


PAPER

Unmet information needs of men with breast cancer and health professionals

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Abstract

Objective: Male breast cancer (MBC) is rare. Information about breast cancer is usually designed for female patients. However, in males this disease and some side effects differ from its female counterpart. Therefore, there is a need for male-specific information. The aim was to assess unmet information needs of (a) MBC patients and (b) health professionals.

Methods: Dutch MBC patients (diagnosed between 2011 and 2016 in 21 hospitals), patient advocates and partners were invited to participate in focus groups and/or complete a paper-based questionnaire on information needs. In addition, an online questionnaire on information needs was sent to health professionals involved in MBC patient care.

Results: In three focus groups with MBC patients ($N = 12$) and partners ($N = 2$) the following unmet information themes were identified: patients' experiences/photographs, symptoms, (delay of) diagnosis, treatments, side effects, follow-up, psychological impact/coping, genetics and family, research and raising awareness. 77 of 107 MBC patients (72%) completed the questionnaire: most patients lacked information about acute (65%) or late (56%) side effects, particularly sexual side effects. Among health professionals, 110 of 139 (79%) had searched for MBC-related information, specifically: patient information, anti-hormonal therapy, genetic testing, research, and psychosocial issues.

Conclusions: Unmet information needs in MBC patients and health professionals were identified. Specific information on MBC should be developed to improve timely diagnosis, quality of life, treatment, and survival. A targeted website is an ideal tool to meet these needs. Therefore, we integrated these results into a user-centered design to develop an informative website, www.mannenmetborstkanker.nl.

KEYWORDS

cancer, health professionals, information needs, male breast cancer, mixed-methods, oncology, website

1 | BACKGROUND

Male breast cancer (MBC) is a rare disease and many people are unaware of its existence. In the Netherlands, approximately 130 men are diagnosed with breast cancer each year and the incidence is rising. MBC accounts for <1 % of all breast cancers.¹

Male and female breast cancer have many commonalities in symptoms (most commonly a lump) and risk factors, such as family history of breast and/or ovarian carcinoma, obesity, higher estrogens, and a history of ionizing radiation on the thorax.²⁻⁵ However, there are also differences between male and female breast cancer. Examples include average age at diagnosis (7 years older for males), biological characteristics (less in situ and lobular, and more hormonally sensitive tumors in males), side effects of treatment (erectile dysfunction), psychosocial issues (stigma of having a female's disease), and health-related quality of life (impaired emotional and physical role functioning in males).^{2,3,6-11} Despite the differences between male and female breast cancer, only a limited number of studies address MBC. Therefore, information, treatment and care for men is largely based on women with breast cancer.^{6,12-14}

Health professionals rarely treat MBC patients. As with other rare diseases, one may surmise that knowledge about symptoms, treatment options, side effects, and care for MBC patients is therefore suboptimal.¹⁵ Health professionals, as well as laypeople are often unaware of the risk of breast cancer in males.¹⁶⁻¹⁸ This lack of awareness can cause patients' as well as doctors' diagnostic delay, and may result in presentation of breast cancer at a more advanced stage and poorer survival as compared to females with this disease.^{1,15,19}

Quincey et al.¹⁸ conducted a qualitative synthesis, including eight studies of men's accounts on living with breast cancer. They identified the following overarching themes: affected masculinities or identities, problems with coping, and feelings of isolation and alienation. The MBC patients in this synthesis reported different themes: disclosure of diagnosis, negative body image, lack of information provision (eg, tamoxifen package leaflet describes only side effects in women) and lack of emotional support.¹⁹⁻²³

Williams et al.²² combined different perspectives of male and female breast cancer patients, and health professionals. In addition to the themes already mentioned,¹⁹⁻²³ health professionals agreed that there is a need for information about side effects of anti-hormonal therapy.²² The availability of images depicting a male mastectomy would also be appreciated. Furthermore, MBC patients reported that partners often play a key role in the disease process, from discovering the first symptoms of the disease and referring them to the doctor to supporting them during the treatment.²²

Information needs of cancer patients are time dependent, varying from diagnosis to long-term survival, and predominantly related to treatment.²⁴ Meeting the information needs for cancer patients could facilitate informed decision making²⁵ thus leading to higher levels of satisfaction,²⁶ a better sense of control,²⁷ a higher compliance with therapy,²⁸ and less anxiety and depression.^{26,29}

Because of the rarity of MBC, better access to information may additionally help to improve treatment, raise awareness, and hopefully minimize delay in the presentation of the disease.³⁰ A study on specific information needs reported that men would have liked more

information specifically tailored to male (and not female) breast cancer.³¹ Websites are relatively new sources of patient information. However, online information about MBC is usually fragmented across different websites, hidden behind or within female information, and therefore not always easy to find.^{31,32}

The aim of this project was to assess unmet information needs of (a) Dutch MBC patients and (b) health professionals. These needs assessments were part of the user-centered design for development of an informative website focused on MBC.

