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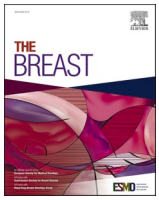

Experiences and preferences about information on treatment-related side effects among patients with early breast cancer

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A B S T R A C T

Background: Treatment-related side effects are common among women treated for early breast cancer and their effective management is essential to maintain quality of life, ensure treatment adherence, and optimise survival outcomes. This study aimed to investigate patient-reported experiences and preferences about information regarding side effects received during breast cancer care.

Methods: An international multi-stakeholder expert group conducted an online patient survey assessing comprehensiveness, timing, and delivery modality of information regarding treatment-related side effects among patients undergoing primary therapy (surgery, radiation, and [neo]adjuvant chemotherapy) and endocrine therapy for early breast cancer. Descriptive analyses were performed.

Results: From June–August 2023, 608 respondents from Brazil, France, Germany, Italy, Japan, and Spain completed the survey: 57.5 % were <50 years old, and all were or had been on endocrine therapy. Fatigue was the most reported side effect (47.0 % for primary and 42.3 % for endocrine therapy). A variable proportion of patients (14.4%–46.8 % across side effects) reported receiving information only after having experienced the side effect. Up to 43.6 % of respondents reported receiving insufficient or no information on side effects from their healthcare providers. Most patients reported preference for proactive communication from healthcare providers about side effects and prevention strategies. Respondents valued direct interactions with physicians and nurses and capitalised on a relevant role for peer-support, however utility of smartphone and web-based platforms to record and manage symptoms was acknowledged.

Conclusion: The survey underscores critical needs and offers insight informing the provision of comprehensive and timely information on treatment-related side effects across the cancer survivorship continuum.

1. Introduction

Breast cancer is the most prevalent cancer among women globally [1]. In 2022, an estimated 2.3 million new cases were reported, accounting for 11.6 % of all cancer cases [2,3]. Advances in screening and multimodal treatment have significantly improved breast cancer outcomes, with the 5-year early breast cancer survival rate reaching approximately 80 % worldwide [4–6]. However, survivors of early stage breast cancer often face reduced quality of life due to physical, emotional, psychosocial, and cognitive impact of cancer and its treatment [7]. Commonly, local treatment-related side effects include post-surgical pain and lymphedema, and radiotherapy-associated dermatitis, whereas systemic treatments frequently induce fatigue, haematologic and gastrointestinal toxicity, hair loss, neuropathy, as well as menopausal symptoms and increased risk of osteoporosis and cardiovascular disease [7–9]. Many of these treatment-related sequelae may persist and severely impact daily functioning and well-being on the long-term, as well as reduce adherence to treatments and cause detriment on outcomes [10–12].

Cancer survivorship should be viewed as a continuum that starts at

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diagnosis of cancer and comprehensive survivorship care models are needed to proactively and effectively address not only cancer treatment but also the multiple needs of cancer survivors [13]. Among these, multidisciplinary management of side effects that includes provision of detailed information regarding their prevalence and effective supportive care, is crucial for maintaining patients' quality of life, enhancing adherence to treatment and avoiding detriment to survival [7,14–16]. This management requires the collaboration of a network of various professionals, including oncologists, supportive care and rehabilitation medical teams, as well as collaboration with community and primary care services [17]. Many patients report insufficient communication about potential side effects, leading to a lack of preparedness and uptake of effective management strategies [18–20]. Recognising this unmet need, we aimed to gather direct insights into experiences and preferences about information on treatment-related side effects from patients having received treatment for early breast cancer. This manuscript seeks to outline key learnings and use them to share results and inform recommendations.

2. Methods

2.1. Survey design

An international multi-stakeholder expert group, including professionals from oncology, surgery, nursing, pharmacy, psychology, patient advocacy, and industry designed an *ad hoc* survey for the present study. The aim was to assess the comprehensiveness, timing, and delivery modality of information about treatment-related side effects, along with perceived impact of the side effects on management and adherence to treatment. The survey, initially designed and reviewed in English, was subsequently forward translated into Brazilian Portuguese, French, German, Japanese, Italian, and Spanish. The list of questions and multiple-choice answers as applicable is available in Table S1.

2.2. Participants selection

Target countries for distributing the survey, i.e., Brazil, France, Germany, Italy, Japan, and Spain, were chosen to ensure representation from different continents and healthcare systems.

Participants were recruited through panel sampling, a convenience sampling method where pre-registered individuals from various market research panels were invited via email to participate in the survey. Patients eligible for the survey were those with early breast cancer treated with primary therapy, including surgery (± breast reconstruction), radiotherapy, and/or (neo)adjuvant chemotherapy (± targeted agents), and/or adjuvant endocrine therapy. Screening questions ensured that respondents were >18 years, had been diagnosed with breast cancer, had early stage of breast cancer at diagnosis, and had discussed therapy options with a healthcare professional.

2.3. Survey distribution and execution

The survey was developed using the Decipher tool (Forsta, version 153.12). Data collection was performed online via a dedicated link generated by the software. All respondents were offered an incentive aligned with the market standards and fair market value of their respective countries, conditional upon answering all survey questions. In cases where respondents did not complete the survey, follow-up calls were made to encourage completion. Prior to participation, respondents were consented and informed about the survey's objectives and the involvement of a healthcare company in the multi-stakeholder group.

2.4. Data analysis

Descriptive statistics were used to analyse the data. Responses were summarised using counts and percentages. Analyses were conducted

Table 1
Demographic characteristics of respondents (N = 608).

Characteristic	N (%)
Gender	
Female	562 (92.4)
Male	45 (7.4)
Prefer not to answer	1 (0.2)
Age distribution	
20-30	62 (10.2)
31-40	109 (17.9)
41-50	179 (29.4)
51-60	146 (24.0)
61-70	91 (15.0)
71-80	21 (3.5)
Years since initial early breast cancer diagnosis	
0–12 months	61 (10.0)
1–2 years	173 (28.5)
3–5 years	183 (30.1)
6–10 years	108 (17.8)
11+ years	83 (13.7)
Medical conditions diagnosed in the past (other than breast cancer)	
Hypertension	89 (14.6)
Depression	87 (14.3)
Diabetes	61 (10.0)
Migraines	62 (10.2)
Rheumatoid arthritis	21 (3.5)
Highest education level	
Less than secondary school	31 (5.1)
Graduated secondary school	90 (14.8)
Trade/technical school	88 (14.5)
Some college, no degree	49 (8.1)
Bachelor's degree	209 (34.4)
Master's degree	99 (16.3)
Advanced degree (Ph.D., M.D., etc.)	33 (5.4)
Prefer not to answer	9 (1.5)
Working status	
Employed – full time	297 (48.8)
Employed – part-time	113 (18.6)
Not employed, looking for work	19 (3.1)
Not employed, not looking for work	42 (6.9)
Retired	95 (15.6)
Not able to work	35 (5.8)
Prefer not to answer	7 (1.2)
Living status	
I live alone	110 (18.1)
I live with my parent(s)	66 (10.9)
I live with my relatives (other than my parents or children)	63 (10.4)
I live with friends	32 (5.3)
I live with my caregiver	69 (11.3)
I live with my child/children	163 (26.8)
Other- please specify	95 (15.6)
Prefer not to answer	10 (1.6)
Number of children (of those who live with their child/children)	
1	63 (38.7)
2	70 (42.9)
3	26 (16.0)
4	3 (1.8)
5	1 (0.6)
Family history of breast cancer	
Yes	240 (39.5)
No	355 (58.4)
Don't know/Can't say	13 (2.1)
Living area	
Large city (>100,000 inhabitants)	283 (46.5)
Suburb area near a large city (<100,000 inhabitants)	135 (22.2)
Small city or town	129 (21.2)
Rural area	58 (9.5)
Don't Know/can't say	3 (0.5)
Care centre type	
Large general hospital	267 (43.9)
Cancer centre	192 (31.6)
Private centre	92 (15.1)
Small community hospital	54 (8.9)
Don't Know/can't say	3 (0.5)
Distance to care centre	
0–20 km	246 (40.5)
21–50 km	199 (32.7)

