRR 0.53; CI 0.34 to 0.82; p=0.036). All active treatment pathways were associated with a lower likelihood of denying having a named CNS compared with the no-treatment group.

A relatively high proportion of respondents reported difficulty contacting their named CNS (15.0%). The likelihood decreased with greater age and was least among patients with non-invasive disease (figure 2E). Socioeconomic deprivation was not associated with ease of contacting a CNS. Similar ethnic disparities were seen as with previous questions, where Black/Black British respondents (IRR 1.31, CI 1.13 to 1.52, p<0.001) and Asian/Asian British respondents (IRR 1.20, CI 1.06 to 1.36, p<0.001) were more likely to report difficulty in access than White British respondents (figure 1E).

In terms of understanding the responses from their CNS, 11.9% of CPES respondents reported difficulties. The proportion who reported difficulty decreased with age (figures 1F and 2F), with the youngest patients most likely to report difficulty (18–39 years IRR 1.38; CI 1.19 to 1.60;

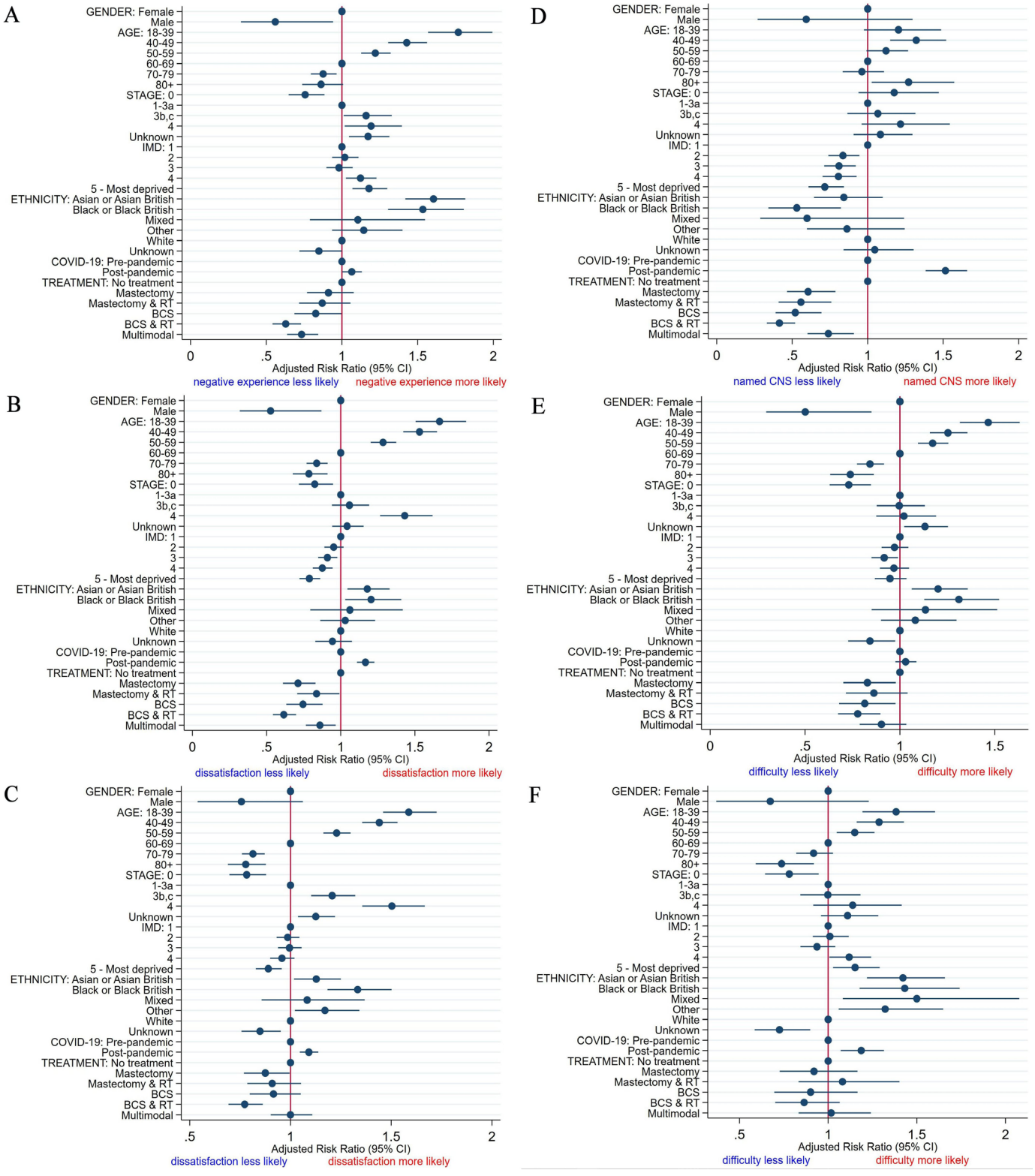

Figure 1 Incidence rate ratios of selected CPES responses for personal, disease and clinical characteristics. (A) Adjusted risk ratios of a negative overall experience by personal, disease and clinical characteristics (n=38 802). (B) Adjusted risk ratios of a dissatisfaction with information provision prior to cancer treatment by personal, disease and clinical characteristics (n= 36 920). (C) Adjusted risk ratios of a dissatisfaction with involvement in decision-making by personal, disease and clinical characteristics (n= 39 291). (D) Adjusted risk ratios of not having a named CNS by personal, disease and clinical characteristics (n= 38 803). (E) Adjusted risk ratios of a reporting difficulty in contacting a named CNS by personal, disease and clinical characteristics (n=33 512). (F) Adjusted risk ratios of reporting difficulty in understanding CNS responses by personal, disease and clinical characteristics (n= 24 322). BCS, breast-conserving surgery; CNS, clinical nurse specialist; CPES, Cancer Patient Experience Survey; IMD, Index of Multiple Deprivation.