2 | METHODS

Abbreviations that are used throughout the manuscript are listed in Table S1.

2.1 | Ethical considerations

The research protocol was examined by the accredited Medical Research Ethics Committee of the Netherlands Cancer Institute (METC AVL). They concluded that the obligation to fulfil the specific requirements of the Dutch law governing Medical Research Involving Human Subjects (WMO) was waived (reference: METC16.1097). Informed consent was received from all individual participants included in the study.

2.2 | Participants

2.2.1 | MBC patients

MBC patients were recruited for participation in the project (focus group and/or questionnaire) if they met the following eligibility criteria: (a) male gender; (b) invasive or in situ breast carcinoma; (c) diagnosis between January 2011 and December 2016; (d) alive; and (e) sufficient language proficiency in Dutch. Male patient advocates of Dutch Breast Cancer Association and partners of MBC patients were also invited to participate in a focus group.

From June to December 2016, clinicians from 21 different general, academic, and cancer specific hospitals (see Acknowledgments) were invited to recruit breast cancer patients that met the inclusion criteria. Patients were approached by phone and/or by sending an information letter by their clinician or nurse specialist. In addition, MBC patients were recruited with assistance from other resources (Dutch Breast Cancer Association and photo project "Replace he for she", see Acknowledgments).

2.2.2 | Health professionals

From July till October 2016, the study team invited health professionals (surgical oncologists, medical oncologists, radiation oncologists, nurse practitioners, oncology nurses, clinical geneticists, general practitioners, psychosocial professionals, physio-, or lymphedema

therapists) to complete a questionnaire about their information needs. They could participate, if they had treated at least one MBC patient during the past 5 years. An email was sent to professional associations with the request to send an invitation to their mailing lists (see Acknowledgments). Also calls were placed in newsletters and/or websites for general practitioners, physio- and lymphedema therapists. Because of the indirect nature of recruitment, it was impossible to calculate the response rate for participation of health professionals.

2.3 | Procedures and measures

A mixed method approach involving both qualitative and quantitative data collection was used to address the aim of the study. We used three methods.

2.3.1 | Focus groups MBC patients

The three 2-h focus groups of each five or six persons (MBC patients, male patient advocates Dutch Breast Cancer Association and partners) were held at the Netherlands Cancer Institute and at the Dutch Breast Cancer Association and led by the first and last author using a semi-structured interview guide. In each focus group at least one male patient advocate participated. The last focus group was organized to check the results of the first two focus groups with male patient advocates. The interview guide queried participants with open questions about how they experienced care and information provision during their treatment for breast cancer and questions about their unmet (information) needs, and their interest in a specific website about male breast cancer.

2.3.2 | Questionnaire MBC patients

The patients were invited to complete questionnaires on their socio-demographic background, diagnosis, possible patient- and doctor delay, awareness of MBC, their treatment and their experiences or ideas about genetic testing. These study specific questions were self-developed, and in part based on Iredale's study.¹⁵

QLQ-BR23

To assess which topics of *acute treatment effects* information were missed, the items of the Dutch version of EORTC QLQ-BR23 were used. Questions about sexuality and body image were replaced by similar items, derived from the EORTC QLQ-PR25.^{33,34}

Late effects symptom list

For measuring which topics of *long term effects* of treatment information were missed, the 27 items (ie, negative emotions, sleep, cognitive problem, dizziness, tingling sensations, neuropathy, hypersensitivity feet soles, pain, lymphedema, fatigue, cardiac problems, lung problems, sexuality (emotional), sexuality (physical), visual impairment or hearing loss, weight problems, family/social problems, nutrition,

mouth problems, bowel movement, condition, skin problems, nail problems, hair problems, fertility problems or infertility, and other problems) of the symptom list of Dutch Breast Cancer Patient Association (B-force) questionnaire Late Effects was used, including two additional questions about osteoporosis and work problems.³⁵

QLQ-INFO25

The Dutch version of the validated and widely used EORTC QLQ-INFO25 was used to assess the need for more information on the specific topics.³⁶

2.3.3 | Questionnaire health professionals

Health professionals were asked about their demographic data, and to indicate the number of male patients treated during the past 5 years. Furthermore, they were invited to report whether they had searched for information and what kind of information they searched for. Health professionals were asked to indicate which information lacked and to report on specific lack of knowledge regarding MBC.