(*continued on next page*)

Table 1 (*continued*)

Characteristic	N (%)
51–100 km	113 (18.6)
101–150 km	25 (4.1)
>150 km	13 (2.1)
Don't Know/can't say	12 (2.0)
Level of physical activity	
Active (at least 150 min of moderate or 75 min of vigorous intensity activity per week, or an equivalent combination)	200 (32.9)
Somewhat active (<150 min of moderate or <75 min of vigorous intensity activity per week, or an equivalent combination)	267 (43.9)
Not active (do not exercise/unable to exercise)	127 (20.9)
Don't Know/can't say	14 (2.3)

using the Q Research Software.

3. Results

3.1. Demographic characteristics of respondents

From June to August 2023, 608 respondents completed the survey from Brazil (n = 101), France (n = 100), Germany (n = 100), Italy (n = 106), Japan (n = 101), and Spain (n = 100). A total of 562 (92.4 %) identified themselves as women and 350 (57.5 %) were under 50 years old. Regarding the time since initial early breast cancer diagnosis, 183 (30.1 %) respondents were diagnosed 3–5 years before completing the survey, whereas 83 (13.7 %) were diagnosed 11 or more years earlier. Characteristics of respondents are provided in Table 1 and in Table S2 for the whole study population, and in Table S3 by country.

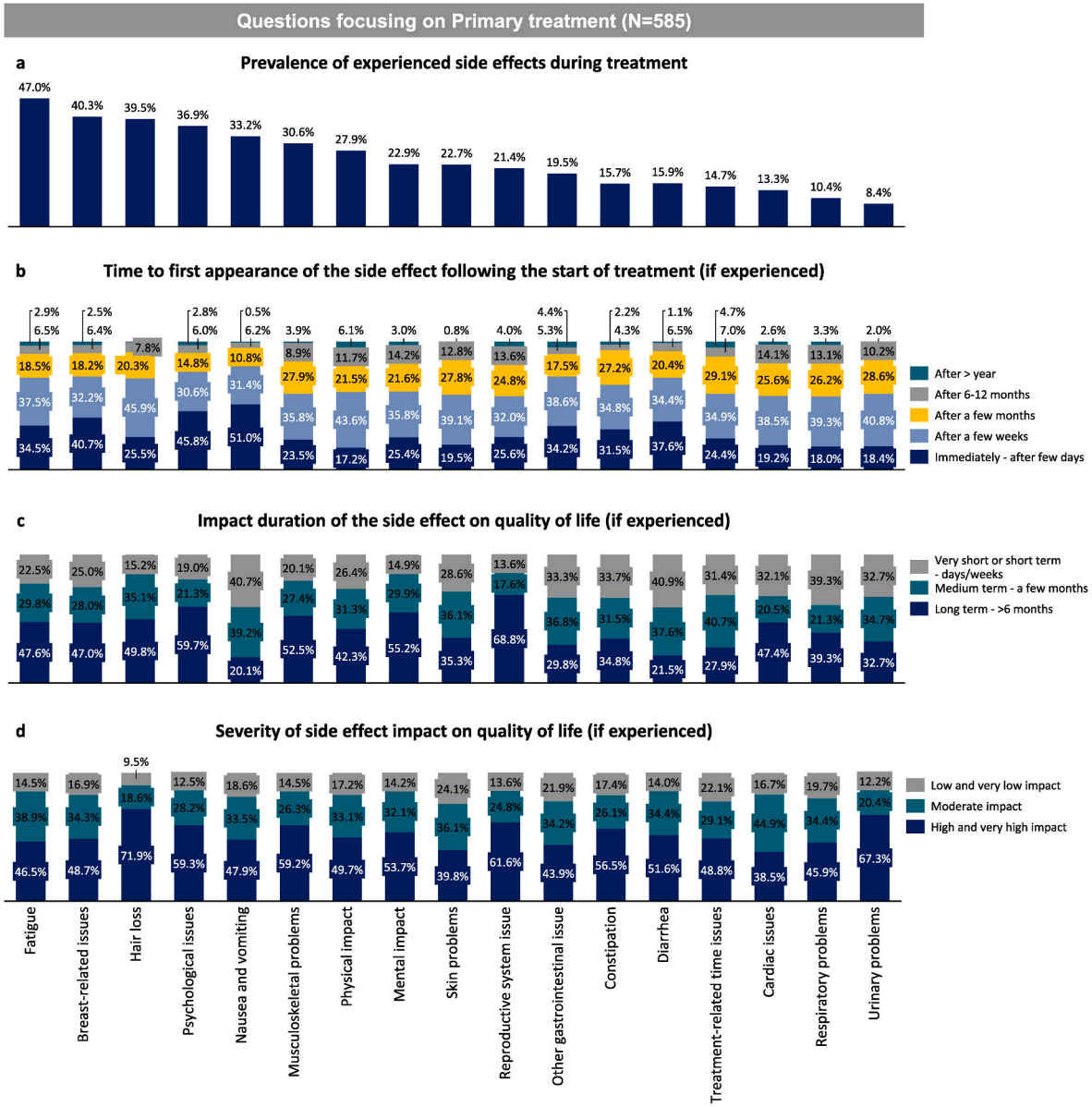

Fig. 1. Prevalence and impact of side effects during primary treatment. (a) Prevalence of experienced side effects during treatment; (b) Time to first appearance of the side effect following the start of treatment (if experienced); (c) Impact duration of the side effect on quality of life (if experienced); (d) Severity of side effect impact on quality of life (if experienced).

