

# **Influencing Factors of Health Inequity among Male Breast Cancer Patients in Germany**

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## **List of Abbreviations**

- BC = Breast cancer
- BCP = Breast cancer patients
- FBCP = Female breast cancer patients
- HCPs = Health care providers
- MBC = Male breast cancer
- MBCP = Male breast cancer patients
- N-MALE = Male breast cancer: Patients' needs in prevention, diagnosis, treatment, rehabilitation, and follow-up care

## 1. Abstract

Breast cancer (BC) is considered a typical woman's issue and is quite rare in men (1% of BC cases occurs in men). Accordingly, cancer care systems and research mainly focus on female breast cancer patients (FBCP), and men are underrepresented. There is less knowledge on male breast cancer (MBC) within patients and society, and male breast cancer patients (MBCP) have lower survival rates than FBCP. It remains unclear how MBCP fare with regard to the female-dominated cancer care situation and what constitutes health inequity. Therefore, a medical sociological perspective can help to understand health inequities, as it is a focus of this discipline. The theoretical approach of Mielck (2005) is used in this study, which aims to find out what could cause health inequities of MBCP in Germany, in order to be able to avoid health inequities for them in the future. Therefore, mediators for health inequities such as differences in health burdens, coping resources and provision of health care are regarded.

Within this cumulative dissertation, a mixed methods design is applied using data of the interdisciplinary N-MALE project (Male breast cancer: Patients' needs in prevention, diagnosis, treatment, rehabilitation, and follow-up care), conducted in Germany. Semi-structured interviews with N=27 MBCP and standardized survey data of N=100 participants were evaluated.

Findings show that differences in health burdens, coping resources, and provision of health care can be found within MBCP. Differences in the experience of having BC for men and women include stigmatization due to ignorance of MBC and feminization of the disease, difficult access to gynecological care for MBCP, study uncertainty in medication with tamoxifen and inconsistent follow-up regulations. Among MBCP, the number of treatment steps taken and the age of the patients are different with regard to experienced stigmatization and the use of social support. Differences in cancer care can be found especially in diagnosis and follow-up care.

To prospectively reduce health inequities in MBCP, structural barriers should be eliminated. To do this, there must be more publicity about MBC, greater equality of men and woman in BC therapy, and improved access to gynecological care for MBCP. Future research should be extended to health care systems of other countries and the analysis of health inequities of MBCP with routine data.

## 2. Introduction and Aims

Male breast cancer (MBC) is rare, as it arises in 1% of breast cancer (BC) cases in the western world per year (Ly et al., 2013; Miao et al., 2011). Currently, BC is frequently treated as a typical woman's disease, as it is the most common type of cancer in women (Bray et al., 2018). In order to achieve a higher quality of care, treatment of BC patients in Germany has been centralized and standardized for several years by the introduction of certified BC centers (Brucker et al., 2009). In Germany, the S3 guideline includes a special chapter about MBC (AWMF, 2020; Wöckel et al., 2018). Treatment is mainly tailored to female needs, from which treatment for male breast cancer patients (MBCP) is derived (Fentiman, 2018; Giordano, 2018; Losurdo et al., 2017). In addition, most existing research concentrates on female breast cancer (FBCP). Since the disease is rare in men (Fentiman, 2018), MBCP are a vulnerable group of patients. Because of the feminization<sup>1</sup> of the disease and its therapy described above, MBCP have a high risk of stigma (Andrykowski, 2012; Bunkley, Robinson, Bennett, & Gordon, 2000; da Silva, 2016), and the general public and patients themselves have less knowledge about the disease (Thomas, 2010). Furthermore, MBCP have a worse prognosis than FBCP do. The lower survival rates result from a more advanced stage of disease, an older age at diagnosis, and the shorter life expectancy of men in general (Giordano, 2018; Siegel, Miller, & Jemal, 2018). It remains unclear how this vulnerable group is doing in how they experience the health care situation during their cancer journey, psychosocial aspects, and what constitutes health inequity. This is supposed to be analyzed, since it is an important goal for public health and health policy to reduce health inequity (Robert Koch-Institut, 2018).

Against the background of a research gap regarding the health care situation and psychosocial aspects of MBCP, the N-MALE project (Male breast cancer: Patients' needs in prevention, diagnosis, treatment, rehabilitation, and follow-up care) was initiated. It was conducted from 2016 to 2018 in Germany to investigate the medical and psychosocial needs of MBCP over the entire cancer care continuum. The Ethics Committee of the Medical Faculty of the University of Bonn (Germany) approved the study. Within this interdisciplinary study, the University Hospitals of Bonn, Cologne,

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<sup>1</sup> Feminization within this context means a female focus of BC and its therapy.

and Munich and the German Cancer Society (DKG) were involved. A mixed methods design was applied using qualitative data of personal interviews with n=27 MBCP and quantitative data from a postal survey (n=100). The present dissertation is part of the N-MALE study.

The author of this cumulative dissertation is settled within the research field of Medical Sociology. This discipline is an intersection of social sciences and medicine with the aim to analyze the effect of social environments on health and disease. One focus is research on social inequalities in health: to find out what social conditions lead to differences in health or disease records on an individual or macro level (Hurrelmann & Richter, 2013).

## 2.1 Theoretical Approach of Health Inequity

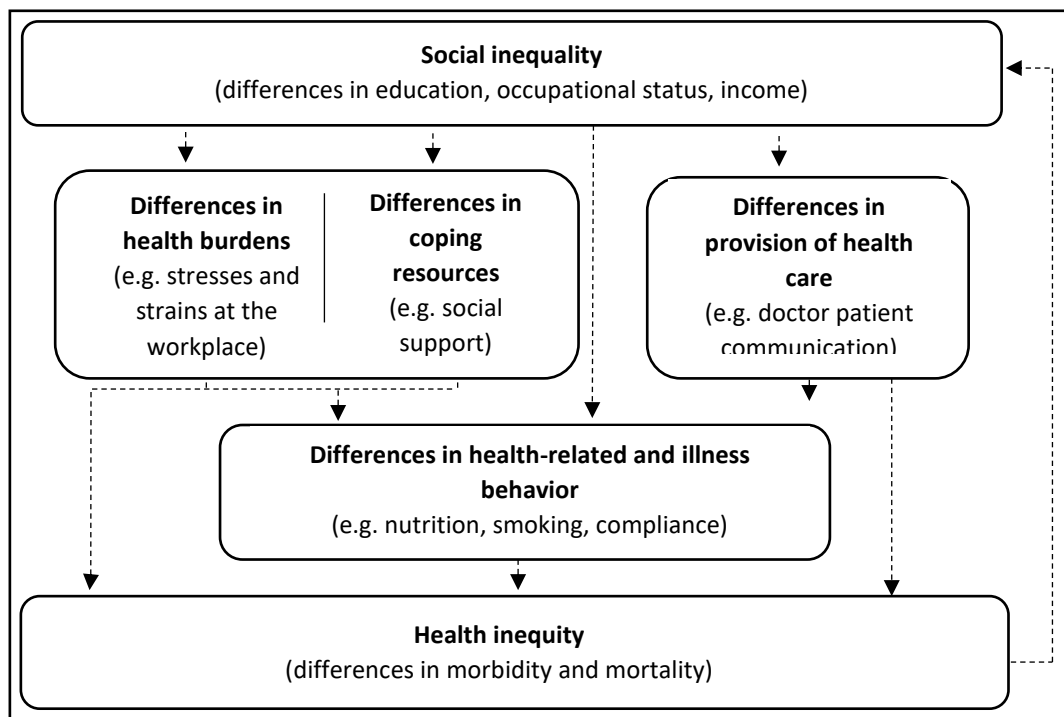
One prominent theory of health inequity is provided by Mielck (2005). He gives theoretical approaches to explain health inequities. The term health inequity includes a judgmental component. It means to focus on the differences in state of health that are considered unjust and hence are not socially legitimated, such as differences in morbidity and mortality (Mielck, 2005).

Social inequalities in living conditions and opportunities for participation are reflected in health and life expectancy (Lampert & Mielck, 2008). Often, differences in education, occupational status, and income are viewed as social inequality, so-called vertical social inequality. In addition, horizontal social inequality like age, gender, family status, and nationality can divide the society, and social inequalities can be found there as well. Vertical and horizontal aspects should be combined to describe vulnerable groups within society. Concerning health status, the influence of social inequalities is indirect and is conveyed through other factors on a meso-level where social contexts are included, such as coping resources (see below). It is emphasized that health burdens themselves are not important, it is more the balance between health burdens and resources of coping. Health behavior is influenced by this balance and by provision of health care. Even though the model of Mielck (2005) (Figure 1) is hierarchical and all higher levels have an impact on health inequities, it does not mean that the intermediate levels are fully explained by social inequality. They can exert influence independent from social inequality. The model should not imply that health inequity

could not be determined deterministically from social inequality. The direction can also be reversed, as health inequities can in turn affect social inequality.

Within the meso level, there are three factors that influence health inequity: 1) differences in health burdens, 2) differences in coping resources, and 3) differences in provision of health care. These three factors related to MBCP were discussed within the three articles of this dissertation and were published in peer-reviewed international scientific journals. In the following section, the main aspects of the articles are presented:

**Figure 1:** Model to explain health inequity (Mielck, 2005)



### 2.1.1 Differences in health burdens – stigmatization

Within this dissertation project, stigmatization is regarded as a health burden for MBCP. Former studies identify stigmatization as a common phenomenon of cancer patients (Ernst, 2016; Fife & Wright, 2000; Lebel & Devins, 2008), as the disease confound social norms (Ernst, 2016) and is accompanied by physical or mental limitations (Fife & Wright, 2000). As previously mentioned, stigmatization plays an important role in MBCP, but to date, there is no study focusing on this topic solely.



The sociological construct of stigmatization describes a process in which stereotyping and negative labelling of specific human characteristics (stigmas) take place (Esser et al., 2017; Link & Phelan, 2001). In social interactions, stigmatization has an orientation function and helps to preserve expectable behavior and social norms (Hohmeier, 1975). Through shame (self-stigmatization) or disapproval (stigmatization by others), stigmatization can lead to social exclusion and isolation (Goffman, 1963).

Reasons for stigmatization of MBCP are shown in previous studies and include the feminization of the disease, physical changes in the body, body image after treatment (Bunkley et al., 2000), and isolation because of feared stigmatization (France et al., 2000; Iredale, Brain, Williams, France, & Gray, 2006).

Within the first article of this dissertation project, health burdens of stigmatization should be regarded from a patient's perspective to explore the following: How do MBCP feel about suffering from a "woman's disease"?