2.4 | Analyses

2.4.1 | Focus group data MBC patients

Three audiotaped focus groups were transcribed and analyzed using conventional content analysis.³⁷ Themes were identified and categorized in different categories. These themes were reviewed independently for completeness by the first and second author and outcomes were discussed with the last author to improve credibility. COREQ guidelines were used.³⁸

2.4.2 | Questionnaire MBC patients

First, demographic and clinical characteristics of the patient study sample were described. To test if the sample was representative for MBC patients in the Netherlands, the data of participants who completed the first year of treatment was compared to data of all patients registered by the Dutch Comprehensive Cancer Center diagnosed in period 2011-2015¹⁰ by the independent t-test, Pearson chi-square test and Fisher's exact test. Descriptive statistics such as frequencies were used to describe unmet information needs, assessed by QLQ-INFO25, QLQ-BR23, and B-Force Late Effects of Dutch Breast Cancer Patient Federation. Free text answers of the questionnaire were coded and categorized.

2.4.3 | Questionnaire health professionals

Frequencies were used to analyze the answers of the self-administered questionnaire for health professionals. Free text answers of the questionnaire were coded and categorized.

TABLE 1 Characteristics MBC patients (diagnosis 2011-2016) questionnaire (N = 77)

Characteristic	Results self-report questionnaire MBC patients
	Mean (SD), [range]
Age at questionnaire (years)	66.9 (10.9), [44-89]
Age at diagnosis (years)	64.5 (10.8), [41-86]
Time since diagnosis (months)	28.7 (18.2), [0-65]
	N (%)
Relationship status: partner	65 (84.4)
Children: yes	61 (79.2)
Education level ^a	
Low	27 (35.1)
Intermediate	15 (19.5)
High	35 (45.5)
Work	
Employed	20 (26.0)
Unemployed	3 (3.9)
Disabled	6 (7.8)
Volunteer	1 (1.3)
Retired	47 (61.0)
Hospital diagnosis	
Academic	5 (6.5)
General	67 (87.0)
Cancer specific	5 (6.5)
Hospital(s) treatment	90
Academic	10 (13.0)
General	67 (87.0)
Cancer specific	13 (16.9)
Time taken to report symptoms	
<1 week	34 (44.2)
<3 months	22 (28.6)
4-6 months	8 (10.4)
7-9 months	3 (3.9)
>9 months	10 (13.0)
Referral GP to hospital	
<5 working days	56 (72.7)
6-10 working days	14 (18.2)
11-15 working days	2 (2.6)
>15 working days	1 (1.3)
unknown	3 (3.9)
referral by other professional	1 (1.3)
Time diagnosis in hospital	
<1 working day	19 (24.7)
1-2 working days	12 (15.6)
3-5 working days	13 (29.9)

(Continues)

TABLE 1 (Continued)

Characteristic	Results self-report questionnaire MBC patients
6-10 working days	15 (19.5)
>10 working days	4 (5.2)
unknown	4 (5.2)
Diagnosis	
In situ	5 (6.5)
Invasive	72 (93.5)
Awareness	
Self	45 (58.4)
General public	17 (22.1)
Treatment(s)	
Mastectomy	71 (92.2)
Breast conserving surgery	2 (2.6)
Surgery	73 (94.8)
Sentinel node biopsy (SNB) alone	26 (33.8)
Axillary dissection + SNB	10 (13.0)
Axillary dissection – SNB	15 (19.5)
Radiation	34 (44.2)
Chemotherapy	34 (44.2)
Anti-hormonal therapy	44 (57.1)
Immunotherapy	2 (2.6)
Nipple reconstruction/nipple tattoo	1 (1.3)
Other: Preventive mastectomy other side	2 (2.6)
Awaiting treatment	2 (2.6)
Refusal treatment	1 (1.3)
Supportive care (N = 36)	36 (46.8)
Psychologist	5 (6.5)
Sexologist	1 (1.3)
Social worker	7 (9.1)
Lymphedema therapist	15 (19.5)
Physiotherapist	19 (24.7)
Dietician	1 (1.3)
Rehabilitation program	1 (1.3)
Genetic testing (N = 56)	56 (72.7)
BRCA1	0 (0)
BRCA2	10 (13.0)
CHEK2	1 (1.3)
Uncertain variant BRCA2	1 (1.3)
Unknown ^b	5 (6.5)
No abnormalities	39 (50.6)