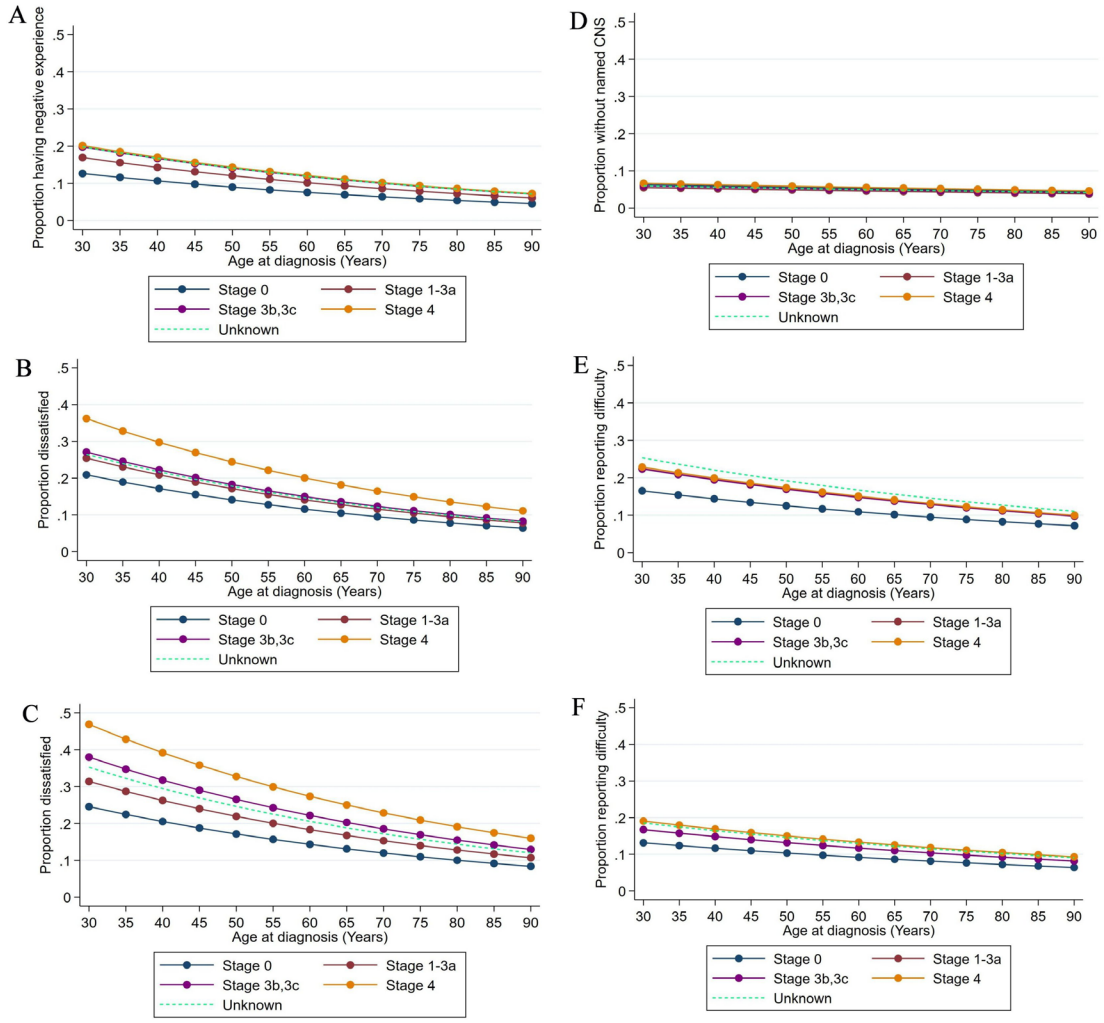

Figure 2 Relationship between selected CPES questions and patient age and disease stage. (A) Adjusted relationship of CPES respondent age and stage of disease with their overall experience of BC care (n=38 802). (B) Adjusted relationship of CPES respondent age and stage of disease and their satisfaction with information provision prior to cancer treatment (n= 36 920). (C) Adjusted relationship of CPES respondent age and stage of disease and their satisfaction with their involvement in decision-making about their cancer care (n= 39 291). (D) Relationship of CPES respondent characteristics and reporting having a named CNS (n= 38 803). (E) Relationship of CPES respondent characteristics and ease of contacting a named CNS (n=33 512). (F) Relationship of CPES respondent characteristics and understanding of CNS (n= 24 322). CNS, clinical nurse specialist; CPES, Cancer Patient Experience Survey.

p<0.001). Compared with White British respondents, Asian/Asian British and Black/Black British respondents were more likely to report difficulties, respectively, IRR 1.42 (CI 1.22 to 1.66, p<0.001) and IRR 1.43 (CI 1.18 to 1.74, p<0.001). No significant associations were observed between this response and socioeconomic deprivation or treatment type.

Differences between men and women in CPES responses