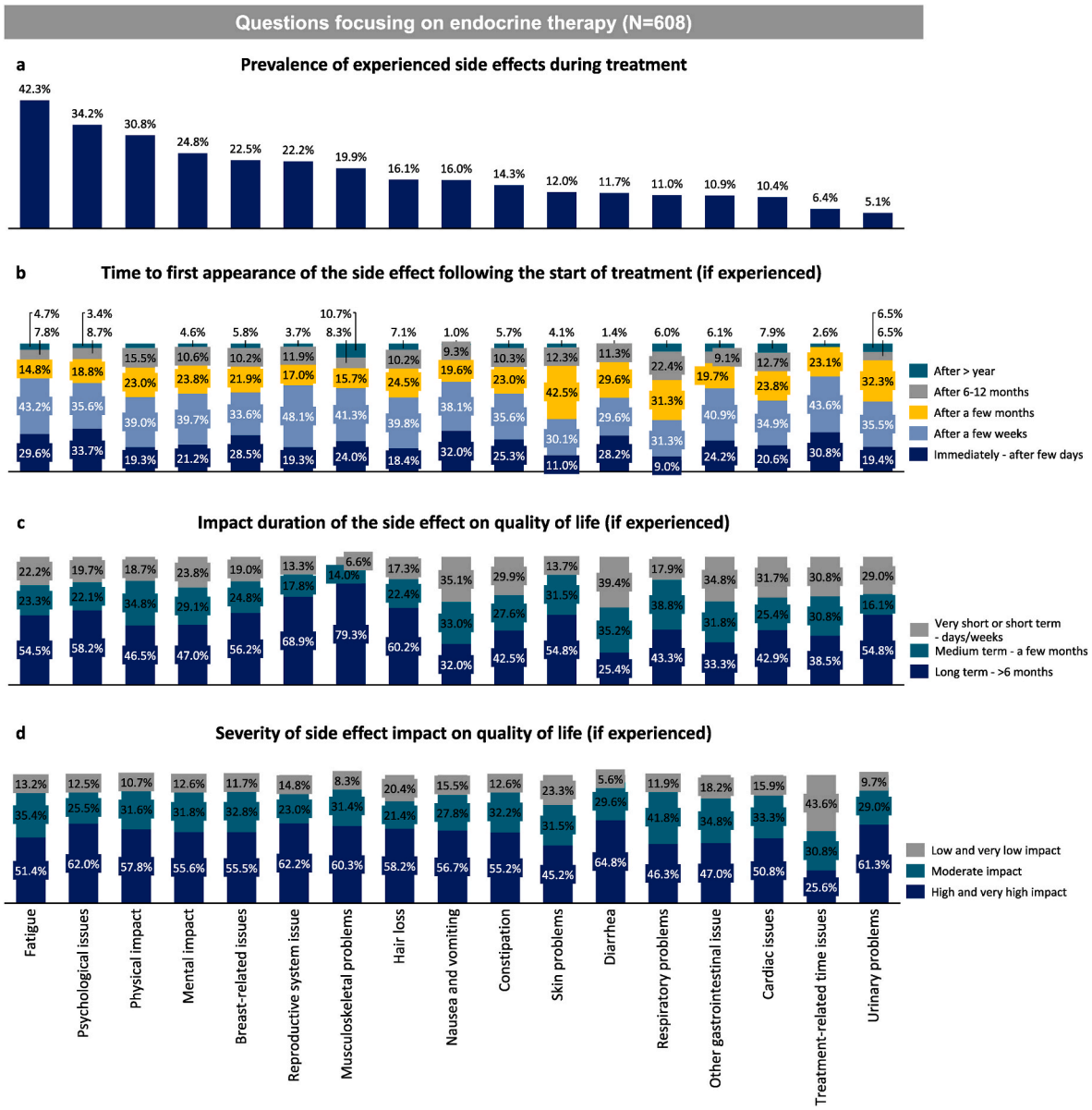

Fig. 2. Prevalence and impact of side effects during endocrine therapy. (a) Prevalence of experienced side effects during treatment; (b) Time to first appearance of the side effect following the start of treatment (if experienced); (c) Impact duration of the side effect on quality of life (if experienced); (d) Severity of side effect impact on quality of life (if experienced).

3.2. Prevalence and impact of reported treatment-related side effects

We analysed side effects experienced during primary therapy (N = 585) or during endocrine therapy (N = 608) separately. The most indicated side effects during primary therapy were fatigue (N = 275, 47.0 %), breast-related issues (N = 236, 40.3 %), hair loss (N = 231, 39.5 %), psychological issues (N = 216, 36.9 %), and nausea and vomiting (N = 194, 33.2 %). During endocrine therapy, respondents in the survey mostly reported fatigue (N = 257, 42.3 %), psychological (N = 208, 34.2 %), physical (N = 187, 30.8 %), and mental issues (N = 151, 24.8 %) (Figs. 1a and 2a).

The onset of side effects generally occurred within a few weeks to a few months after the initiation of therapy (Figs. 1b and 2b). For primary therapy, side effects such as diarrhoea (N = 38, 40.9 %) and nausea and vomiting (N = 79, 40.7 %) persisted for a few days to weeks, while reproductive system issues (N = 86, 68.8 %), psychological (N = 129, 59.7 %) and mental issues (N = 74, 55.2 %) lasted longer than six months. Conversely, for endocrine therapy, side effects predominantly lasted longer than six months, affecting between 25.4 % and 79.3 % respondents. The longest-lasting side effects were musculoskeletal problems (79.3 %) and reproductive system issues (68.9 %) (Figs. 1c and 2c).

When assessing the severity of the impact of side effects on quality of life, most respondents rated the impact as high or very high for most side effects, both for primary therapy (ranging from 38.5 % to 71.9 %) and endocrine therapy (ranging from 25.6 % to 64.8 %) (Figs. 1d and 2d).

3.3. Timing and comprehensiveness of information received about treatment-related side effects

Most respondents received, to some extent, information on side effects before their occurrence. However, a notable proportion of respondents, ranging from 14.4 % to 46.8 % across different side effects and both primary and endocrine therapy, reported receiving information only after first experiencing the side effect (Figs. 3a and 4a). Discussions regarding side effects were initiated by healthcare professionals