#### 2.1.2 Differences in coping resources – social support

As differences in coping resources, social support is considered. Social support describes an interpersonal interaction to change a person's problematic situation or at least make it more bearable if nothing can be changed about it (Schwarzer, 1996). Social support comprises three dimensions: emotional support (caring, compassion, spending warmth, consolation and physical affection), instrumental support (material goods, tangible assistance), and informational support (giving advice, imparting information) (Knoll, Scholz, Rieckmann, & Schwarzer, 2011). As most social support can be found within close social environments like partnerships, family relationships, or friendships (Schwarzer, 1996), the current dissertation project concentrates on these settings as well.

For cancer patients in general, social support has positive effects on coping (Kim, Han, Shaw, McTavish, & Gustafson, 2010), the healing process, and the mindset (Helgeson & Cohen, 1996), and it fosters less depression (Hann et al., 2002). Recent studies show the importance of social support for MBCP. Partner support is important for MBCP (Co et al. 2020; France et al., 2000; Iredale et al., 2006; Pituskin, Williams, Au, & Martin-McDonald, 2007), as men are less able to fight and experience more psychological distress without this support. Female friends diagnosed with BC can also

be a resource for informational support (France et al., 2000). Support groups for MBCP are rare, and support groups for FBCP are not that popular in MBCP (da Silva, 2016; Iredale et al., 2006; Robinson, Metoyer, & Bhayani, 2008; Smolin & Massie, 2002). Despite the importance of social support for MBCP, they receive less support than FBCP (da Silva, 2016; Donovan & Flynn, 2007; Iredale et al., 2006; Robinson et al., 2008).

The second article of this dissertation project concentrates on the social support usage of MBCP to find out differences in coping resources within the community of MBCP: How do MBCP use social support?

### 2.1.3 Differences in provision of health care – patient perspective on their health care situation

Health inequity is evident in the fact that there are differences in health care provision for MBCP and FBCP, as some studies show: These contain, for example, a later diagnosis, poorer survival rate, and different behavior of health care providers (HCPs) towards MBCP compared to FBCP (Lautrup et al., 2018; Robinson et al., 2008). In addition, information about BC is focused on FBCP, and information is less available to MBCP (Brain, Williams, Iredale, France, & Gray, 2006; Iredale et al., 2006; Williams et al., 2003). In addition to this gender-based inequity, there might be also differences of health care provision between MBCP. Therefore, the whole process of cancer care should be regarded, diagnosis, treatment (including surgery, chemotherapy, radiation therapy, hormone therapy), rehabilitation, and aftercare.

The third article of this dissertation project deals with the entire MBCP care process in the German cancer care system. The main question is as follows: How do MBCP experience the health care situation with respect to every step of the cancer care process?

## 2.2 Main Questions

Keeping these three factors that influence health inequity in mind, this cumulative dissertation focuses on the experiences of MBCP from patients' perspectives during their cancer journey. Experiences with the cancer care system as well as psychosocial aspects, such as stigmatization and social support, were investigated. Since MBC is

rare, this woman-dominated disease can be a special situation that MBCP have to deal with. In sum, the aim of this dissertation project is to explore the following:

1) What could cause health inequities of male breast cancer patients in Germany? To answer this, areas of health burdens (stigmatization), coping resources (social support), and provision of health care (cancer care) are considered.

2) How can health inequities of male breast cancer patients be reduced in the future?

Hereinafter, the three original articles are inserted. In the concluding discussion, the results are presented, limitations of this dissertation are shown, and important implications for further research and care practice are provided.

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### 3. Publications<sup>2</sup>

#### 3.1 Men With a “Woman’s Disease”: Stigmatization of Male Breast Cancer Patients – A Mixed Methods Analysis<sup>3</sup>

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<sup>2</sup> The articles were left as required by the respective publisher.

<sup>3</sup> Published 2018 in *American Journal of Men’s Health*, 12 (6), 2194-2207.

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**Abstract**

Male breast cancer (MBC) is rare and known as a typical woman's disease. This study is part of the N-MALE project and aims to investigate how MBC patients (MBCP) feel about suffering from a "woman's disease", what character the stigmatization has, and how it can be prospectively reduced. Therefore, a mixed methods design is applied including data of N=27 qualitative interviews with MBCP and quantitative data of N=100 MBCP. Findings identify a diverse picture, as stigmatization varies between contexts and patients: Most stigmatization concentrates on sexual stigmatization and ignorance of MBC and mostly occurs in cancer care system and work-related contexts. The level of stigmatization varies with age and amount of treatment methods received, as reported within the created typology of different MBCP stigma types. To prospectively reduce stigmatization in MBCP, more publicity of MBC is needed, as well as gender-neutral communication and information material.

**Keywords**

stigma, (male) breast cancer, MBC, rare disease, medical sociology, health services research, mixed methods

## Introduction

Breast cancer in men is a rare disease that accounts for around 1% of breast cancer cases in the western world (Ly, Forman, Ferlay, Brinton, & Cook, 2013; Miao et al., 2011). However, the incidence has risen over the past decades (Hodgson, Button, Franceschi, Moffat, & Livingstone, 2004), and it has been suggested that this rise will continue in the future (Contractor, Kaur, Rodrigues, Kulkarni, & Singhal, 2008). Risk factors include a family history of breast cancer, genetic and hormonal aspects (da Silva, 2016; Giordano, 2018). As breast cancer is known as a typical woman's disease, most research to date has focused on female breast cancer. Consequently, there is a need for more research on male breast cancer (MBC), especially concerning the psychosocial aspects of cancer care. Besides this female focus in breast cancer research, there is also a social construct that connects breasts in general and breast cancer with femaleness (da Silva, 2016). These social constructs can have significant implications for men who have breast cancer, wherein, besides having to cope with the disease, males also have to deal with gender aspects because of suffering from a perceived woman's illness and feminization in therapy (da Silva, 2016). Emasculation is a big issue discussed in several studies of male breast cancer patients (MBCP) (da Silva, 2016; Donovan & Flynn, 2007; France et al., 2000; Iredale, Brain, Williams, France, & Gray, 2006; Smolin & Massie, 2002; Swergold, Murthy, & Chamberlain, 2014) and can lead to stigmatization.

Stigmatization as a sociological construct was first characterized by Goffman (Goffman, 1963). It has been variously defined as a process in which specific human characteristics, so-called stigmas, are stereotyped and negatively labeled (Link & Phelan, 2001; Esser et al., 2017). Stigmatization can lead to social exclusion, isolation, and changes in the life situation of the affected person such as employment opportunities or housing (Link & Phelan, 2006) and has also been reported to influence personal identity (Goffman, 1963; Link & Phelan, 2001). This labeling process, whether placed by others or oneself, often includes shame as part of self-stigmatization or disapprobation (Goffman, 1963). It is important to distinguish between self and external stigmatization, because stigmatized people sometimes do not identify themselves with the negative labeling of others (Ernst, 2016). Stigmatization has an orientation function in social interactions, as it helps to maintain

norms and expectable behavior. To distance oneself from a stigmatized person retains our own identity as it normalizes the own identity or depreciates the other (Hohmeier, 1975). Also, as stated by Tang, Mayer, Chou, and Hsiao (2016), stigmatization is not consistent but depends on personal aspects, social relationships, and contexts, as to whether the stigmatized person interprets something as stigmatizing or not.

Health-related stigmatization means the labelling of people because of certain characteristics of illness (Fife & Wright, 2000; Goffman, 1963; Link & Phelan, 2001). Illness is a stigmatizing element for the reason that it is connected with (physical and/or mental) limitations (Fife & Wright, 2000). Stigmatization of individuals, based on health in general or illness, typically results in their exclusion from social roles or functions (Link & Phelan, 2001). As past studies identify, stigmatization is a very common aspect for cancer patients (Ernst, 2016; Fife & Wright, 2000; Lebel & Devins, 2008), as cancer is a disease that confounds the social norms of society and provokes fear and insecurity, which is reported and explained in detail elsewhere (Ernst, 2016).

Although several studies of stigmatization of (female) breast cancer patients (Meacham, Orem, Nakigudde, Zujewski, & Rao, 2016; Nyblade, Stockton, Travasso, & Krishnan, 2017; Tripathi, Datta, Agrawal, Chatterjee, & Ahmed, 2017; Trusson & Pilnick, 2017) exist, no studies, to date, have focused solely on stigmatization of MBCP. Instead, the issue of MBCP stigmatization is raised within the discussion of the patients (Brain, Williams, Iredale, France, & Gray, 2006; Donovan & Flynn, 2007; Iredale et al., 2006; Kipling, Ralph, & Callanan, 2014). Stigmatization plays an important role in MBCP. One issue of concern for MBCP surrounds the physical changes and changes in body image after treatment (Bunkley, Robinson, Bennett, & Gordon, 2000), especially because men often associate their body (and their chest) with masculinity (Donovan & Flynn, 2007; Pituskin, Williams, Au, & Martin-McDonald, 2007; Robinson, Metoyer, & Bhayani, 2008). Particularly, the scar on the breast is an important contributor to the altered body image, which is perceived controversially by the patients (France et al., 2000; Iredale et al., 2006; Pituskin et al., 2007; Robinson et al., 2008; Williams et al., 2003), and younger men tend to find it of greater concern than older patients do (Iredale et al., 2006). An altered body image is also connected with psychological distress (Brain et al., 2006). Additionally, the rareness of the disease, connected with a lack of awareness of MBC and the perception of breast

cancer as a woman's disease, can lead to isolation (Bunkley et al., 2000; Iredale et al., 2006) brought about by stigmatization and nondisclosure because of feared stigmatization (France et al., 2000; Iredale et al., 2006).

In the context of these aspects raised in the preceding text, four major areas were explored to examine how MBCP feel about suffering from a "woman's disease": (a) the contexts in which the stigmatization occurs; (b) what kind of stigmatization the patients' experience; (c) how, from the patients' perspective, stigmatization can be reduced; and (d) if different levels of stigmatization can be created and how they differ regarding demographical and cancer-related aspects.

## **Methods**

### *Study Design*

This study was approved by the Ethics Committee for Bonn (Germany). It was carried out by an interdisciplinary research team (psychology, sociology and health economics) with members representing care providers, patient representatives, and a psychotherapist.

The study is part of the N-MALE project (Male breast cancer: patient's needs in prevention, diagnosis, treatment, rehabilitation and follow-up-care) conducted in Germany. N-MALE, which started in April 2016 and ends in March 2018, was undertaken to examine the medical and psychosocial needs of MBCP across the cancer care continuum (from prevention to follow-up). It is an interdisciplinary study involving the *University Hospital of Bonn, the University Hospitals of Cologne and Munich and the German Cancer Society (DKG)*. The N-MALE study applies a mixed methods design capturing data via qualitative interviews with MBCP and a quantitative questionnaire. This triangulation of methods intends to create more depth and breadth in the analysis of data (Carell, 2005; Flick, 1992) and thereby gain more insight into the participants' perspective (Carell, 2005; Denzin & Lincoln, 2003). In the following text, qualitative and quantitative methods are described successively based on the so-called *between-method* triangulation described by Carell (2005), where both methods — qualitative and quantitative — are treated equally. Mixed methods were chosen to exploit the strengths of both approaches: the exploratory and comprehending character of qualitative analysis since little is known about stigmatization of MBCP.