Men comprise 0.55% of the study population, limiting the statistical power to compare their experience to those of women. The analysis suggests that, overall, men were less likely to report a negative overall experience (IRR 0.56, CI 0.33 to 0.94, p=0.029). On the specific questions, men were less likely than women to report dissatisfaction with information provision (IRR 0.53, CI 0.32 to 0.87, p=0.012) and ease of contacting a named CNS (IRR 0.50, CI 0.30 to 0.85; p=0.010).

CPES responses during the COVID-19 pandemic

While fewer patients provided CPES responses during the COVID-19 pandemic, the overall experience did not differ greatly compared with the preceding period (IRR 1.06; CI 1.00 to 1.13; p=0.043). However, differences were observed on the questions about specific issues. Postpandemic respondents were marginally less satisfied with the information provided prior to treatment (IRR 1.17; CI 1.11 to 1.23; p<0.001) and in their involvement in decision-making (IRR 1.09; CI 1.05 to 1.14; p<0.001). A greater proportion of pandemic respondents reported not having a named CNS (IRR 1.52; CI 1.38 to 1.66; p<0.001). Although dissatisfaction with CNS accessibility did not increase (IRR 1.03; CI 0.98 to 1.09; p=0.280), the likelihood of reporting difficulty understanding CNS responses increased postpandemic (IRR 1.19; CI 1.07 to 1.31; p=0.001).