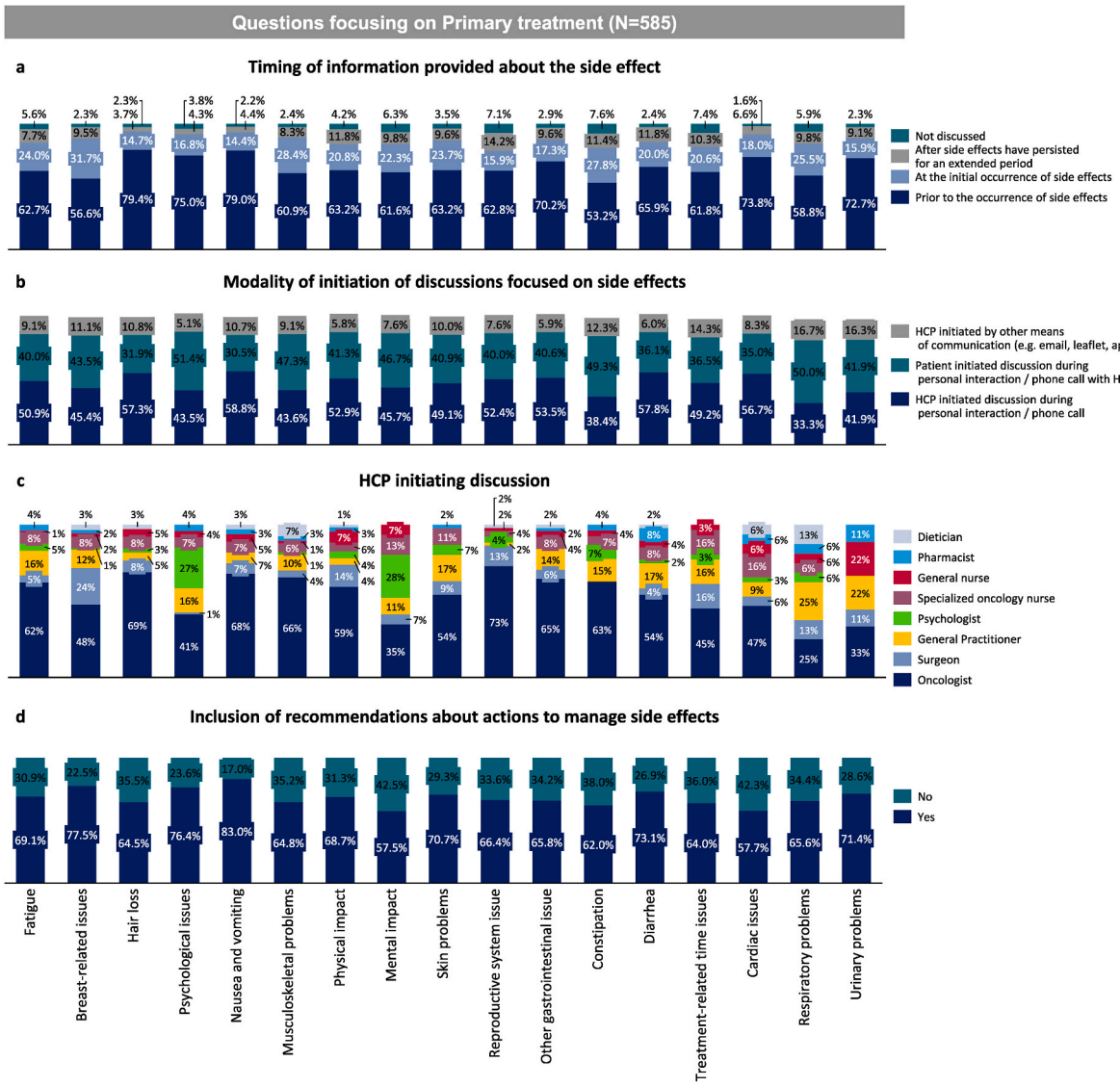

Fig. 3. Timing and modality of information on primary treatment side effects. (a) Timing of information provided about the side effect; (b) Modality of initiation of discussions focused on side effects; (c) Healthcare professional initiating discussion (decimal digits omitted for readability; Other healthcare professionals: radiologist, gynaecologist, physiotherapist, osteopath); (d) Inclusion of supporting actions in side effect information.

in approximately 50 % of cases during face-to-face interactions or phone calls, and by patients themselves in the remaining cases (Figs. 3b and 4b). Other means of communication including email, leaflets, apps were used by healthcare professionals in a minority of cases. Medical oncologists were the providers most frequently giving side effect information and their involvement was reported in 25.0%–73.1 % of cases, depending on the side effect. For specific side effects, other specialists seemed also to be involved including breast surgeons for breast-related issues (N = 139, 23.9 % for primary therapy and N = 73, 12.1 % for endocrine therapy), and psychologists for psychological or mental issues (N = 160, 27.5 % for primary therapy and N = 132, 21.8 % for endocrine therapy) (Figs. 3c and 4c). A substantial proportion of respondents reported that information that they had received also included recommendations about actions to take to manage side effects (Figs. 3d and 4d).

Up to 44.9 % of respondents, reported that the severity of treatment side effect caused them to stop their treatment completely, pause it temporarily, or take it less frequently than prescribed (Figs. 5a and 6a). Regarding comprehensiveness of side effect information provided by healthcare professionals, most respondents reported receiving sufficient or very comprehensive information (range from 56.4 % to 85.7 %). However, a proportion ranging from 14.3 % to 43.6 % respondents across different side effects, reported receiving insufficient or no information on side effects from their healthcare professionals (Figs. 5b and 6b). Proportions of patients that were adherent to treatment varied according to the comprehensiveness of information received about side effects. During primary therapy, 207 (29.9 %) respondents who reported receiving insufficient or no information from healthcare professionals had stopped their treatment completely, paused it, or took it less frequently than prescribed, compared to 295 (15.9 %) of those who reported receiving sufficient or very comprehensive information. Similarly, for those receiving endocrine therapy, 187 (30.3 %) respondents with insufficient information stopped or altered their treatment, compared to 272 (20.6 %) of those with sufficient information.

3.4. Preferences regarding information received about treatment-related side effects

Respondents evaluated various sources of side effects information for their usefulness. Direct discussions with healthcare professionals, as well as indirect sources such as leaflets, website, and support groups/patient advocacy groups/peer discussions were rated as somewhat useful to