The qualitative content analysis was performed according to Mayring (2016). Data collected from the quantitative analysis were used to support the qualitative results, as the results of more MBCP can be considered within this study because of a bigger number of participants within the quantitative sample. By using both methods, the results can validate each other. Furthermore, quantitative methods help to describe “facts” as demographic or disease-related characteristics of the participants. Results of both analyses are brought together at the end of results section within a mixed methods matrix per patient to complement each other to make a typification of participants possible.

Data were collected between April 2016 and October 2017. This process included qualitative and quantitative data.

#### *Inclusion Criteria and Participants*

Inclusion criteria were the confirmed breast cancer diagnosis (C50.x or D05.x) and a written informed consent. Exclusion criteria for the interviews were defined as aspects that made it difficult to set up an interview and included, for example, deafness, speech or comprehension problems, psychosis, dementia, advanced cancer, and related issues like pain, difficulties in concentrating, or if the written declaration of consent was missing or withdrawn. The exclusion criteria for the quantitative questionnaire was a missing or withdrawn declaration of consent.

Access to the field was given through the Men with Breast Cancer Network (*Netzwerk Männer mit Brustkrebs e.V.*) and breast cancer centers that were certified in accordance with the criteria of North Rhine Westphalia State (Äkzert) and the requirements of the German Cancer Society (*Deutsche Krebsgesellschaft, DKG*) and the German Society for Breast Diseases (*Deutsche Gesellschaft für Senologie*). Furthermore, MBCP interested in taking part in the study contacted us via email or telephone, as there were some invocations in the form of press releases and short articles.

From this number of interested MBCP, participants were selected for qualitative interviews. Sampling was done according to the precepts of the Glaser and Strauss model (2008) for theoretical sampling. This strategy is used to find cases as significant and contrasting as possible until theoretical saturation is reached (Glaser, Strauss, &

Paul, 2008). For sampling, data of the standardized questionnaire was used.<sup>1</sup> The interviewed subjects included participants varying in sociodemographic factors like age, family status (status of relationship, children) and education; facts of disease like date of diagnosis (recent and less recent), disease status (stage, relapse), and treatment (breast cancer center or hospital); and other aspects like contact with support group and experiences during treatment (positive or negative).

Reasons for non-response for the qualitative interviews were lack of interest in an interview in general, issues of the disease like a progressed stage or cancer-related problems (exclusion criteria), or death between sending the questionnaire and appointment for an interview. For the quantitative questionnaire, we have no information of reasons for non-response.

### *Data Collection*

#### *Qualitative interviews*

The recruiting and the participant interviews were conducted by two female (and one male) research fellows (PhD candidates) of the N-MALE project who were trained in interviewing skills. One was experienced in interviewing and did an advanced intern training of the other interviewers. In addition, all interviewers completed an interviewer training with a psychotherapist, focusing on how to deal with serious situations that could arise within the interviews (e.g., strategies for talking about sensitive topics, like sexuality of the participants with those who have a different gender, how to deal with psychological stress that could arise by the interview).

The semistructured face-to-face interviews were done according to an interview guideline (Helfferich, 2011), which leaves enough space for open-ended answers and was structured along all steps of cancer therapy.<sup>2</sup> The guideline was developed within the interdisciplinary N-MALE team, pilot-tested by three interviews with MBCP and customized as discussed in the results of pretests in the project team. Each interview was between 1 and 2 hours and was audiotaped, anonymized, and transcribed towards specific rules according to Fuß and Karbach (Fuß & Karbach, 2014). After each interview, field notes on non-verbal aspects, abnormalities, first interpretations, and other information that could be helpful for the interpretation were recorded. The

participants could choose the location of the interview, mostly their place of residence. To ensure an undisturbed atmosphere, care was taken to exclude others from the interview setting so that only the participant and the interviewer were present, except cases in which participants requested their partners. Before the interview, participants signed an informed consent and were advised about the procedure, the study objective, and the use of the data.

#### *Quantitative data*

The quantitative questionnaire was developed within the interdisciplinary N-MALE team and pretested with four MBCP. After the pretests, the questionnaire was modified and mailed to all interested participants (117 participants).<sup>3</sup> Following Dillman's total design survey method (1978), three reminders were sent at 1, 3 and 7 weeks, to achieve the highest response rate (Dillman, Smyth, & Christian, 2014).

#### *Sociodemographic characteristics*

Sociodemographic aspects of the MBCP were measured. They included age, marital/relationship status, children, education, occupation, and residential area (urban, rural).

#### *Disease-related characteristics and breast cancer treatment*

The participants were asked about aspects of their disease, like date of diagnosis, first time breast cancer or relapse, and types of cancer treatment (current breast cancer treatment, surgery, chemotherapy, adjuvant radiation, hormonal therapy, rehabilitation), as well as contact with (MBCP) support group, experiences of cancer care (positive and negative) and comorbidities.

#### *Measurement of stigmatization*

Participants were questioned about stigmatization during the course of cancer treatment and in private surroundings. The questionnaire was structured in the different stages of cancer care, with filter questions about specific cancer care steps, in which the participants were simply required to indicate whether they have received in the past or will receive it in the future. Concerning stigmatization in the process of cancer care, the following five variables were used:

- (1) *Have you felt excluded during hospitalization in terms of your breast cancer disease?*
- (2) *Have you felt excluded during chemotherapy in terms of your breast cancer disease?*
- (3) *Have you felt excluded during radiation therapy in terms of your breast cancer disease?*
- (4) *Have you felt excluded during medical rehabilitation in terms of your breast cancer disease?*
- (5) *Have you felt excluded during aftercare or follow-up survey in terms of your breast cancer disease?*

Concerning the private surroundings, the survey asked about stigmatization in different circumstances like close and wider social relationships with three variables in total:

- (1) *Have you felt excluded from your family in terms of your breast cancer disease?*
- (2) *Have you felt excluded from your friends or acquaintances in terms of your breast cancer disease?*
- (3) *Have you felt excluded from your colleagues or superiors in terms of your breast cancer disease?*

The answer categories for all questions were *never, rarely, sometimes, often, and always* with single selection. If men felt any stigmatization, the next question asked was in which form they experienced stigmatization to explain their experiences. This open-ended answer category was also included in the qualitative content analysis.

## *Data Analysis*

### *Analysis of qualitative data*

For qualitative analysis, transcript data of the interviews, after-interview notes, as well as the open-ended answer categories of the quantitative questionnaire (reasons for stigmatization) were analyzed using qualitative content analysis according to Mayring (Mayring, 2016). Coding was deductive and inductive<sup>4</sup> using MAXQDA version 12.2.1 (VERBI GmbH, 2016) software for managing the data. The codings were described. One scientist who mainly conducted the interviews also did the coding process. During



this process, there were regular consultations within the research team for validation. It was an alternating interviewing and analyzing process, where categories were developed and tested in the interviews that followed. This alternating strategy was also needed for the purposeful sampling (Helfferich, 2011). At the end of the coding process, the codes were discussed in a research workshop.

### *Statistical analysis*

For statistical analysis, SPSS version 25 (IBM SPSS Statistics, 2017) was used. The sociodemographic, disease-related characteristics and breast cancer treatment were analyzed using descriptive statistics. For analysis of stigmatization, descriptive statistics were used as well. Mean values are reported separately for each item. Furthermore, t-tests were derived to estimate significant differences between items.

### *Mixed methods analysis*

For mixed methods analysis, qualitative and quantitative data of 27 MBCP were included. Qualitative and quantitative data of those participants were merged, including codes of qualitative analysis (dimensions of stigmatization, no subjective stigma experienced) and data of quantitative analysis such as sociodemographic aspects (age, education), disease-related aspects (breast cancer for the first time/ relapse, stage(s) in the cancer care system) and context of stigmatization (results per person of Measurement of Stigmatization)<sup>4</sup>.

Qualitative and quantitative data of those participants was merged including codes of qualitative analysis (dimensions of stigmatization, no subjective stigma experienced) and data of quantitative analysis such as sociodemographic aspects (age, education), disease related aspects (breast cancer for the first time/ relapse, stage(s) in the cancer care system) and context of stigmatization (results per person of *Measurement of Stigmatization*).

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<sup>4</sup> In the original publication there is an editorial error in this sentence which has not yet been corrected. In this dissertation, it has been corrected.

## Findings

### *Characteristics of Participants*

Concerning quantitative data, the cleared response rate was 85,5% (N=100).

Twenty-seven Interviews with MBCP were conducted. Table 1 gives an overview of sociodemographic and disease-related characteristics of the quantitative sample and the (qualitative) subsample.

### *Context of Stigmatization*

Findings based on the interviews with MBCP identify that most stigmatization occurs in the cancer care system. In addition, MBCP feel stigmatized by female breast cancer patients, especially if they have the feeling that the women are unaware of the disease in men:

*“I remember that woman in the breast cancer center. She said: ‘What do YOU want here? (Laughing) You don’t belong here.’” (ID no. 63)*

The statistical analyses (Table 2) indicate that in the cancer care system, most stigmatization takes place in rehabilitation settings (mean=1.50), significantly more than during chemotherapy ( $p=.006$ ), radiation ( $p=.019$ ), follow-up survey ( $p=.031$ ) and within family ( $p=.004$ ). In the cancer care system, the men experienced significantly higher stigmatization during hospitalization (mean=1.20) than during chemotherapy (mean=1.14;  $p=.049$ ). The experienced stigmatization is higher within the cancer care system than within social surroundings. One exception from this finding was the feeling of exclusion in the working environment, which showed the highest value (mean=1.69). The men felt significantly more excluded in the working environment than in hospital ( $p=.000$ ), during chemotherapy ( $p=.000$ ), radiation ( $p=.000$ ), follow-up survey ( $p=.000$ ) and within family ( $p=.000$ ) and friends ( $p=.000$ ). In qualitative data – in contrast – stigmatization is mostly being found within the cancer care system. In social surroundings, the closer the relationship, the less the stigmatization. That is, there is significantly less stigmatization with close family and friends than in broader social settings, for instance, with colleagues.

### *Categories of Stigmatization*

Within the interviews with MBCP, five main categories of stigmatization were identified and are shown in Figure 1.

The category *Experiences of stigmatization* is a form of direct stigmatization. It describes situations in which MBCP were treated differently than other patients. The category *Bodily dimension* includes aspects associated with the changes to the body and body image after the surgery. In addition, there is a horizontal category of indirect stigmatization. Indirect stigmatization comprises situations that cause shame and indisposition and can lead to self-stigmatization. This category is called *Hidden and feared stigmatization*. Those direct and indirect dimensions led to the category *Hints for reducing stigmatization* given by the participants.