DISCUSSION

Summary of findings

This study of 40 018 CPES respondents with BC linked at a patient level to national cancer registry data provides insights into how personal, disease and clinical characteristics influence patient-reported experiences about their involvement in treatment decision-making and care coordination, including overall experience, satisfaction with information provision, involvement in decision-making and contact with a CNS.

Younger respondents (18–39 years) were most likely to report negative care experiences in five out of six questions analysed, whereas those with metastatic breast cancer (MBC) were more likely to do so in three of the six. The steepest age-related disparities were observed in satisfaction with information provision and involvement in decision-making, with the disparities being most pronounced among those with MBC (figure 2A–F). Only the assignment of a named CNS was unaffected by age or stage. A weaker relationship was observed with increasing age and reduced likelihood of reporting difficulty contacting a named CNS and understanding their responses, with these disparities most evident in those with MBC. These differences suggest that younger patients and those with MBC may have specific emotional, informational and support needs that are not adequately met.

Respondents from the most deprived IMD quintile and those from non-white ethnic backgrounds were more likely to express dissatisfaction with their overall care, whereas those receiving BCS and radiotherapy or multimodal anticancer treatment were less likely to do so. The response patterns across the six analysed questions varied greatly between these dissatisfied subgroups.

Study strengths and limitations

A notable strength of this study is the use of a large national cohort of CPES respondents, which enabled sufficient statistical power to analyse the relationship between patient experience and personal, disease and clinical characteristics, even in groups with under-represented characteristics. The application of Poisson regression further strengthened the validity of our conclusions by accounting for variations in response distributions.

Parallel workstreams in NAoMe and NAoPri have identified the potential for bias in CPES results, with over-representation among CPES respondents of individuals receiving more intensive anticancer treatment, with the highest representation seen in those receiving chemotherapy.[29] Conversely, younger individuals (aged 18–39), those from non-white ethnic groups, and individuals in the most deprived IMD quintile were under-represented. While these limitations may introduce some bias, the large overall sample size and consistency of findings across subgroups mitigate these effects and lend confidence to the conclusions, providing statistically robust insights into under-represented groups.

The reliance of CPES on voluntary participation and self-reported data introduces potential biases, the impact of which may be increasing due to declining survey response rates in recent years.[30]

Survey response bias is a key concern, as individuals with particularly strong positive or negative experiences may be more likely to participate, potentially distorting the conclusions that can be drawn from the findings. Furthermore, recall bias may affect those completing CPES after their year of diagnosis, as their recollection of care experiences may be less accurate or influenced by subsequent events.

Comparison with other studies

Consistent with previous analyses of English CPES data across multiple tumour sites, we found that younger patients, particularly those aged 18–39 years, were significantly less likely to report positive overall care experiences, satisfaction with information provision or involvement in decision-making.[31–34] The findings of this study highlight the propensity of young women with BC for dissatisfaction with their care. As these patterns align with those reported in other tumour sites, they may have relevance for improving younger patient experience across the wider cancer population.

The greater likelihood of young women with BC reporting negative overall experiences may be driven by unmet needs, higher expectations and real differences in the care they receive. Disentangling whether these disparities arise from variations in care provision or from differing needs requires qualitative investigation. Young women are reported to experience higher levels of psychological distress and a greater incidence of depressive illness following BC diagnosis and treatment.[35] Contributing factors include the often-aggressive nature of their disease, the intensity of treatment regimens and the unexpected nature of a cancer diagnosis at a young age, all of which necessitate additional psychosocial support.[11 36] This distress may be exacerbated by concerns about the impact of treatment on sexuality, fertility, lactation, body image and survival. These concerns likely contribute to higher information needs and expectation for active involvement in decision-making, contrasting with older patients who were shown to prefer a more passive role.[37 38] Heightened information requirements can leave young women vulnerable to the dissatisfaction with both the information provided and their involvement in treatment decisions, a pattern observed in this study and consistent with existing literature.[39 40] Such unmet needs can contribute to negative experience of care and ultimately impact their quality of life.[16 17] Additionally, genuine disparities in care for younger patients with BC may exacerbate dissatisfaction, including perceived delays in diagnosis. Negative care experiences in this cohort are particularly concerning, given they are reported to have disproportionately poorer survival outcomes across all stages, histological subtypes and hormone receptor expression subgroups.[41]