^aEducation level: low = primary/lower secondary education; intermediate = upper secondary education; high = higher vocational training/university.

^bGenetic testing unknown: tested and waiting for results.

2.4.4 | Statistical Analysis

Statistical analysis relates to both questionnaire MBC patients and Questionnaire health professionals.

Statistical analyses of the questionnaires were computed by using IBM SPSS version 22.0. [Correction added on 09 April 2020, after first online publication: the new heading “2.4.4 Statistical Analysis” has been added to this version].

3 | RESULTS

3.1 | Characteristics of the study populations

3.1.1 | Focus groups MBC patients

A total of 12 MBC patients and two partners participated in three focus groups. Two MBC survivors (eg, patient advocates) participated twice. The mean age of MBC patients was 66 (49–88) years. Most were married or living with a partner ($N = 11$), had children ($N = 10$), had a high educational level ($N = 8$), and were retired ($N = 8$). One participant was diagnosed with an in situ carcinoma. Year of diagnosis was between 1991 and 2014. MBC patients received different treatments (mastectomy, sentinel node biopsy, axillary dissection, radiation, chemo-, and anti-hormonal therapy). Nine patients were tested for *BRCA1/BRCA2/CHEK2* mutations; five were tested positive.

3.1.2 | Questionnaire MBC patients

Of the 107 eligible patients, 77 completed the questionnaire (response = 72%). Table 1 shows all the characteristics of MBC patients diagnosed between 2011 and 2016 who responded to the questionnaire. The average age at diagnosis was 65 years. The mean time since diagnosis was 29 months. Most patients had a partner (84%) and children (79%). Education level varied from low (35%), intermediate (20%) to high (46%). Most men were retired (61%). Most patients (87%) were diagnosed and treated in a general hospital. Few men (7%) were diagnosed with an in situ carcinoma. Most patients were treated with surgery (95%), 57% with anti-hormonal therapy, and 44% were treated additionally with chemotherapy and/or radiation. Approximately half of the patients ($n = 36$) used supportive therapy, including for example physical therapy (25%), lymphedema therapy (20%), and professional psychosocial support (16%). Most men ($n = 72$, 94%) reported to be informed about genetic testing. Of these, 56 (78%) underwent genetic testing. Ten of the 56 men that had genetic testing (18%) were found to be carrier of a *BRCA2* mutation and one (2%) of a *CHEK2* mutation. Approximately one quarter of the MBC patients (27%) waited to report symptoms more than 3 months after discovering their symptoms. One fifth of general practitioners (22%) did not refer MBC patients within 5 working days. In one quarter of the patients (25%), the time in the hospital before being diagnosed took more than five working days.

Unawareness of the existence of MBC was reported by patients themselves (42%) and patients also experienced this in their communication with other people (78%).

To investigate whether our group of MBC patients, who completed at least the first year of treatment ($n = 66$) is comparable to the total group of men diagnosed in 2011–2015 and registered in the Netherlands Cancer Registry, we compared age, diagnosis and treatment characteristics of both groups.¹⁰ Table S2 shows that our treated MBC patient group, as compared to the MBC patients in the Netherlands Cancer Registry, had received more frequently radiation therapy (44% vs 28%) or chemotherapy (44% vs 32%).