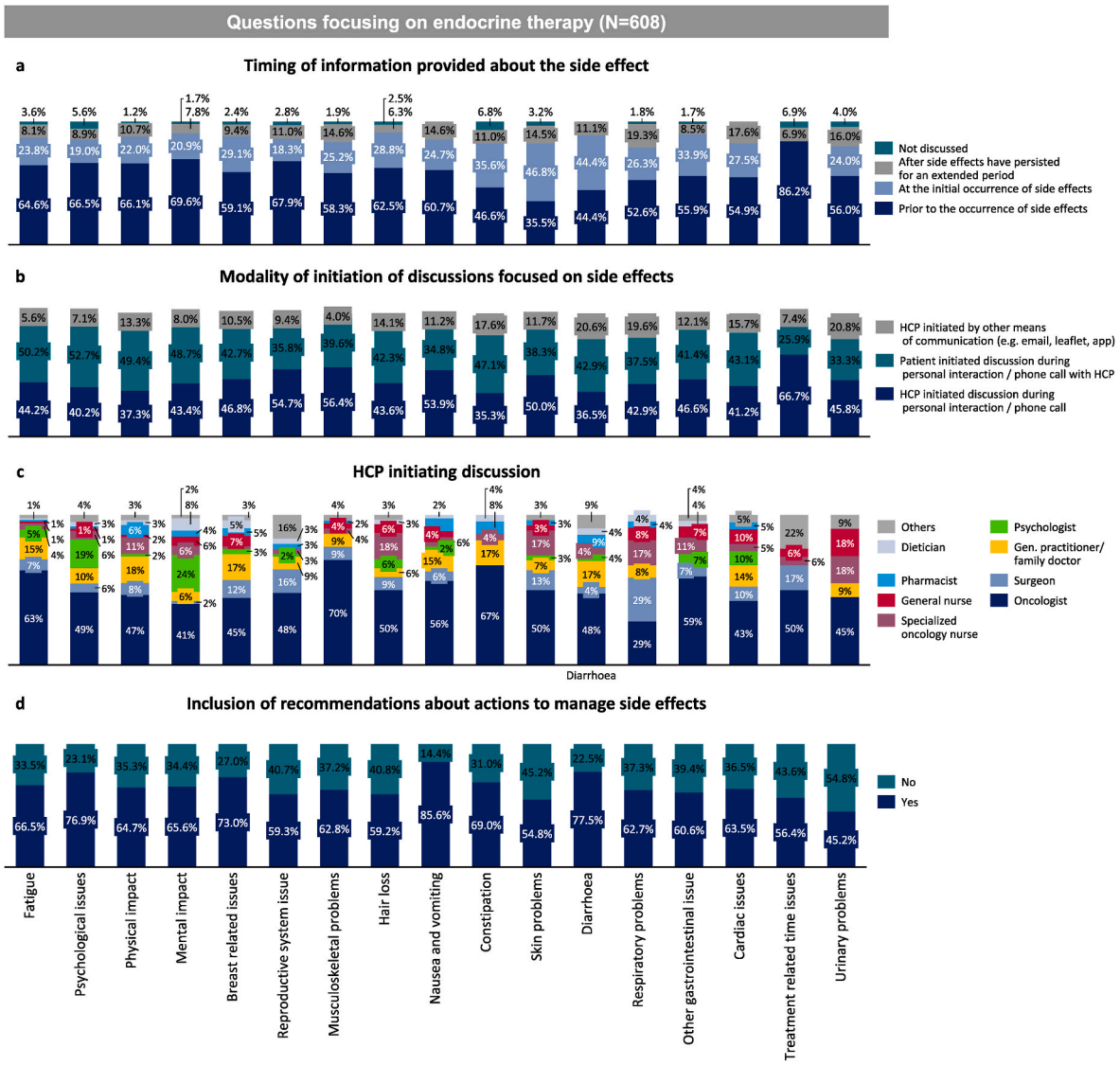

Fig. 4. Timing and modality of information on endocrine therapy side effects. (a) Timing of information provided about the side effect; (b) Modality of initiation of discussions focused on side effects; (c) Healthcare professional initiating discussion (decimal digits omitted for readability; Other healthcare professionals: radiologist, gynaecologist, physiotherapist, osteopath); (d) Inclusion of supporting actions in side effect information.

very useful (Figs. 5c and 6c). However, respondents reported feeling more confident in managing side effects after discussions with healthcare professionals or participation in support groups/patient advocacy groups/peer discussions compared to using sources like social media, mobile apps or websites (Figs. 5d and 6d).

Respondents reported using a variety of sources for managing side effects beyond discussions with their healthcare team. The most used source was print materials provided by an healthcare provider (N = 376 [64.3 %] for primary therapy and N = 323 [53.1 %] for endocrine therapy) (Fig. 7a and b). Notably, some respondents undergoing endocrine therapy also mentioned other sources for managing side effects, including relying on friends and family (34.0 %) (Fig. 7b).

The preferred timing for receiving information related to treatment side effects (e.g. proactive information on side effects, preventative measures) was primarily before or immediately after starting the treatment (range from N = 403 [66.3 %] to N = 447 [73.5 %]) (Fig. 7c). Face-to-face discussions with healthcare professional, particularly doctors, were perceived as the most effective method for improving patient support in managing side effects, with 427 (70.2 %) respondents rating it as extremely or very much improving support. Phone discussions with a doctor were also rated highly, with 372 (61.2 %) respondents finding them useful. In contrast, indirect methods received lower ratings. Information leaflets containing quotes from breast cancer survivors about their experiences were rated very or extremely useful in improving support by 320 (52.6 %) respondents. Smartphone-based applications to record side effects and report adherence were considered very or extremely useful by 299 (49.2 %) respondents. Web-based platforms to record side effects and report adherence were rated as very or extremely useful in improving support by 271 (44.6 %) respondents (Fig. 7d).

4. Discussion

In this survey study, we investigated patient-reported experiences and preferences about information on side effects received during early breast cancer care among 608 respondents across Brazil, France, Germany, Italy, Japan, and Spain. The results provide new insights and highlight unmet needs and areas for improvement previously underexplored that can inform interventional studies and feed policy recommendations.

First, the survey confirms the significant prevalence and impact of side effects during both primary and endocrine therapy. In line with literature, this survey shows a high frequency of common side effects