### *Experiences of stigmatization*

The stigma aspects of most of the men are represented within this dimension. Sixteen men (59.26%; second highest stigma rate) experienced sexual stigmatization in the process of cancer care. This dimension of stigmatization occurs the most (Table 3). It includes the aspect that cancer care focuses on female breast cancer patients. Also, discrimination in treatment was experienced because of being male. For example, several men reported that some outpatient gynecologists who were specialists for breast cancer rejected them because treating a man might cause billing issues. Furthermore, some men were called by a female name in the waiting room:

*“I think I was called as ‘Mrs. Miller’ once (laughing). Something like this is also unpleasant.” (ID no. 95).*

The highest stigma rate can be found within the dimension *having the feeling of being the only rooster in the yard* beside all the women in breast cancer therapy (occurs in 18 men; 66.67%). The participants experienced this stigma in two different ways. One, from a positive view:

*“You then feel like an exotic. Many women. But me as the only man. [...] Anyway, you’re the only rooster in the yard.” (ID no. 9)*

But also from a more negative one:

*“I’ve been the only men among women. An exchange of experience was not possible at the rehabilitation center.” (ID no. 91)*

Moreover, 12 men (44.44%; third highest stigma rate) experienced ignorance because nearly no one knows about breast cancer in men, both in their social and professional environments. Also, men experienced changes in social relationships, including social isolation, because some people do not know how to deal with a man having breast cancer.

Although 10 men (37.04%) reported having no experiences of stigmatization, the codes (Table 3) reveal that this number is lower (N=3). Hence, there is a difference between the self-reporting of stigmatization (when they were asked if they experienced stigmatization) and the results of coding concerning stigmatization.<sup>5</sup>

#### Bodily dimension

There were four aspects found in which the disease influences body issues related to stigmatization. Three of them are visible (e.g., the scar on the breast). Some men were ashamed to show themselves shirtless in public, for example, in a swimming pool. The loss of hair is also a problem for some men — on the head and especially on the face, that is, loss of the beard:

*“This is a time when the disease is also disfiguring. Nobody sees the surgery. There is a shirt over it. You have your scars, [...] but you can hide them. But when the hair is gone, mustache away, eyebrows away.” (ID no. 32)*

Not visible but also important for the men is the change in body image after the disease. Some men felt emaciated and less strong:

*“This was a big problem for me at the beginning. Because I said, I’m distorted. The nipple is gone. [...] It was a learning process. [...] I have a certain body image of mine. I’m tall, I’m strong, I’m intact, I’m in working order. I’m reasonably good*

*looking. And at that time, this body image got a first crack. [...] Some years ago, I had a hip replacement surgery. There is also a scar. That didn't matter to me. Only here I had doubts." (ID no. 77)*

#### *Hidden and feared stigmatization*

Within this indirect dimension of stigmatization, some men mentioned receiving questioning glances while sitting in the waiting room of a gynecologist:

*"[While sitting in the waiting room] the women are thinking: 'He accompanies his wife. She's in treatment.' And when you're being called: 'Mr. Miller please.' All heads are turning, and you feel kind of observed." (ID no. 55)*

**Table 1.** Sample Characteristics of the Quantitative and Qualitative Sample of Male Breast Cancer Patients.

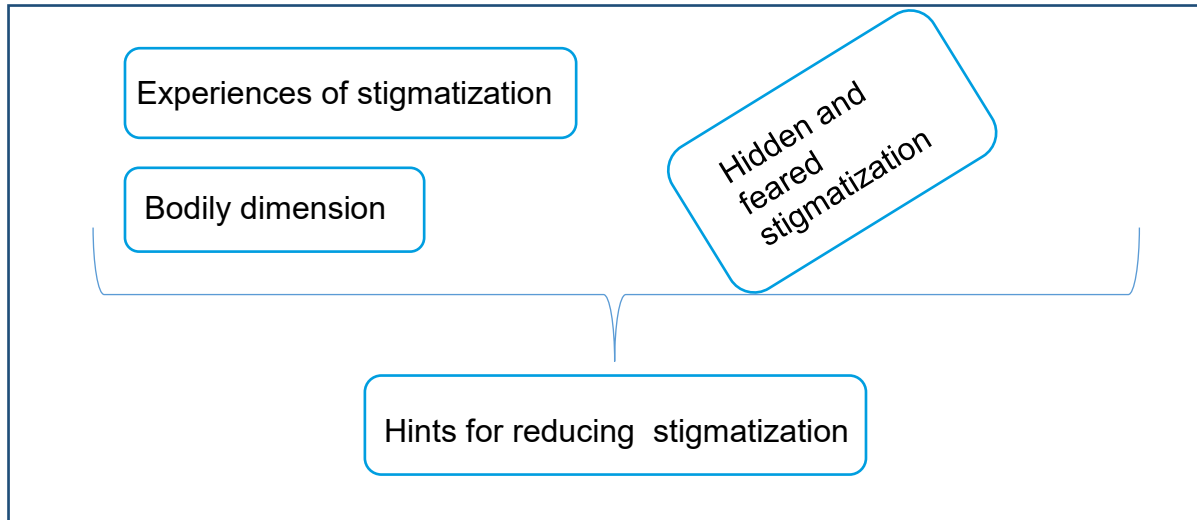
<b>N=100 (N=27)</b>	<b>N (N)</b>	<b>% (%)</b>	<b>Mean (Mean)</b>	<b>Min (Min)</b>	<b>Max (Max)</b>
<b><i>Sociodemographic characteristics</i></b>					
<i>Age</i>					
In years			66.91 (64.8)	39 (42)	89 (89)
Missing	2 (1)	2 (3.7)			
<i>Living with a partner</i>					
Yes	82 (19)	87.2 (79.2)			
No	12 (5)	12.8 (20.8)			
Missing	6 (3)	6.0 (11.1)			
<i>Children</i>					
Yes	79 (20)	84.0 (76.9)			
No	15 (6)	16.0 (23.1)			
Missing	6 (1)	6.0 (3.7)			
<i>Education (multiple answers)</i>					
No school certificate	2 (0)	2.0 (0)			
Lower school certificate	41 (11)	41.8 (42.3)			
Intermediate school certificate	27 (8)	27.6 (30.8)			
Vocational diploma/ university entrance certificate	35 (11)	35.7 (42.3)			
Missing	2 (1)	2.0 (3.7)			
<i>Occupation</i>					
Full time	26 (7)	26.8 (26.9)			
Part time	4 (1)	4.1 (3.8)			
Occupational rehabilitation	2 (0)	2.1 (0)			
Certified sick	12 (6)	12.4 (23.1)			
(Early) retired	54 (12)	55.7 (46.2)			
Unemployed	1 (0)	1.0 (0)			
Missing	3 (1)	3.0 (3.7)			
<b><i>Disease-related characteristics</i></b>					
<i>Time since first diagnosis</i>					
In years			3.61 (4.1)	<1 (<1)	20 (17)
Missing	5 (1)	5 (3.7)			
<i>Types of treatment received</i>					
Surgery	97 (27)	97.0 (100)			
Chemo-therapy	56 (16)	56.0 (59.3)			
Radiation therapy	65 (16)	65.0 (59.3)			
Antihormone therapy	75 (22)	75.0 (81.5)			
I don't know	2 (0)	2.0 (3.7)			
Missing	0 (0)	0 (0)			
<i>Newly diagnosed</i>					
Yes	92 (24)	95.8 (96.0)			
No	4 (1)	4.2 (4)			
Missings	4 (0)	4.0 (7.4)			

*Note.* Quantitative sample N = 100; qualitative sample (subsample) N = 27, Numbers of qualitative sample are in brackets.

**Table 2.** Stigmatization of Male Breast Cancer Patients (N=100)

	<b>N</b>	<b>Range</b>	<b>Minimum</b>	<b>Maximum</b>	<b>Mean value</b>	<b>Standard deviation</b>	<b>Significance in reference to (p)<sup>a</sup></b>
Excluded during hospitalization	97	1-5	1	4	1.20	.606	Chemo (.049), radiation (.017), family (.016), colleagues (-) (.000)
Excluded during chemotherapy	57	1-5	1	3	1.14	.398	Rehab (-) (.006), colleagues (-) (.000)
Excluded during radiation therapy	62	1-5	1	3	1.10	.349	Rehab (-) (.019), colleagues (-) (.000)
Excluded during medical rehabilitation	48	1-5	1	5	<b>1.50</b>	.968	Follow-Up (.031), family (.004)
Excluded during aftercare or follow-up survey	80	1-5	1	4	1.14	.497	Colleagues (-) (.000)
Excluded from family	100	1-5	1	3	1.05	.297	Friends (-) (.011), colleagues (-) (.000)
Excluded from friends or acquaintances	100	1-5	1	3	1.16	.487	Colleagues (-) (.000)
Excluded from colleagues or superiors	94	1-5	1	5	<b>1.69</b>	.776	
Valid terms (list wise)	28						

Note. <sup>a</sup>Key *Significance in reference to* = For interpreting the terms: Positive values indicate higher feelings of exclusion within the term than within the comparative value.

**Figure 1:** Categories of Stigmatization

Besides, participants had the feeling of being an oddity or outsider because of being the only male and not being integrated into the circle of female breast cancer patients:

*“Well, in those occupational therapies there are predominantly women. [...] My impression was that they did not want to have men with them. [...] That’s why I kept out of it.” (ID no. 16)*

In treatment, some men also had the sense of being treated differently from the women with breast cancer. Moreover, men reported fear of other people’s reactions that made them ashamed of their disease:

*“I was ashamed at first [...]. Because men and breast cancer? [...] It’s the basis of several thoughts as: That could provoke mockery or strange questions. How can a man get breast cancer. [...] And I thought didn’t tell anyone at first.”(ID no. 99)*

#### *Hints for reducing stigmatization*

From the men’s perspective, stigmatization can be reduced in two different ways. One is by increasing the awareness of MBC in the cancer care system and in public:



*“Thus, enlightenment is the most important. In therapy, it should be taken for granted that also men can get breast cancer and that it isn’t extraordinary.” (ID no. 16)*

*“If the people were more enlightened, there would be less insecurity in social environment, I guess.” (ID no. 32)*

Second, the men wish for equality of men and women in cancer care. Notably, the documents and information materials should be gender-neutral or contain aspects for both genders:

*“As I said those forms... It always annoys me. [...] Why it isn’t possible to create a form which says dear patient [female AND male salutation].” (ID no. 32)*

### *Stigma Types*

As the mixed methods matrix (Table 3) indicates, most of the 27 participants experienced stigmatization during their course of the disease. However, the level of stigmatization varies between the participants. The participants were divided into three different groups according to their experiences of stigmatization (how many experiences of stigmatization and number of areas the stigmatization was experienced).<sup>6</sup> To allocate the MBCP into those three stigma groups, their answers within the questionnaire and the interview were added, concerning stigmatization.