3.1.3 | Questionnaire Health Professionals

A total of 139 healthcare professionals met our inclusion criteria and completed our questionnaire (Table 2). The mean age of the health professionals was 50 years. Most of the professionals were female (84%). More than half of the professionals had more than 10 year of

TABLE 2 Characteristics health professionals questionnaire ($N = 139$)

Characteristic	M (SD), [range]
Age at questionnaire, years	49.5 (8.7) [29–65]
	n (%)
Gender: female	116 (83.5)
Position	
Medical specialist	59 (42.4)
Nurse practitioner or Oncology nurse	68 (48.9)
Other ^a	12 (8.6)
Hospital/institution	
Academic	26 (18.7)
General	92 (66.2)
Cancer specific	10 (7.2)
Other ^b	11 (7.9)
Experience function	
<1 year	2 (1.4)
1–5 years	29 (20.9)
6–10 years	30 (21.6)
>10 years	78 (56.1)
Experience MBC patients (past 5 years)	
1 MBC patient	26 (18.7)
2–5 MBC patients	95 (68.3)
6–10 MBC patients	16 (11.5)
11–20 MBC patients	2 (1.4)

^aPsychiatrist, psychologists, social worker, lymphedema therapists, physiotherapists, general practitioner or physician assistant.

^bHealth care center, own practice, multidisciplinary radiotherapy center or aftercare center.

experience (56%). Almost all of the professionals worked either as a nurse practitioner or oncology nurse (49%), or medical specialist (42%). A majority of all professionals was working in a general hospital (66%).

3.2 | Unmet information needs

3.2.1 | Focus groups MBC patients

When inquiring patients about their experiences with care and information provision, their unmet information needs and interest in an informative website, the following themes were identified: patients' experiences and photographs, symptoms, (delay of) diagnosis, treatment options, follow-up care, side effects, psychological impact and coping, genetics and family, and MBC research. [Correction added on 09 April 2020, after first online publication: in the preceding sentence the word "preventing" has been removed in this version]. It should also help to raise awareness in general

population. Table 3 shows the eight themes and examples of quotes of participants.

3.2.2 | Questionnaire MBC patients

Unmet information needs of acute effects (QLQ-BR23)

In total, 50 out of 77 patients (65%) missed information about one or more acute effects of treatment. The most frequent unmet information need related to acute effects of cancer and treatment was about sexuality (interested in sex [23%], sexual activity (with or without intercourse) [22%], and sexual enjoyment [17%]). Other unmet information needs were: treatment side effects (swollen breast, different taste) and psychosocial problems, for example worries about health in future (Table 4).

Unmet information needs of late effects (B-Force)

In total, 43 out of 77 patients (56%) missed information about one or more late effects of treatment. Most prominent unmet information

TABLE 3 Identified themes focus groups MBC patients

Theme	Quotations focus group (patient [age])
1. Patients' experiences and photographs	"Here in [name of hospital] I was referred to as "Miss""(patient [49]).
	"And add some photographs, like after you get surgery this is what it's going to look like. That's pretty important to me" (patient [69]).
2. Symptoms and (delay of) diagnosis	"After I discovered a lump, I went [to the GP] right away. First I ended up with a replacement (for my GP) and he said it [breast cancer] wasn't possible" (patient [49]).
3. Treatment options and follow-up	"Didn't you use <i>Adjuvant online</i> ?".... "For me, for instance, chemo still provided 4% better chances. I deliberately chose, precisely because of neuropathy, not to opt for chemo. I thought of the gain. Chemo can also go so wrong that you cannot even do your grocery shopping as a 45-year-old man. That's a choice, and it was made jointly" (patient [49]). "I go for a check-up with the surgeon once a year, and once a year with the oncologist, too. One for every 6 months. The last time I saw the surgeon, the 5 years were almost up, and after that I will not go anymore. But the doctor wants to do a check-up with you once every 10 years. Well, we'll see about that" (patient [70]).
4. Side effects of treatment	"Total surprise. The drain was removed and I've been back here three or four times to remove the swelling. That was hard. I did not know that this could happen." (patient [69]).
	"After chemotherapy this foot became numb, and it's always cold. I told my oncologist. This was just a year in. Now she says I need to learn to live with this" (patient [69]).
5. Psychological impact and coping	"[The diagnosis] hit me hard, emotionally" (patient [50]).
	"It hits you hard. More surgery. You just have to wait and see if [the cancer] comes back" (patient [64]).
	"It's not that I go around and tell people I was in the hospital, oh, what for?, and so on. What I mean is, a lot of people do not know about my surgery at all" (patient [88]).
6. Genetics and family	"So you can just request genetic testing?"(patient [64])
	"Eventually, good news from the results of the genetic testing, no genetic abnormalities were found. This was such relief for my son as well" (patient [70]).
7. Male breast cancer research	"I do not know how many men only went to their GP at the last moment and died of it. Is there any research about that?" (patient [50])
	"I know that black men have an increased risk for MBC. I thought they investigated the risk in this population. Do you know what the exact numbers are?" (patient [78])
8. Raise awareness in general population	"It is an unknown disease and it's important to get the media to show that men can get breast cancer too" (patient [69]).