This study demonstrated that patients with MBC were more likely to report negative experiences across three

of the six analysed questions. The findings align with the complex supportive care needs of MBC patients, who face intense treatment regimens and poorer prognoses.[42] It is further compounded by the shortage of specialist MBC nurses with the expertise to meet these needs.[43] The demonstrated relationship between advanced disease stage and worsening patient-reported experience is a novel finding within BC, enabled by our unique linkage of CPES data to cancer registration records. Prior CPES analysis among colorectal cancer patients identified stage as an important confounding factor for patient experience.[32] While analyses linking CPES responses to cancer registration data for prostate cancer similarly found that patients with advanced disease reported a worse experience.[44] In contrast, a similar study among lung cancer patients reported more positive experiences in patients with late-stage disease, particularly regarding support, which the authors attribute to the pivotal role of CNS support.[31]

This study found ethnic disparities, with Asian/Asian British and Black/Black British patients about 50% more likely to report a negative overall experience. Weaker but consistent associations were also observed between these groups and greater difficulty accessing a CNS, as well as challenges in understanding CNS responses. These findings align with prior literature.[45] As with young women, these differences in experience may reflect a higher likelihood of advanced or aggressive cancer biology at presentation,[46 47] combined with differing needs, expectations and variations in the care received. Other factors known to be associated with those from ethnic minority groups that may also be drivers of negative patient experiences include higher levels of deprivation and poorer general health.[47] Further work is needed to understand the underlying reasons for these disparities within a healthcare system intended to provide universal and equitable access. While not the primary focus of this study, future research should employ more granular ethnic categories and examine how patient experience varies by ethnicity in the context of personal and disease-related characteristics.

Men comprise 0.55% of the study population, limiting statistical power and the reliability of conclusions. Available evidence suggests men do not report a worse patient experience and may be less likely to report a negative experience for certain aspects of care, including overall experience, satisfaction with information provision and access to their CNS. Although this trend is in keeping with existing literature demonstrating men are more likely to report an overall positive experience of their cancer care,[33] the lack of gender differences is notable, as men with BC are a minority treated on a pathway designed for women. A larger study with more male respondents may reveal further insights.

While this study demonstrated no association with age or stage of disease and the likelihood of having a named CNS, a clear gradient was observed whereby younger patients and those with later stage disease were more likely to report difficulties in contacting their CNS and understanding responses. NICE guidance stipulates each person with BC should have a named CNS or keyworker,[48] which recognises their key role in delivering a positive patient experience. Evidence from over 100 000 patients in a mixed tumour site study, including those with BC, demonstrated that having a named CNS is strongly associated with better patient-reported experiences across multiple aspects of care, particularly involvement in treatment decisions, care coordination, respect and dignity and overall satisfaction.[18] Improving access to CNS care in young patients and those with MBC may represent an opportunity to improve overall patient experience.

Implications

This study highlights the challenges faced by younger women with BC and patients with MBC, who were most likely to report negative care experiences. Addressing unmet needs with tailored support for these groups, alongside improving bespoke information provision and shared decision-making, will likely enhance satisfaction. The findings also emphasise the need to better understand how tailored CNS support can improve patient experiences, aligning with the NAoMe scoping survey, which highlighted the importance of dedicated MBC CNS roles.[43] This study provides supporting evidence for advancing that goal and offers guidance for future qualitative research to further explore patient and CNS perspectives. Interventions and policies, codesigned with patients, that ensure equitable access to high-quality, individualised CNS support could drive improvements in patient experience for all BC patients, regardless of personal or disease-related characteristics. NHS organisations should consider implementing regular patient-reported outcome questionnaire mechanisms designed for younger patients and those with MBC to better understand and address their specific concerns.

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