The first group “not stigmatized” experienced no or minimum stigmatization. It includes participants who in the interview said they experienced no stigmatization and who had no hint of any stigma dimension within the coding of the interviews (or just one) and stated in the questionnaire, that they did not experience any stigmatization among the different contexts of cancer care and social surroundings. This group consists of four participants (ID nos. 36, 48, 63 and 87), who have in common that they have breast cancer for the first time (no relapse) and have minimal therapy — surgery and, in some cases, hormone therapy. Another characteristic of this first group is their higher average age (74 years) compared to the other two groups. Additionally, two of the men

are still suffering from other types of cancer or have already experienced another cancer.

In contrast to that group, another group of MBCP experienced much more stigmatization during their process of disease (“stigmatized”), as evidenced within the *Dimensions of stigmatization* and the *Context of stigmatization* (Table 3), having more aspects or rather higher rates in some contexts (cancer care and social surroundings). To be part of this group, the participants need to have experiences in  $\geq 5$  categories of stigmatization (counted crosses [x]) in *Dimensions of stigmatization* and all values  $\geq 3$  in *Context of stigmatization*). Within this group, there are seven participants (ID nos. 11, 16, 32, 52, 67, 78, 82). All of them have received more types of therapy than the “not stigmatized” group and two of them had a relapse (all relapse cases are within this group). The average age of those men is much lower than in group one (62 years). The third group of MBCP represents those that received “average stigma levels”, as their level of stigmatization is located in the middle of the two former groups. It is the biggest group, consisting of all participants (N=16) who experienced more than “no stigmatization” and less than a lot (i.e., stigmatization in  $\geq 2/3$  and  $< 5$  categories). They have an average age of 68 years, which is between the ages of group 1 and 2. The stage of cancer varies among the members of this group, from a lower to a higher stage in regards to the therapy. All participants within this group have breast cancer for the first time.

**Table 3. Mixed Methods Matrix: Overview Stigmatization of Male Breast Cancer Patients (N=27)**

ID	Age	Education <sup>a</sup>	Disease-related characteristics <sup>b</sup>	Dimensions of stigmatization <sup>d</sup>																						
				Context of stigmatization <sup>c</sup>							Experiences of stigmatization			Bodily dimension				Hidden and feared stigma			No subjective stigma <sup>e</sup>					
				Clinic	Chemo	Radiation	Rehab	Aftercare	Family	Friends	Job	Sexual rooster in stigma	Only the yard	Ignorance	Scar	Change of hair	Image in body	Emaciated	Questioning glances	Being the odd one		Receiving different treatment				
5	87	Diploma	First time (S,H)	1	np	np	np	1	1	1	1	x	x													
9	73	LS certificate	First time (S,C,A,R,H)	1	1	1	4	1	1	1	2	x	x													
11	66	LS certificate	3x Relapse (S,C,A,H)	1	1	1	np	1	1	1	2	x	x	x	x				x					x		
12	50	Diploma	First time (S,C,A,H)	1	2	999	np	1	1	1	2		x													
14	79	LS certificate	First time (S,H)	1	np	np	np	1	1	1	1	x												x		
16	61	Diploma	First time (S,C,A,R,H)	3	1	1	3	1	1	1	2	x		x					x	x				x		
18	59	Diploma	First time (S,C,A,H)	1	1	1	np	1	1	1	1	x	x													
19	57	LS certificate	First time (S,C,A,R,H)	1	1	1	1	1	1	1	1		x	x		x										
22	88	IS certificate	First time (S,C,A,R,H)	2	2	1	2	2	1	1	1														x	
28	61	IS certificate	First time (S,C,A,R,H)	1	1	1	1	1	1	1	2		x	x	(x)	x		x						x		
31	70	LS certificate	First time (S,C,A,R,H)	1	1	1	1	1	1	1	2		x	x	(x)	x				x						
32	54	IS Certificate	First time (S,C,A,R,H)	4	2	2	2	2	1	2	2	x	x			x					x					
36	69	LS certificate	First time (S)	1	np	np	np	1	1	1	1														x	
43	41	LS Certificate	First time (S,C,A,R,H)	2	1	1	1	1	1	2	3	x	x												x	
48	73	IS certificate	First time (S,H)	999	999	999	999	999	999	999	999														x	
52	59	IS Certificate	Relapse (S,C,A,R,H)	1	2	2	1	1	3	3	3	x		x											x	
55	51	Diploma	First time (S,C,A,R,H)	1	1	999	999	fut.	1	1	2			x							x					
63	74	Diploma	First time (S)	1	np	np	np	1	1	1	1		x													
67	74	LS certificate	First time (S,H)	1	np	np	np	3	1	1	1	x	x	x						x					x	
74	75	999	First time (S,A,H)	1	np	1	np	1	1	1	1	x	x		(x)										x	
77	63	Diploma	First time (S,H,R)	1	np	np	999	1	1	1	2				(x)		x									
78	60	LS certificate	First time (S,C,A,R,H)	1	1	1	1	1	1	3	5	x	x	x		x					x				x	
82	56	IS certificate	First time (S,C,A,R,H)	4	3	2	fut.	999	3	3	1	x	x	x												
87	80	IS certificate	First time (S,H)	1	np	np	np	1	1	1	2		x													x
91	65	Diploma	First time (S,H,R)	2	np	np	1	1	1	1	1	x	x	x		(x)										
95	49	LS certificate	First time (S,A,R,H)	1	np	1	1	1	1	1	2	x														
99	55	Diploma	First time (S,C,H)	1	1	np	fut.	fut.	1	1	2	x	x	x	x						7	3	3		x	
<b>Total</b>				2	1	0	2	1	2	3	3	16	18	12	3(8)	4(5)	2	1			7	3	3		3(10)	

Note. <sup>a</sup> Key Education: Diploma = Vocational-/ university entrance diploma; LS Certificate = Lower school certificate; IS Certificate = Intermediate school certificate; 999 = missing

<sup>b</sup> Key Disease-related characteristics: First time = breast cancer for the first time; Relapse = relapse of breast cancer; S = surgery; C = chemo therapy; A = adjuvant radiation; R = rehabilitation; H = hormone therapy

<sup>c</sup> Key Context of stigmatization: quantitative stigma results of Table 2 per patient; np = not provided therapy; 999 = missing; fut. = treatment in the future; Intensity of stigmatization: 1 = never, 2 = rarely, 3 = sometimes, 4 = often, 5 = always

<sup>d</sup> Key Dimensions of stigmatization: qualitative stigma results per patient; x = stigmatization experienced within this dimension

<sup>e</sup> Key No subjective stigma = self-reporting that no stigmatization was experienced

## Discussion

This study aimed to determine how MBCP feel about suffering from a “woman’s disease”. To address this research question, it investigated (a) the surroundings in which the stigmatization is experienced; (b) the kind of stigmatization experienced; (c) how, from the patients’ perspective the stigmatization can be reduced; and (d) if there is a typology of different stigma types in terms of the level of stigmatization.

The results reveal that MBCP feel stigmatized in different settings within the cancer care system as well as in social surroundings. The men mention more stigmatization in the cancer care system and by female breast cancer patients within the care system than in their close social environment, based on the qualitative data. The quantitative data reveals a different picture, as most stigmatization was significantly experienced within the working environment, followed by stigmatization in the cancer care system — within rehabilitation. The reasons for this difference may be an issue of measurement. In general, stigma rates in the quantitative analysis are low. In comparison to the other rates, those of exclusion within rehabilitation and working environment are higher. Nevertheless, they are not high absolutely. Another explanation for this difference in the qualitative and quantitative results may be that stigma was measured indirectly, by the feeling of exclusion. Maybe for MBCP, feeling excluded is not the same as feeling stigmatized. For example, in the working environment the men might feel excluded because they are no longer participating in the lived-in working environment after their cancer diagnosis, but this does not have to mean that they feel stigmatized by colleagues and superiors. Results of other studies support this interpretation of the results, as they indicate that there is low stigmatization in the work context (Ernst, Mehnert, Taubenheim et al., 2017; Fife & Wright, 2000).

Transferring the aspect of feeling excluded to the other high rate of stigma (i.e., rehabilitation), it can mean that MBCP are feeling excluded from the group of female breast cancer patients because they are not part of this group. In the absence of a specialized rehabilitation center for MBCP, they are going to the same institutions as women do and mostly constitute a minority among the female breast cancer patients. MBCP reported that often they are not allowed to visit the same programs as female breast cancer patients. For many MBCP it is the first time to be in such close contact with female breast cancer patients within rehabilitation programs. All these aspects

mentioned may lead to the feeling of being excluded as a man in a rehabilitation surrounding that is dominated by women and designed for female breast cancer patients.

In the context of the private social surroundings, it was observed that MBCP experience significantly most stigma or exclusion within the work-related context. A reason this feeling is much higher than in other social surroundings, such as family or friends, may be connected to the role within the working environment. When getting ill, the role expectation as a working person can no longer be fulfilled, which may lead to stigmatization. At the same time, this role loss can be seen as a social effect of stigmatization, as Link and Phelan (2001) state within their theory of labeling approach. Stigmatization in the work-related context is not only the case for breast cancer but an issue of cancer in general (Ernst, Mehnert, Taubenheim et al., 2017). A man might assume that he cannot continue to fulfill his role of feeding his family, which can lead to self-stigmatization. The working environment is not very intimately connected to the person, unlike friends or the family. Within those closer social environments, there is often more understanding towards the individual's needs and worries and the efficiency aspect does not have the same priority as within the working context.

Referring to the different dimensions of stigmatization, it was identified that the category *Experiences of stigmatization* was most prevalent among the patients. It includes aspects demonstrating the unique position of the men regarding gender aspects. Many men feel they are in an exclusive position (*Being the only rooster in the yard*), which can be regarded as a positive kind of stigmatization because the men experienced more attention from the providers than other (female) patients did. Men are also experiencing *Sexual stigmatization*, as breast cancer is known as a typical women's disease among the providers and the other patients. As a result, providers act according to these role expectations and regard MBCP as women initially. There is confusion about the role expected of a breast cancer patient if the disease is not automatically connected with femaleness anymore. This confusion is intensified by the fact presented within the category *Ignorance*, such as breast cancer in men is mostly unknown.