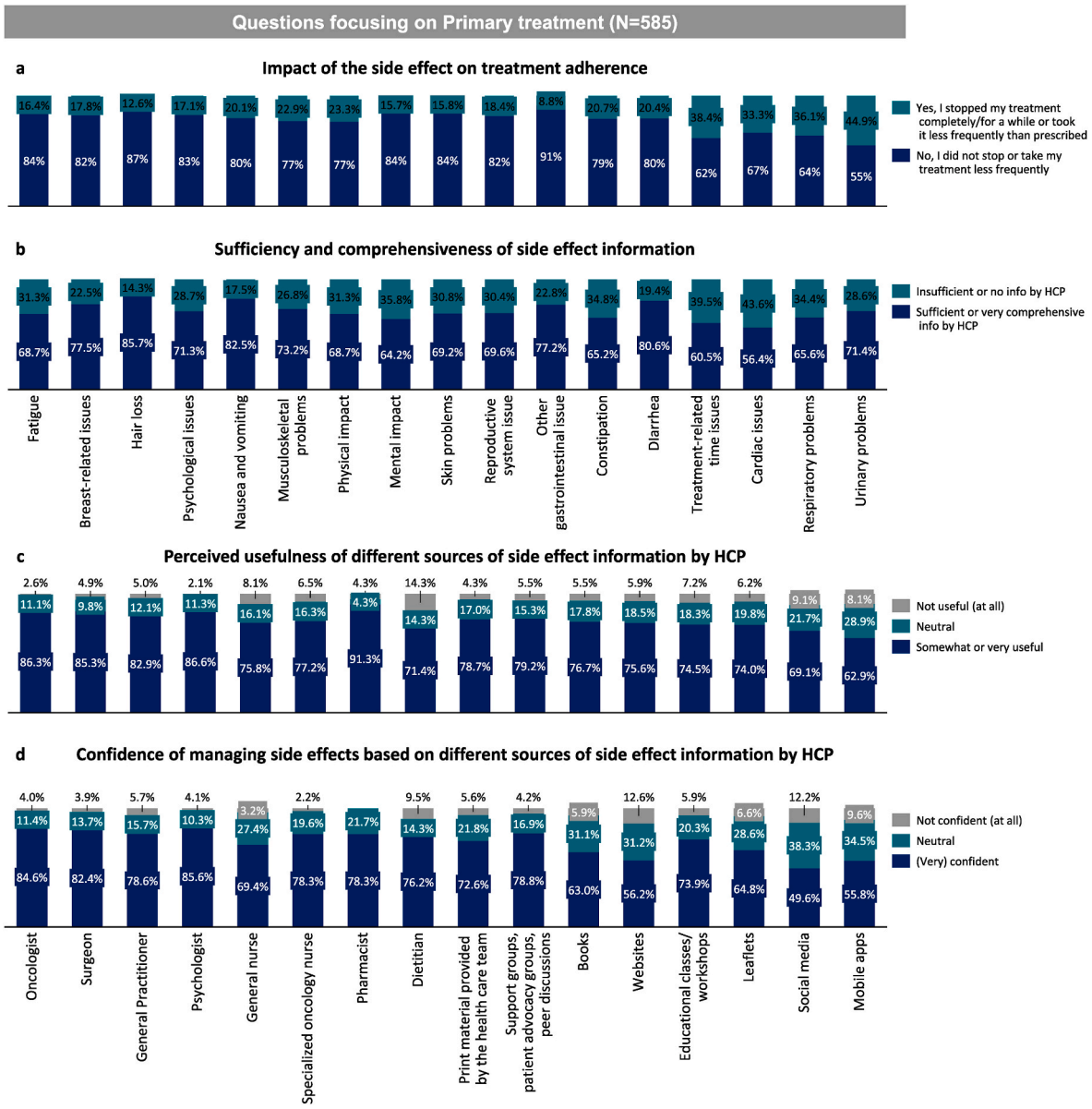

Fig. 5. Impact and perceived usefulness of information on primary treatment side effects. (a) Impact of the side effect on treatment adherence; (b) Sufficiency and comprehensiveness of side effect information; (c) Perceived sefulness of different sources of side effect information by healthcare professional; (d) Confidence in managing side effects based on different sources of side effect information by healthcare professional.

such as fatigue, breast-related issues, hair loss, psychological issues, nausea and vomiting, and physical and mental issues [7]. In addition, the study indicates that the downstream sequelae of treatment can persist months to years, with a high or very high impact even for less prevalent side effects. This aligns with previous research suggesting that while most physical and psychosocial symptoms usually resolve within the first year after diagnosis and most survivors recover high functional levels of quality of life, patients may experience long-term and distressing issues [18,21–25]. Furthermore, a variable proportion of patients in our survey indicated modifying or stopping their treatment due to severity of side effects consistently with studies showing that, if unaddressed, side effects can reduce patients' adherence to treatment prescriptions, particularly to oral endocrine therapy [26–28].

Second, the survey reveals important gaps in the timing and comprehensiveness of information provided to patients about side effects. Although most respondents received some information about side effects early on and before these would occur, a significant proportion of respondents only received information after experiencing side effects. Moreover, discussions about side effects were initiated in almost the same proportions by healthcare professionals and patients, suggesting a reactive rather than a proactive approach by healthcare professionals. In addition, concerns about information on side effects being rather non-comprehensive were raised. Systematic reviews have highlighted that most patients, across tumour types and phases of the cancer care continuum, report unmet informational needs [29]. Healthcare professionals often neglect treatment-related symptoms during interactions with patients for multiple reasons, including limited consultation time and lack of knowledge about evidence-based management strategies [30]. Lack of symptom-focused communication then leads to poor coordination of care and inadequate referrals to supportive care services. In contrast, detailed and timely communication between healthcare professionals and patients, especially if addressing issues of particular relevance for the patient such as symptom management, and providing actionable solutions to manage symptoms, is crucial and can improve medication adherence and optimise outcomes [31,32].

Third, responses to the survey highlight the importance of the role of

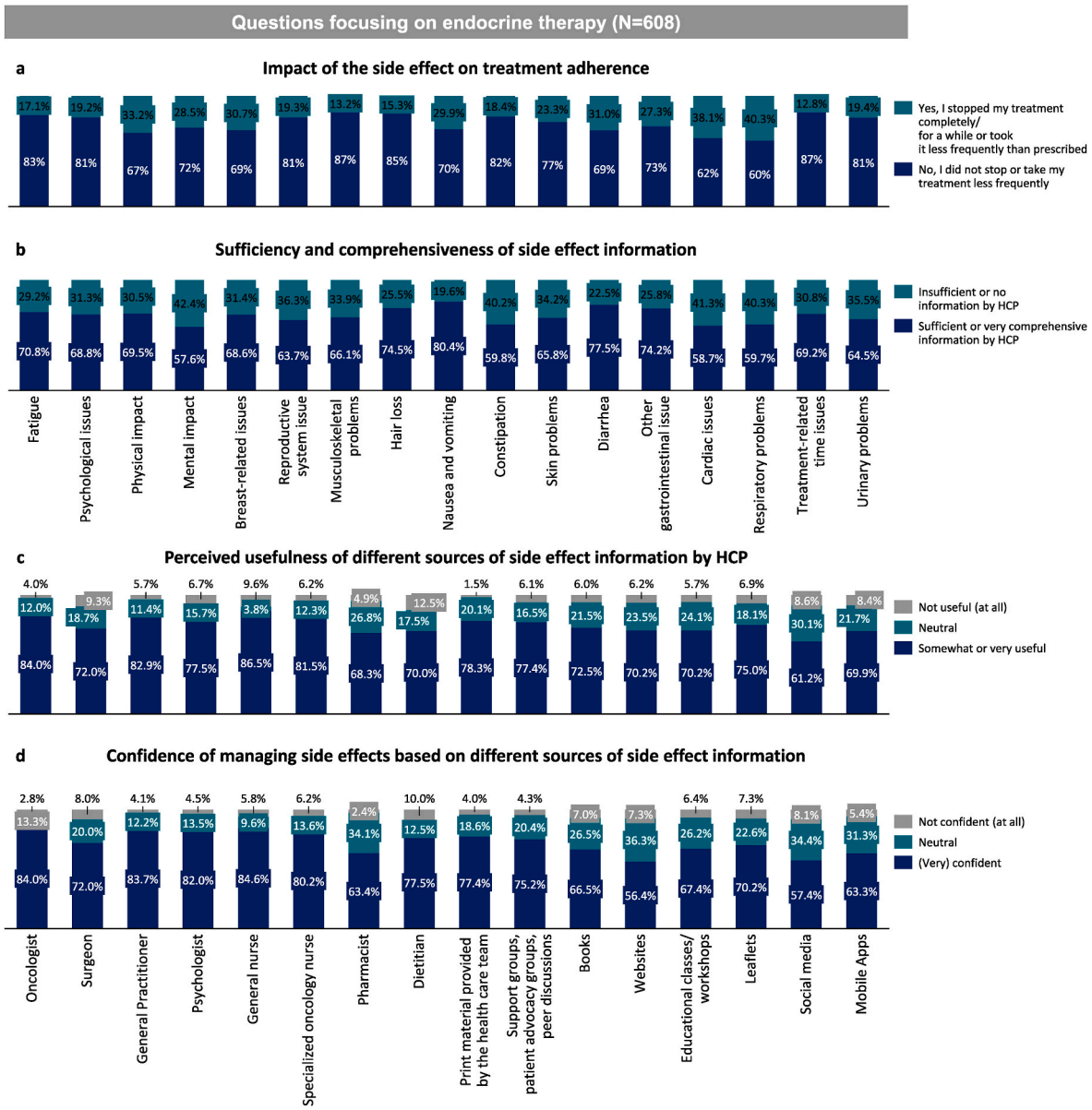

Fig. 6. Impact and perceived usefulness of information on endocrine therapy side effects. (a) Impact of the side effect on treatment adherence; (b) Sufficiency and comprehensiveness of side effect information; (c) Perceived usefulness of different sources of side effect information by healthcare professional; (d) Confidence in managing side effects based on different sources of side effect information by healthcare professional.

the healthcare professional but also of peer support, including from other patients and caregivers, when it comes to obtaining information about treatment-related side effects and their management. Direct or indirect interactions with healthcare professionals were rated as extremely valuable by survey respondents, however the shared direct experience from another patient was also considered as an important means of information. The survey results show that patients may also value printed materials, websites, and apps to gather information. These results suggest that indirect sources, including digital solutions, can represent an important complement to human interactions to facilitate patient education and empowerment in managing symptoms.