TABLE 4 Top six unmet information needs of MBC patients (N = 77) and health professionals (N = 139)

Acute effects (QLQ-BR23) MBC patients (N = 77)		Late effects (B-Force) MBC patients (N = 77)		Health professionals (N = 139)	
	n (%)		n (%)		n (%)
Interested in sex	18 (23.4)	Sexuality emotionally	19 (24.7)	Male patient information	65 (46.8)
Sexually activity	17 (22.1)	Sexuality physical problems	18 (23.4)	Anti-hormonal therapy	59 (42.4)
Worried about health in future	15 (19.5)	Weight problems	18 (23.4)	Genetic testing	52 (37.4)
Area affected breast swollen	14 (18.2)	Hypersensitivity foot soles	18 (23.4)	Research results	42 (30.2)
Food and drinks tasted different	13 (16.9)	Cognitive problems	18 (23.4)	Research participation	36 (25.9)
Sexual enjoyment	13 (16.9)	Neuropathy	18 (23.4)	Psychosocial issues	34 (24.5)
Total lack of information one or more acute effects	50 (64.9)	Total lack of information one or more late effects	43 (55.8)	Total searched one or more topics of information	110 (79.1)

need of late effects was sexuality (emotional: eg, embarrassment and loss of libido and physical problems; eg, erectile dysfunction). Information needs of other treatment side effects were also mentioned (weight problems, cognitive problems, neuropathy, and hypersensitivity foot soles after treatment) (Table 4).

Unmet information needs (QLQ-INFO25)

A total of 28 out of 77 men (36%) wanted to receive more male-specific information about one or more of the following topics: symptoms and diagnosis, treatment (shared decision making, surgery, sentinel node procedure, anti-hormonal therapy, chemotherapy, alternative, and preventive therapy) and follow-up, side effects (neuropathy, loss of memory, fatigue, hair loss, and sexuality [common side effects of anti-hormonal therapy: loss of libido and erectile dysfunction]), prognosis, psychosocial impact for patients (fear of recurrence, psychological effects), partners and family, peer group support, supportive therapy (edema therapy), and research.

3.2.3 | Questionnaire health professionals

In total, 110 out of 139 professionals (79%) had searched for information on MBC. The top six of information topics searched for by these professionals: male-specific patient information, anti-hormonal therapy, genetic testing, research, and psychosocial issues (Table 4). Almost one sixth of all professionals (20/139; 14%) indicated that they were unable to find the information that they were searching for. Moreover, approximately one third (40/139; 29%) commented that, among their colleagues, there is a lack of knowledge on MBC.

3.3 | Discussion

In this mixed methods study, unmet information needs of Dutch MBC patients and health professionals were assessed. Identified themes included patients' experiences and photographs, symptoms and (delay of) diagnosis, treatment options and follow-up, side effects, psychological impact and coping, genetics and family, research, and raising awareness.

The identified themes of the focus group results are comparable to those of other qualitative studies.^{15,18-20} For example, we found in our data all of the dominant themes of Iredale's qualitative study: diagnosis and disclosure, information needs (a photograph and side effects), support and raising awareness.¹⁵ However, we also found several new topics for unmet information needs: patients' experiences, treatment options and follow-up, genetics and family, and research.

3.3.1 | Clinical implications

Because of the rarity of the disease, experiences of MBC patients are important to other MBC patients.^{39,40} The need for information on treatment choices and follow-up matched with the treatment-related needs of other cancer patients.²⁴ MBC patients with genetic mutations (*BRCA2/CHEK2*) were also present in our sample.^{6,41} Studies show that in families the impact on communication with their children about genetic testing and having a genetic mutation is prominent, and therefore specific information is needed.⁴² MBC is still an under-researched area, a website with information could facilitate in the search for participants and to draw attention to new results for health professionals.

Iredale et al. reported 56% of MBC patients wanted more gender-specific photographs of men after mastectomy or additional information on the side effects of the treatment.³¹ In our study, a lower percentage of patients, 36% had unmet information needs on this question. A possible explanation for this difference might be that more patients in Iredale's study were in the acute phase of their treatment.