In relation to the *Bodily dimension*, the visible aspects of the disease, such as the scar on the breast or the loss of hair, were perceived differently in men. Pituskin et al. (2007)

report similar results, stating that men differ in perceived stigmatization because of the scar. The loss of hair has not been mentioned in any studies on MBC so far, maybe because hair loss is seen as a typical problem for female (breast) cancer patients. Trusson and Pilnic (2017) note that hair loss can be very traumatic for female breast cancer patients, but physicians often underrate it. As some men within this study demonstrate, losing hair can also be a problem for MBCP especially losing the beard, as it is a typical element of masculinity. As a disease becomes outwardly visible (e.g., formation of the scar on the breast or the loss of hair after cancer therapy), it often interferes with the social interactions because from this point on, one is identified as being sick and cannot fulfill one's role expectations in society as a functioning member of society (Parsons & Turner, 2005; Reuter, 2015). Cancer patients are seen as goners, who came back to life (Holmberg, 2005; Reuter, 2015). Physicality is gaining in importance in performance-oriented societies, not at least because of the boom in health and fitness with its corresponding ideal of beauty (Reuter, 2015), and does not stop when it comes to fulfilling the roles of gender seen as typically female or male. Breast cancer can produce changes in body image, as some men feel emaciated due to the loss of physical strength (maleness) by cancer therapy.

In terms of indirect stigmatization, MBCP mentioned receiving questioning glances from other female patients and feeling observed within this women-dominated area of breast cancer care. This feeling may arise because breast cancer is connected with femaleness in society and being a man in this breast cancer care surrounding does not correspond to the social norms. As Hohmeier (1975) describes, stigmatization takes place to protect the social norm as well as the own identity – within this context – of female breast cancer patients.

Therefore, MBCP feel self-stigmatization, sensing they are intruding into a women's area, and women or female breast cancer patients want to protect their identity as breast cancer patients and hence consider MBCP as intruders.

Some MBCP sensed they were receiving different treatment than female breast cancer patients. Prior studies arrived at similar outcomes, as MBCP felt ignored by physicians (Pituskin et al., 2007) or experienced isolation in treatment because they had to use separate entrances and waiting rooms in some clinics (Donovan & Flynn, 2007).

To reduce stigmatization in the future, the participants wish for awareness and equality of cancer care, so that breast cancer is not seen as an only woman's disease anymore. In concurrence with the literature, increased awareness is needed to make the disease more public in general and in the cancer care system, as ignorance of MBC is a major issue within those areas (Iredale et al., 2006; Pituskin et al., 2007; White et al., 2011). For equality in breast cancer care, the results revealed that the needs of MBCP should be considered in cancer care, in the form of gender-neutral documents and information materials. Similarly, other studies advocate the creation of breast cancer information material (France et al., 2000; Pituskin et al., 2007) or separate sections (Williams et al., 2003) within the information specifically for men.

The three stigma groups identified in the research help to explain stigmatization of MBCP as they reveal the effect of age and extent of cancer treatment: With increasing age, the experienced stigmatization seems to decrease, as demonstrated by the contrary groups, the "not stigmatized" and the "stigmatized". Within the "not stigmatized" cohort, the comparatively older age of the participants seems to protect from stigmatization because of some aspects that are connected with older age. First, all of the men are retired, so they are not in the work context anymore and hence do not experience exclusion. Second, at a relatively older age one may have more experiences with cancer, as people in the social surroundings may have cancer so it may seem more normal. Additionally, two of the men experienced cancer themselves, so they may have become hardened by that experience. A third explanation may be the perception of masculinity changes with age. Therefore, the men within this group might not have experienced any sexual stigmatization. Maybe the gender factor is not that important anymore for them compared to men of a younger age. Also, one of the men within this group is already suffering from another disease, which is dominating his life, so he did not attach too much importance to breast cancer. In contrast, the men within the "stigmatized" cohort have the youngest age on average and some of them are still working, so they also have a higher potential to feel excluded compared to the "not stigmatized" participants, who are retired.

Concerning the effect of extent of cancer treatment, the participants within the group of the "not stigmatized" had not had a long period of treatment and consequently had few points of contact (Bloom, Stewart, Chang, & Banks, 2004) with the cancer care

system. In addition, none of them experienced chemotherapy or adjuvant radiation, so they did not lose any hair, and as such, the disease is not visible for at first sight. It is only when the shirt is removed that the scar is visible. Among the three groups, the “stigmatized” members experienced more cancer treatment, so they have more potential to be stigmatized: first, within the different steps of cancer care and second, from the effects the treatment has on the body like losing hair because of chemotherapy. Therefore, the disease becomes visible for everyone in society and increases the potential for stigma attacks, as already discussed above within the category *Bodily dimension*.

The literature recognizes that sociodemographic aspects like age can play an important role when it comes to stigmatization (Bloom et al., 2004; Moyer & Salovey, 1996). In some studies, associations with educational level and stigmatization were reported (Holman, 2015; Tripathi et al., 2017), but this effect cannot be observed in the current investigation.

Interestingly, some men reported in the interviews that they have not experienced any stigmatization over the course of their breast cancer journey, as Table 3 reveals (category: *No subjective stigma*). However, aspects of stigmatization could be identified within the interviews. Maybe this difference in subjective perception and narration is because those participants have not purposely acknowledged their experiences or feelings of stigmatization, and hence, only appear within narrations. Besides, it can be regarded as a kind of protective mechanism to consider oneself as not stigmatized.

It can be recognized that other cancer patients are also stigmatized — not only MBCP — and there might exist worse stigmatizations than the men within this study experienced. As already stated, stigmatization is very individual and subjective. If someone conceives something as stigmatizing, it can sometimes also be connected with the individual’s perception. However, this study did not set out to compare the level of stigmatization of several groups. Instead, it aims to call attention to the problem of stigmatization of MBCP to raise the awareness of this issue among society and caretakers. The study also wanted to point out, from a patients’ perspective, how their experienced stigmatization can be reduced. It can be appreciated that stigmatization



of MBCP often happens by mistake and in good faith, which highlights the importance of raising public awareness of the disease.

### *Strengths and Limitations*

The strengths of this study are the diverse sample (due to the purposeful sampling), the high response rate of the MBCP, and the mixed methods design. Accordingly, the results could be described from a broad perspective and for a large sample of MBCP in Germany.

As limitations, it can be stated that this study is restricted to the German cancer care system because the health-care systems vary dramatically; therefore, the results cannot be transferred unrestrictedly to other countries with different cancer care systems. Furthermore, the data of disease-related characteristics and breast cancer treatment was gathered by the participants, introducing the possibility of mistakes if the participant's knowledge is not accurate.

### *(Practical) Implications*

As MBCP experience most stigmatization in the cancer care system, there is a need to devise strategies to manage this, including a need for creating awareness and providing equality of cancer care so that breast cancer is not seen only as a woman's disease anymore. As MBCP within this study stated, specific needs of MBCP should be considered in cancer care.

Overall, there is a need for publicity and increased attention of MBCP to prevent stigmatization. As mentioned by Ernst, Mehnert, Taubenheim, et al. (2017), cancer-specific approaches must be taken against stigmatization to avoid psychological and psychosocial problems, because every group of cancer patients has different needs (Ernst, Mehnert, Dietz, Hornemann, & Esser, 2017). For MBCP, one idea is to place a blue stripe on the pink-colored breast cancer ribbon as a symbol for MBC. Moreover, the restricted connection of breast cancer with femaleness must be dismissed, which demands a gender-neutral affiliation of breast cancer — in society as well as in breast cancer care.

Body image problems of MBCP like the scar on the breast or the loss of hair should also be taken more seriously by the health-care professionals, as these can be traumatic for all cancer patients. For instance, periwigs for male patients should be

offered by physicians. Implications for further research are the multivariate testing of the stated hypotheses, notably, the correlation of stigmatization, age, and intensity of cancer care.

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### **Notes**

1. Within this standardized questionnaire, the men were asked for their willingness to conduct an interview. If they agreed, the men were called, during which their desire was confirmed, and an appointment made for a personal interview.
2. The interview guideline included questions about how the participants experienced the cancer care during their course of disease, which persons were involved in what way, how the participants experienced their disease, and how they deal with their breast cancer disease. The narrative-generating introducing question was: "If you think back to the time before you were diagnosed with breast cancer. What was it like when you noticed signs of physical change / possible illness in your body for the first time?"

3. Because we did not know if the participants meet the exclusion criteria before having contacted them personally, we sent the questionnaire to all interested MBCP we had established contact with. Also, the declaration of consent was sent with the questionnaire.

The questionnaire was sent before the interviews were conducted to facilitate a purposeful selection of participants for the qualitative interviews as described earlier.

4. Coding was inductive from the data and deductive based on the literature, especially from Link and Phelan (2001) and Reuter (2015).
5. For coding of stigmatization within the interview material, a systematic coding system was developed. Every aspect within the transcripts that described stigmatization, according to the definition stated within this article, was coded as stigmatization (among the related subcategories). Further information about the coding process is available from the authors.
6. For interpreting Table 3: The qualitative and quantitative results of stigmatization and as well demographic aspects of participants are merged within this table per participant. The heading *Context of stigmatization* comprises the results of the quantitative analysis of experiences of stigmatization during the course of cancer treatment and in private surroundings described in Table 2. The values 1-5 demonstrate the intensity of stigmatization (1) *never*, (2) *rarely*, (3) *sometimes*, (4) *often*, and (5) *always*. The aspect *Dimensions of stigmatization* shows the results of the qualitative analysis from the interview per participant, which are the five main categories of stigmatization that could be found within the interviews. The category *No subjective stigma* means that the participant stated within the interview that he experienced no stigmatization concerning his breast cancer disease.

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### 3.2 Social Support of Male Breast Cancer Patients – A Mixed Methods Analysis<sup>5</sup>

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**Abstract**

The aim of this study is to explore the social support of male breast cancer patients (MBCP) in Germany. In particular, three aspects of social support focus on: a) the used resources within social environment, b) the received support, and c) the differences of used social support between MBCP. A mixed-methods design is applied including data of qualitative interviews (N=27 MBCP) and a written questionnaire (N=100 MBCP). MBCP use different resources of support from their social environment like partners, family, friends, colleagues, other breast cancer patients, and medical experts. Mostly, MBCP receive emotional and informational support. They often receive emotional support from their partners and informational support from medical experts. Different types of social support usage can be identified dependent on age, occupation, and severity of disease. The older the patients and the less the disease severity, the less social support MBCP use. Within cancer care, partners and the closer social environment should be included more as they are a key resource for MBCP. As health-care professions might also be an important resource of support for MBCP, further research should examine this resource.