The evolving landscape of breast cancer care highlights the need of a growing emphasis on improving how side effects information is communicated to patients, driven by both clinical advancements and patient-centered approaches [7]. Historically, patients often received limited or delayed information about the potential side effects of their treatments, with many only learning about them after experiencing symptoms. The results of this survey are consistent with such trends. This reactive approach left gaps in patient care and hindered early intervention strategies [33]. There is a clear need to shift toward more proactive and comprehensive communication, enabling patients to anticipate and manage symptoms more effectively. As a framework for this shift, the European Quality Assurance Scheme for Breast Cancer Services, developed under the European Commission Initiative on breast Cancer (ECIBC), provides evidence-based guidelines to ensure high-quality, patient-centered care [34]. It emphasizes the importance of clear, accessible resources, the integration of digital tools, and the important role of patient advocacy groups in shaping communication strategies [34]. These principles align with the goals of the Europe's Beating Cancer Plan (EBCP), which promotes patient empowerment through enhanced informational support and tailored interventions throughout the treatment journey [35].

The study was conducted across different countries to reflect the broader early breast cancer population, including different health care systems and heterogeneous respondents' characteristics such as urban, education, and distance from centers of care. We acknowledge some

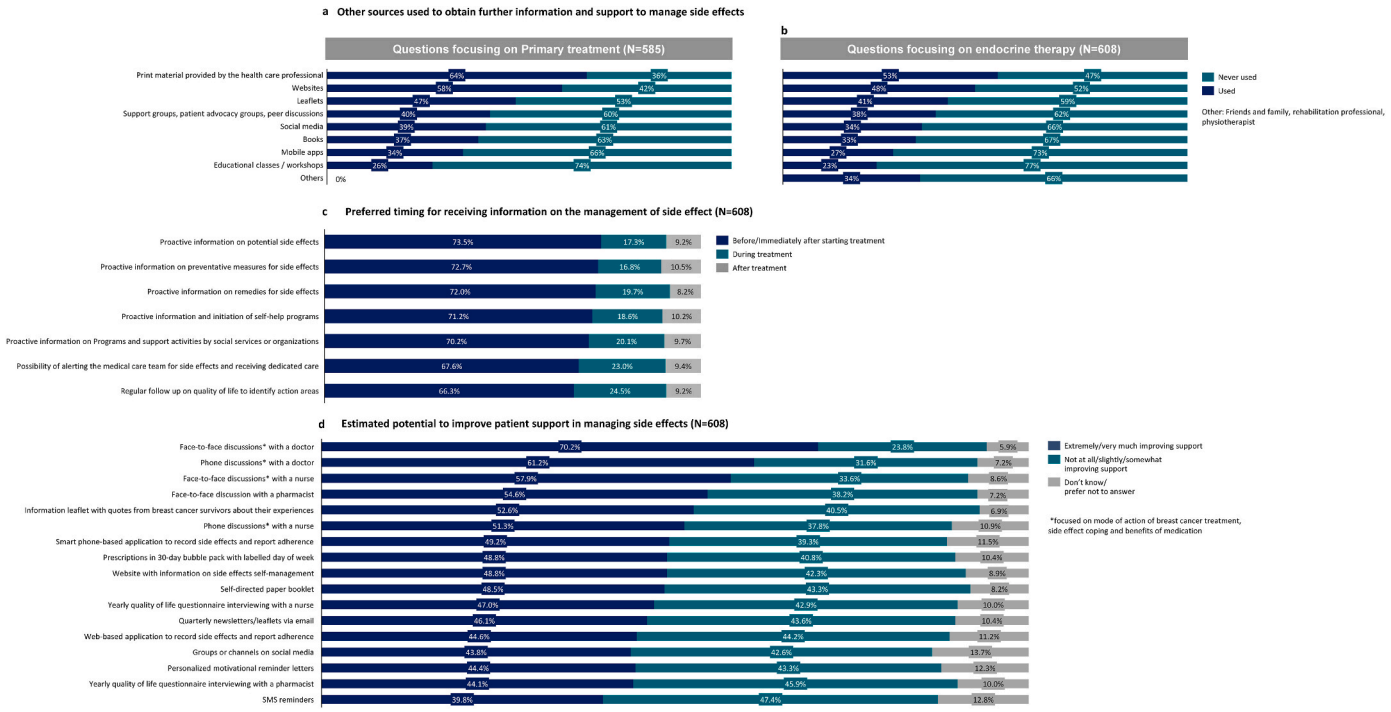

Fig. 7. Preferences regarding information on treatment-related side effects. Other sources used to obtain further information and support to manage side effects (a) on primary treatment and (b) on endocrine therapy; (c) Preferred timing for receiving information on the management of side effect; (d) Estimated potential to improve patient support in managing side effects.

limitations. Despite our efforts, some systems such as North America or Africa are not represented by the present survey. Unfortunately, we could not describe ethnic diversity in the present study. Particularly, for some countries, such as France, race and ethnicity cannot be routinely registered by law. In addition, the online survey modality may have enhanced the inclusion of younger participants. The voluntary nature of participation and the electronic format of the survey may imply that our respondents might possess other specific characteristics - such as digital literacy and a particular sensitivity towards side effects, potentially limiting the generalizability of our findings. Furthermore, data was self-reported and may be subject to recall bias, potentially leading to inaccuracies in patient recollection, and to misclassification, particularly regarding breast cancer stage and treatment. Nevertheless, stage information was only intended to be used to include patients with non-metastatic breast cancer at the moment of diagnosis. Moreover, our analysis might not fully capture the comprehensive experience of patients as much as by using validated scales and thresholds for individual side effects. It is important to note that the primary goal of this survey was to gather insights to understand current gaps in comprehensive survivorship care and inform policymakers, rather than to conduct an in-depth study on patient-reported outcomes. As such, the design and focus of the survey may not fully reflect the complexities of individual symptoms.

5. Conclusions and recommendations

This survey emphasizes the importance of providing comprehensive and timely information on side effects to patients undergoing treatment for early breast cancer. By addressing the unmet needs reported by patients and incorporating their preferences into recommendations for care and research, healthcare professionals can leverage improved communication strategies that are co-created with patients and facilitate patient empowerment. Comprehensive side effect information enables patients to better understand and manage their symptoms, reducing the physical and psychological burden associated with cancer treatment. Early and thorough communication about potential side effects can help patients prepare and cope more effectively, thereby minimising disruptions to their daily lives. Furthermore, by involving patients in the development of side effect management strategies, healthcare providers can ensure that the information and support provided are relevant and tailored to individual needs.