Sexuality was most frequently reported as unmet information need by MBC patients. This may include for example loss of interest in sex and sexual activity during the acute phase of treatment. In the phase after treatment, MBC patients needed information about sexuality topics related to emotional (eg, embarrassment and loss of libido) and physical (eg, erectile dysfunction) side effects. [Correction added on 09 April 2020, after first online publication: in the third paragraph of 3.3.1. the second sentence has been replaced in this version]. The theme sexuality was mentioned in other qualitative studies in MBC patients as well and this finding corresponds to previous research

showing that men are more likely to need information about sexual function than women.^{23,24,43} A well-known side effect of tamoxifen is sexual problems (loss of libido and erectile dysfunction).⁴⁴ Previous qualitative studies on experiences of MBC patients reported themes as body image and affected masculinities which could have an influence on sexuality.^{18,20} As it is well known that sexuality is not always easy to discuss in patient-provider relationship. Therefore, targeted information may help to provide in the needs of MBC patients.⁴⁵

MBC patients reported a lack of awareness by themselves (42%) and experienced this also in the communication with other people (78%). This finding is comparable to the findings of Thomas et al. that 80% of the participants, representative for the general population, were not aware of the fact that men can get breast cancer.¹⁷

In our study, 27% of patients went to the general practitioner more than 3 months after discovering their symptoms. Although the study of Iredale was conducted in 2002, less men (16%) went to the general practitioner after 3 months.¹⁵ Moreover, in approximately one quarter of the patients the referral to the hospital by the general practitioner or the diagnosis in the hospital took more than five working days. Our study showed that patients' and doctors' diagnostic delay is still a problem in this patient group. We found that health professionals could need information about very similar topics as male patients. Therefore, a website (www.mannenmetborstkanker.nl) was developed that could be used as practical guide with up-to-date information about MBC.

3.3.2 | Study strengths

The strengths of this project are the combination of qualitative and quantitative methods and the inclusion of the patients' and professionals' perspective, known as triangulation.

The focus group consisted of a diverse group of patients. Purposive sampling was not used, because of the rarity of the disease. In the last focus group we presented the results of the first two focus groups to validate the results by member checking.

The response rate of the questionnaire of patients was satisfactory (72%). The MBC patients who participated in the questionnaire study seem to a large extent representative, as indicated by the similarities in demographic and clinical characteristics of the Dutch MBC patient population. However, our study group had of a higher proportion of patients treated with chemotherapy and radiation. This may be explained by the fact that men who experienced more adverse side effects more frequently participated in this study.

3.3.3 | Study limitations

We recruited patients diagnosed during the past 5 years, although some participants in the focus groups were diagnosed at earlier dates. We took sufficient time to assist the patients and patient advocates to recall their long-term memory and minimize the effect of recall bias. The sample was too small for subgroup analysis. Our study should be

interpreted as exploratory, because there are no reliability data available.

Although we included a large number of health professionals, our results on their perspective may not be generalized to all members of this group. It was difficult to reach general practitioners for participation. Because of the rarity of the disease, a general practitioner will rarely see a MBC patient. However, their role in referral of patients to the hospital is very important to prevent doctor's diagnostic delay.

4 | CONCLUSIONS

MBC patients and health professionals could have comparable unmet information needs. These could include a need for information on: patients' experiences and photographs, symptoms and (delay of) diagnosis, treatment options and follow-up, side effects, psychological impact and coping, genetics and family, and results of research. Attention should be paid to raise awareness, to facilitate early detection of MBC. To meet these needs, we developed an up-to-date website for MBC patients, their partners, families and health professionals. This website could help to raise awareness, decrease delay, improve quality of life, treatment and survival (see: <http://www.mannenmetborstkanker.nl>). Future research should amongst others focus on sexuality, genetic testing and decreasing the diagnostic delay MBC.

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CONFLICT OF INTEREST

The authors have no conflict of interest to declare.

STATEMENT REGARDING ETHICS

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional (Medical Research Ethics Committee of the Netherlands Cancer Institute (METC AVL) reference: METC16.1097) research committee and with the 1964 Helsinki declaration and its later amendments or comparable.

DATA AVAILABILITY STATEMENT

Data are only available on request because of privacy/ethical restrictions.

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SUPPORTING INFORMATION

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