**Keywords**

health services research, (male) breast cancer (MBC), mixed methods, social support

## Introduction

Breast cancer is the most common type of cancer in women (Bray et al., 2018) and is often treated as a typical women's disease in Western societies. Nevertheless, with a rising number (Giordano, 2018; White et al., 2011), 1% of new breast cancer diagnoses in Western societies occur in men (Miao et al., 2011,). The disease is rare in men and because of its feminization, patients experience psychosocial burdens such as emasculation (da Silva, 2016; Donovan & Flynn, 2007; France et al., 2000; Iredale, Brain, Williams, France, & Gray, 2006; Swergold, Murthy, & Chamberlain, 2014), stigmatization (Andrykowski, 2012; Bunkley, Robinson, Bennett, & Gordon, 2000; da Silva, 2016; Midding et al., 2018), and isolation (Bunkley et al., 2000; Iredale et al., 2006). Some male breast cancer patients (MBCP) experience clinical burdens, as many health-care providers are never confronted with an MBCP. Because of the rareness of disease (Fentiman, 2018), it can be assumed that experiences in dealing with MBCP are missing among health-care providers. Since clinical studies of breast cancer are mostly based on clinical studies and needs of female breast cancer patients, needs of MBCP are hardly represented (Giordano, 2018; Gómez-Raposo, Zambrana Tévar, Sereno Moyano, López Gómez, & Casado, 2010). Because of these aspects, social support is important for MBCP, as it may buffer the burdens. For cancer patients in general, social support positively affects the mindset and the healing process (Helgeson & Cohen, 1996) and coping (Kim, Han, Shaw, McTavish, & Gustafson, 2010). Social support is associated with less depression (Hann et al., 2002). Kulik and Mahler (1993) state that male cardiac patients were released from the hospital faster if they received social support. Especially for (female) breast cancer patients, social support reduces the stress of cancer diagnosis (Israel & Schurman, 1990) and enhances emotional well-being (Dukes Holland & Holahan, 2003; Dunkel-Schetter, 1984).

Former studies identify that it is important to investigate social support of MBCP in particular, as men are different from women with regard to this dimension in many ways: MBCP without support of a partner experience more psychological distress and are less able to fight. In contrast, for women, partner support has no effect on psychological support and coping (Taniguchi, Akechi, Suzuki, Mihara, & Uchitomi, 2003). Several studies report that MBCP receive less social support than female breast

cancer patients (da Silva, 2016; Donovan & Flynn, 2007; Iredale et al., 2006; Robinson, Metoyer, & Bhayani, 2008). Moreover, MBCP often do not talk about their diagnosis beyond their closest social environment to prevent stigma and embarrassment (Andrykowski, 2012; Bunkley et al., 2000; da Silva, 2016; Midding et al., 2018).

Social support describes the interaction between two or more people with the aim to change or to make a problem of a person more bearable if nothing can be changed (Schwarzer, 1996). There are three dimensions of social support: *emotional support* like caring, compassion, spending consolation, warmth and physical affection; *instrumental support* like tangible assistance or material goods; and *informational support* like imparting information or giving advice (Knoll et al., 2011; Schwarzer, 1996). The sources of support can be extensive. However, most processes of social support take place in closer social relationships, such as in a partnership, with family, or in friendships (Schwarzer, 1996). Accordingly, referring to this concentration, the present study concentrates on this (closer) social environment of MBCP. As studies of the state of research report, MBCP receive mainly support from their partners (Pituskin, Williams, Au, & Martin-McDonald, 2007; France et al., 2000; Iredale et al., 2006), both in terms of doctor visits, as well as in the course of the disease (Williams et al., 2003). France et al. (2000) also identify that female friends suffering from breast cancer can be a resource for receiving informational support, and some MBCP have the feeling that no professional support is needed. Concerning support groups as a source of social support, MBC-specific support groups are rare (Bunkley et al., 2000; da Silva, 2016) and men often do not want to attend female breast cancer support groups (da Silva, 2016; Iredale et al., 2006; Robinson et al., 2008; Smolin & Massie, 2002).

Keeping those aspects in mind, the state of research gives an idea of available support resources of MBCP, but not in a satisfying way. It further remains unclear what dimensions of social support MBCP use (emotional, informational, instrumental) and which specific resource they use for the different dimensions of support. Therefore, the aim of this study is to investigate a) what resources of social support MBCP in Germany use within their social environment, b) what kind of social support (dimensions) they use, and c) if different types of support-seeking and support-using behavior in MBCP concerning the heterogeneity of used resources can be identified.

## **Methods**

### *Study Design*

This study is part of the N-MALE project conducted between 2016 and 2018 in Germany. It was funded by the German Cancer Aid and approved by the Ethics Committee for Bonn (Germany).

A mixed-methods analysis was used to explore and understand the needs of MBCP. Within this triangulation, both methods, qualitative and quantitative, were treated equally (Carell, 2005). Therefore, semistructured interviews and a postal survey were conducted. The postal survey was conducted before the interviews. For further information on the methods used in the N-MALE project, please have a look at Midding et al. (2018; open access publication).

### *Study Inclusion and Participants*

To take part in the study, MBCP had to have a confirmed breast cancer diagnosis (C50.x or D05.x) and a written declaration of consent. Exclusion criteria comprised a missing or withdrawn written declaration of consent or aspects that complicate interviewing (e.g., speech or comprehension problems, advanced cancer, psychosis, and dementia).

Access to the field was given through certified breast cancer centers, the Men with Breast Cancer Network (Netzwerk Männer mit Brustkrebs e.V.), and personal contacting of interested MBCP.

For qualitative data, sampling was carried out using the strategy of theoretical sampling of Glaser, Strauss and Paul (2008) to find as significant and contrastive cases as possible. Therefore, the postal survey was used to find participants who varied in sociodemographic aspects, facts of disease, experiences during treatment, and contact with support groups. Patients were included into the study until theoretical saturation was reached.

### *Data Collection*

Collection of data was between April 2016 and October 2017.

### *Qualitative data*

For the semistructured face-to-face interviews, an interview guideline structured along the steps of cancer therapy was created and pilot tested. The interviews lasted between 1 and 2 hours and were audio recorded and anonymized transcribed following approved standards (Fuß & Karbach, 2014).

### *Quantitative data*

Social support was measured by the validated Modified Medical Outcomes Study Social Support Survey short scale (mMOS-SS) by Moser, Stuck, Silliman, Ganz, and Clough Gorr (2012). It refers to social support within the private social environment and has two subscales: emotional support and informational support. The scale contains eight items (four items for each subscale) to be answered on a five-point scale from 1 (*never*) to 5 (*always*).

The questionnaire included instruments of support accomplished by self-generated factual items. The first instrument measures the contact of MBCP with other breast cancer patients (BCP) with three dichotomous (yes/no) items: (1) "Do or did you have contact with other men with breast cancer?" (2) "If no, have you wished to have contact with other men with breast cancer?" (3) "Do or did you have contact with women with breast cancer?" A fourth item measures MBCPs' needs of support from support group: (4) "Do you need support from support groups since your breast cancer diagnosis?" with the answer categories: (a) "Already taking part in support group", (b) "No I do not need the support of a support group",; and (c) "Yes I need the support of a support group" (unmet need).

Aspects of the disease (time since breast cancer diagnosis, first time or relapse, received cancer treatment) and sociodemographic data (age, family status, children, education, and occupation) were collected with factual single items.

## **Data Analysis**

### *Analysis of qualitative data*

The transcripts were analyzed using summarizing qualitative content analysis<sup>1</sup> (Mayring, 2016). Coding was done deductively and inductively using MAXQDA software version 12.2.1 (VERBI GmbH, 2016). An alternating interviewing and

analyzing process was applied, where categories were developed and tested within the following interviews to make purposeful sampling possible (Helfferich, 2011).

#### *Statistical analysis of quantitative data*

For statistical analysis, SPSS version 25 (IBM SPSS Statistics, 2017) was used and descriptive statistics (cross-tables, quantities) were applied. The social support scale was analyzed according to the “Social Support Survey Instrument Scoring Instructions” (RAND Health). A score for each item and a score index for each subscale were computed. A higher score indicates a higher amount of support (RAND Health).

#### *Mixed-methods analysis*

For mixed-methods analysis, data of N=27 MBCP with both available qualitative and quantitative data were included. The data were merged, containing codes of qualitative analysis (dimensions of social support) and data of quantitative analysis such as sociodemographic aspects (age, family status), disease related aspects (breast cancer for the first time/ relapse, treatment in cancer care system), contact with other BCP (contact with support group, contact with male/female BCP). Scores of the social support scale (emotional and instrumental support) per person and per type were included.

## **Findings**

### *Sample Characteristics*

N=100 MBCP sent back an evaluable questionnaire (cleared response rate=85.5%). N=27 interviews with MBCP were conducted from this sample. Sociodemographic and clinical characteristics of the quantitative sample and the (qualitative) subsample are presented in Table 1.

### *Resources of Social Support in Social Environment*

Findings of the qualitative interviews demonstrate that MBCP use different resources of social support in their social environment (non-professional support; Figure 1). Within the close social environment, they use their partner, family, and friends. Within their wider social environment, resources like colleagues<sup>2</sup> and other male or female BCP or support groups are used. Some MBCP have personal contact with medical

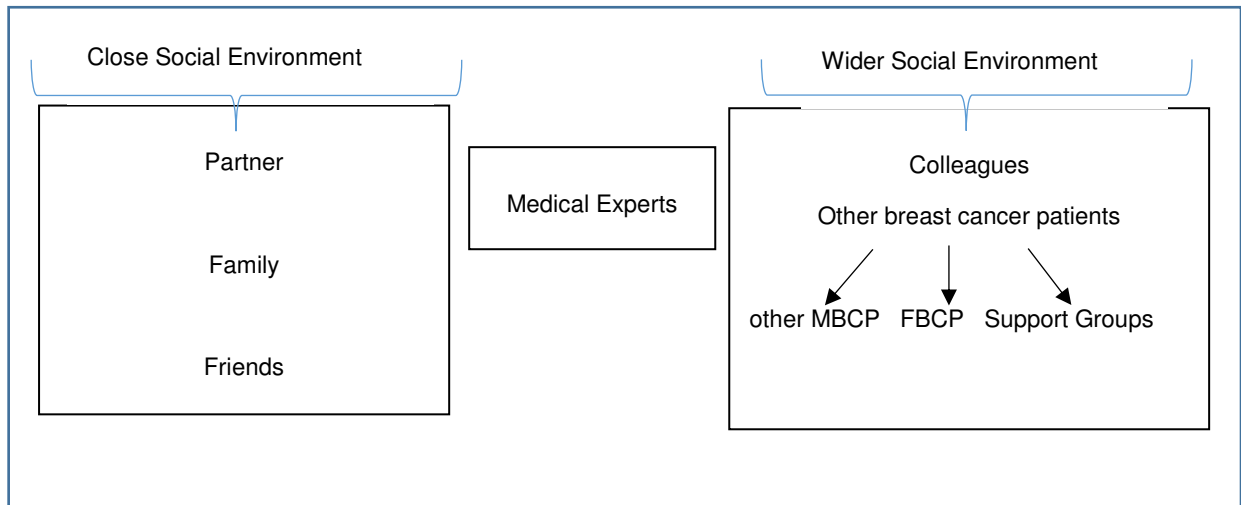
experts who can be a source of social support for them. Medical experts can be classified into closer and wider social environment, as they can be part of both (e.g., a family member with a medical background or colleagues/ other BCP with a medical background).