The journey of patients who receive a diagnosis of early-stage breast cancer offers multiple opportunities to improve communication with patients. This survey provides several suggestions and can inform recommendations to fill important gaps and address patients' needs across supportive care domains (Fig. 8). Informational needs may peak at the moment of diagnosis of cancer, when uncertainty about disease course and treatments is particularly pronounced. However, such needs may persist, evolve, and vary throughout the treatment and post-primary treatment follow-up phase. It is therefore essential to adapt the provision of information to the needs of the individual patients across these phases. A thorough assessment of clinical state, tumour type and stage, and anticipated treatment characteristics since the moment of diagnosis may help inform about risk of developing persistent long-term symptoms and therefore help stratify patients that may need more attention and dedicated supportive care [36,37]. Therapeutic education delivered both in-person (e.g., by specialised nurses) or remotely, including via digital support, can help patients feel more comfortable with treatments and potential onset of side effects and available management strategies [38]. Remote patient monitoring may support patients during active treatment, facilitating connection with the medical care team, optimizing reaction time and side effect management, and reducing emergency unit accesses and hospitalisations [39]. In the post primary treatment setting, detailed survivorship care plans, summarising past medical history and received treatments, as well as implementation of structured needs assessment and referral networks to address individual needs can help optimise resources and support patients for persistent or new symptoms associated with longer-term treatment [17].

CRediT authorship contribution statement

Antonio Di Meglio: Writing – review & editing, Writing – original

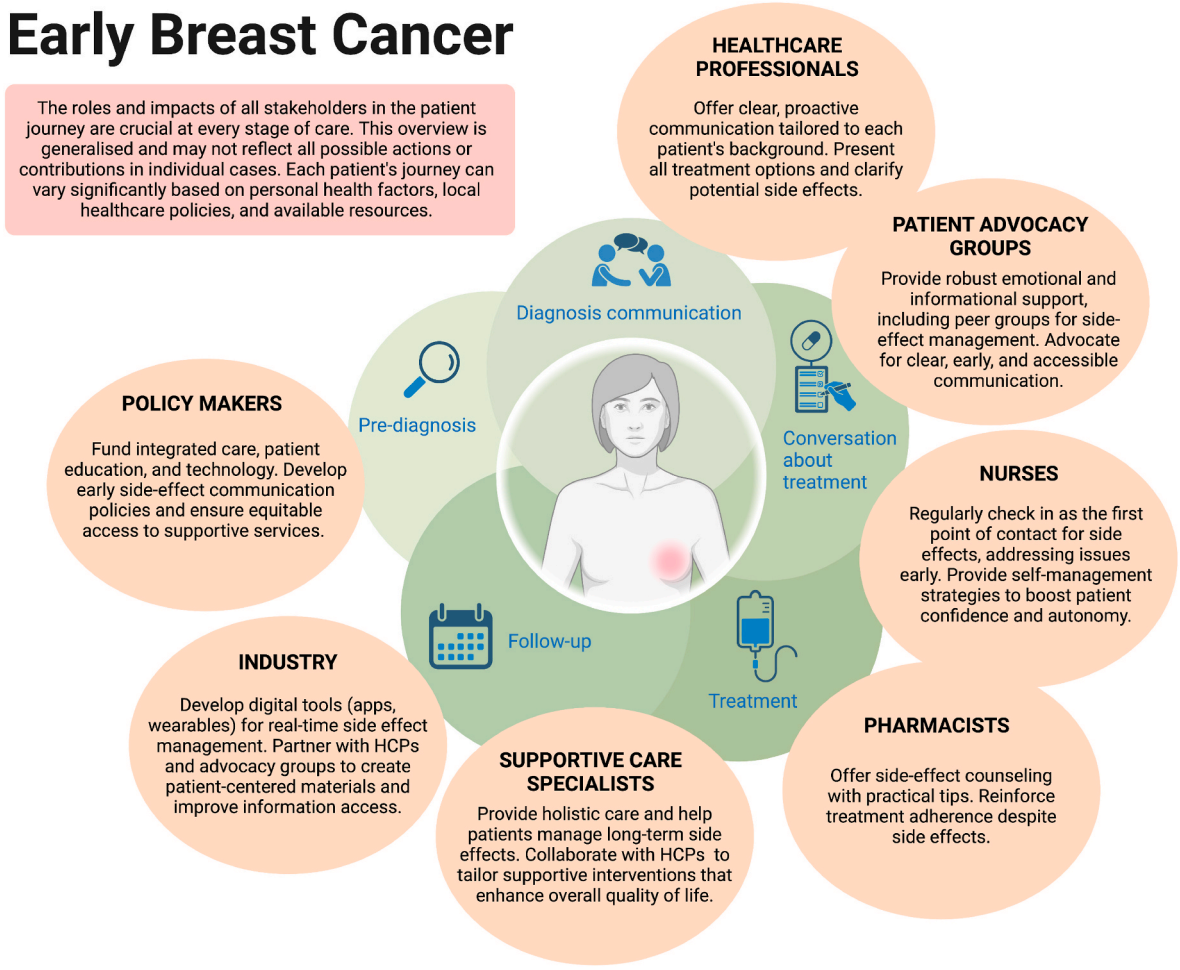

Fig. 8. Stakeholders' recommendations. HCP= Healthcare professional.

draft, Visualization, Validation, Supervision, Methodology, Investigation, Conceptualization. **Giuseppe Catanuto:** Writing – review & editing, Writing – original draft, Validation, Supervision. **Marzia Zambon:** Writing – review & editing, Writing – original draft, Validation, Supervision. **Alexandre Chan:** Writing – review & editing, Writing – original draft, Validation, Supervision. **Angelos P. Kassianos:** Writing – review & editing, Writing – original draft, Validation, Supervision. **Constantina Cloconi:** Writing – review & editing, Writing – original draft, Validation, Supervision. **Silvia Rohr:** Writing – review & editing, Writing – original draft, Visualization, Supervision, Formal analysis, Data curation, Conceptualization. **Rebecca Steele:** Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision. **Monique Coersmeyer:** Writing – review & editing, Writing – original draft, Validation, Supervision. **Sonia Ujupan:** Writing – review & editing, Writing – original draft, Visualization, Supervision. **Fedro Peccatori:** Writing – review & editing, Writing – original draft, Visualization, Supervision, Methodology, Investigation, Conceptualization.

Ethical approval

Participants were informed about the survey's objectives, data privacy, and adverse event reporting. Consent was required to start the survey. The study adhered to market research Codes of Conduct (EPHMRA) and internal market research guidelines.

Previous presentations

Part of the work presented in this manuscript was previously shared at the ESMO Breast Cancer Congress 2024 and published in the conference proceedings: *Annals of Oncology* (2024) 9 (suppl_4): 1–12. https://doi.org/10.1016/esmoop/esmoop103324 - 273P - Experiences and preferences about information on treatment (tx)-related side effects (SE) among patients (pts) with early breast cancer (EBC). The abstract, first-authored by Antonio Di Meglio, was recognized for its quality with an ESMO Merit Travel Grant.

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Appendix A. Supplementary data

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