**Table 1.** Demographic and Clinical Characteristics of Participants

<b>N=100 (N=27)</b>					
<b><i>Sociodemographic characteristics</i></b>					
	<b>N (N)</b>	<b>% (%)</b>	<b>Mean (Mean)</b>	<b>Min (Min)</b>	<b>Max (Max)</b>
<i>Age</i>					
In years			66.9 (64.8)	39 (42)	89 (89)
Missing	2 (1)	2 (3.7)			
<i>Children</i>					
Yes	79 (20)	84.0 (76.9)			
No	15 (6)	16.0 (23.1)			
Missing	6 (1)	6.0 (3.7)			
<i>Living with a partner</i>					
Yes	82 (19)	87.2 (79.2)			
No	12 (5)	12.8 (20.8)			
Missing	6 (3)	6.0 (11.1)			
<i>Education (multiple answers)</i>					
No school certificate	2 (0)	2.0 (0.0)			
Lower school certificate	41 (11)	41.8 (42.3)			
Intermediate school certificate	27 (8)	27.6 (30.8)			
Vocational diploma/ university entrance certificate	35 (11)	35.7 (42.3)			
Missing	2 (1)	2.0 (3.7)			
<i>Occupation</i>					
Full time	26 (7)	26.8 (26.9)			
Part time	4 (1)	4.1 (3.8)			
Occupational rehabilitation	2 (0)	2.1 (0)			
Certified sick	12 (6)	12.4 (23.1)			
(Early) retired	54 (12)	55.7 (46.2)			
Unemployed	1 (0)	1.0 (.0)			
Missing	3 (1)	3.0 (3.7)			
<b><i>Disease-related characteristics</i></b>					
	<b>N (N)</b>	<b>% (%)</b>	<b>Mean (Mean)</b>	<b>Min (Min)</b>	<b>Max (Max)</b>
<i>Time since first diagnosis</i>					
In years			3.6 (4.1)	<1 (<1)	20 (17)
Missing	5 (1)	5 (3.7)			
<i>Newly diagnosed</i>					
Yes	92 (24)	95.8 (96.0)			
No	4 (1)	4.2 (4)			
Missing	4 (2)	4.0 (7.4)			
<i>Types of treatment received</i>					
Surgery	97 (27)	97.0 (100)			
Chemo-therapy	56 (16)	56.0 (59.3)			
Radiation therapy	65 (16)	65.0 (59.3)			
Anti-hormone-therapy	75 (22)	75.0 (81.5)			
I don't know	2 (1)	2.0 (3.7)			
Missing	0 (0)	0 (.0)			

<sup>a</sup> Notes: Quantitative sample N=100; qualitative sample (*subsample*) N=27. Numbers of qualitative sample in brackets

**Figure 1. Resources of Social Support of Male Breast Cancer Patients**

<sup>a</sup> Notes: MBCP = Male breast cancer patients; FBCP = Female breast cancer patients

Basic requirements to use resources are availability and access. Most participants have a partner (quantitative sample = 87.2%, (qualitative sample = 79.2%)) and children (84.0% (76.9%); Table 1). Support from colleagues depends on the occupational position. Since participants are 66.9 (64.8) years on average and only 30.9% (30.5%) are still working (full-time and part-time), the resource of colleagues for social support is not available for most participants. Concerning other BCP, most men have contact with female breast cancer patients (63.2% (73.1%); Table 2). In comparison, 24.2% (46.2%) of the participants have contact with other MBCP. The majority of participants who had not had any contact with other BCP so far do not want to have contact with them (contact with MBCP 82.4% (64.3%) and contact with female BCP 90.0% (75.0%)). As it is known from personal interviewing, medical experts are not available for every participant, as not everyone knows a person working in the medical system within their social environment.

Regarding contact with other BCP within a support group, 15.3% (40.0%) of the participants are part of a support group; the majority of participants are not (84.7% (61.5%); Table 3). Further, most participants state that they do not wish to be part of a support group (96.3% (93.8%)).

Qualitative results suggest that there are different reasons why participants do not want support from a support group: They may feel no personal need to have contact with other BCP or they are afraid of depressing talks and do not want to be confronted with the disease any more:

“I had no interest in that. [...] I said: Okay I had it, but it's over. Basically, I don't want to [...] always be confronted with it. [...] they partly described their complaints there” (ID no. 91)

**Table 2.** Contact of Male Breast Cancer Patients to Other Breast Cancer Patients

<b>Contact with other breast cancer patients</b>	N (N)	% (%)
<b>Contact with other male breast cancer patients</b>		
Yes	24 (12)	24.2 (46.2)
No	75 (14)	75.8 (53.8)
Missing	1 (1)	1.0 (3.7)
<i>Among those with no contact</i>		
No but contact wanted	13 (5)	17.6 (35.7)
No and no contact wanted	61 (9)	82.4 (64.3)
Missing	2 (0)	2.0 (0.0)
<b>Contact with female breast cancer patients</b>		
Yes	60 (19)	63.2 (73.1)
No	35 (7)	36.8 (26.9)
Missing	5 (1)	5.0 (3.7)
<i>Among those with no contact</i>		
No but contact wanted	3 (1)	9.1 (25.0)
No and no contact wanted	30 (3)	90.0 (75.0)
Missing	6 (3)	6.0 (11.1)

<sup>a</sup> Notes: Quantitative sample N=100; qualitative sample (subsample) N=27. Numbers of qualitative sample in brackets.

**Table 3.** Male Breast Cancer Patients' Needs of Support from Support Group

<b>Need of support from support group</b>	N (N)	% (%)
<i>Already taking part in support group</i>		
Yes	15 (10)	15.3 (40.0)
No	83 (16)	84.7 (61.5)
Missing	2 (1)	2.0 (3.7)
<i>Among those with no contact</i>		
<i>Need of support group</i>		
Yes	3 (1)	3.7 (6.3)
No	79 (15)	96.3 (93.8)
Missing	3 (0)	3.0 (0.0)

<sup>a</sup> Notes: Quantitative sample N=100; qualitative sample (subsample) N=27. Numbers of qualitative sample in brackets

## *Dimensions of Social Support*

### *Emotional support*

As the results of the qualitative analysis identify, emotional support is the support the participants receive the most. The key resources of this support are widely spread over the close social environment such as partner, family and friends, colleagues and other BCP. The resources differ in functions.

Many participants state their partner is the key resource of support, when it comes to talking about the disease and emotional or personal aspects:

*“My wife is also the first contact person for me, of course.” (ID no. 43)*

Furthermore, they spend emotional support by being present, backing, creating an everyday atmosphere, and giving confidence and hope:

*“Everything went on as before. It wasn’t a huge thing: “And you are sick.” [...] Everything was going on. I knew the disease was a burden for the family. But they somehow dealt well with it. So I did not get the impression that this would be a thing for the family that took their joy in life. [...] And of course that’s something that helped me a lot.” (ID no. 16)*

Friends are also there for talking and being around but also *“to blow away the cobwebs”* or to be insightful:

*“How they contacted me, how OFTEN they contacted me. They just came over and knocked at the door: “We just wanted to check on you.” ” (ID no. 19)*

Colleagues spend emotional support by understanding the patient’s situation or if the relationship is more intense even as a conversation partner:

*“The reactions were extremely positive. So JUST from my students, that was really great and gave me a lot of power.” (ID no. 99)*

Other male or female BCP or other patients of support groups send recovery wishes, give confidence, and keep them grounded. They are further a resource for communication about the disease and disease related aspects, as they are in a similar situation:

*“So now I have written again that I'm in the clinic now. And they've answered briefly and wished me all the best.” (ID no. 11)*

Some participants completely avoid emotional support and do not want to talk about their disease: *“I'm not like that, [...] that I absolutely need someone to talk to.” (ID no. 67)*

### *Informational support*

Informational support is the second most received form of support (after emotional support). It is more often provided by persons who are experts because they have either a medical background or experience with the disease and therefore can provide MBCP with information.

Partners and family members can give informational support independent of their medical or breast cancer experiential background, as they are often the ones who send the men to the doctor:

*“And then my wife actually said: “Your left nipple looks a bit different than the right one.” Pulled in so easily inside. The edge of the nipple. I didn't even think about that [...]. But still, that was actually the trigger then. And then I actually went to my family doctor.” (ID no. 55)*

In the personal surrounding, family members with a medical background can play an important role. They have a special position because they belong to both systems, the personal surrounding and the health-care system. In this case, they can give advice, for example, to health-care facilities or act as a medical counsellor and explain ambiguous medical statements (also being a translator) to the participants or give information on breast cancer:

*“My sister is a doctor. That's also my best guide. She isn't a medical specialist. She's an anesthesiologist, but of course has contacts. And of course, then can enlighten directly.” (ID no. 99)*

Other BCP play a key role for MBCP if they have and want to have contact with them: For some men they are the first person of contact when it comes to breast cancer specific aspects, not at least because of their availability compared to providers. Moreover, they are important for MBCP to inform themselves about experiences of the

disease and to get some advice (e.g., concerning health-care facilities). They also have a function as translators for medical information:

*“It was is a bit like that, you just think, when you talk to an AFFECTED guy, that’s quite different from talking to doctors. And that has really been good for me.” (ID no. 43)*

Other participants avoid informational support, as they do not want to have too much information:

*“I’m not the person who reads everything in particular. I’ve already said in the beginning. But I take things the way they come. And it doesn’t help me if there is a lot of information [..]. I have to help myself.” (ID no. 63)*

#### *Instrumental support*

The third dimension of social support is the least used by participants and is mainly focused on the private surrounding – mostly on the partner. However, the participants also use support of colleagues and other BCP.

Instrumental support is usually given by the partner, for example, by providing a shuttle service, joining medical consultations, providing body care, caring for the participants, taking care of everything, subordinate themselves, and providing social security:

*Wife: “He can’t wash himself properly. So I washed him. I also put some cream at him at the moment, I cut his fingernails and toenails.” (ID no. 82)*

The family has the role of providing shuttle service, being present at medical consultations and taking care:

*“As the diagnosis was breast cancer he said [father]: “I drive you, I support you, I’m with you.” And so he got involved very, very much and later on to chemotherapy. He always picked me up here, drove me there, then at noon, when I was through, then I could call him and he picked me up.” (ID no. 12)*

Friends are there as well for shuttle service and offer support, which the men often did not make use of:

*“Yes, so I was asked from my [...] friends if there is something to do somewhere, where I just can’t do physically or anywhere, or I need support: “If you need someone or something”– that actually worked.” (ID no. 55)*

Colleagues offer flexibility within the job or concerning working conditions:

*“Within the therapy, I always went back to work when I felt better. So I talked to my employer and he said it’s okay for him, I can do that.” (ID no. 16)*

Other BCP provide instrumental support, as they help accelerate the processes within the health-care system or help with the transfer to the breast cancer centre:

*“In fourteen days or three weeks, the result was there. [...] That was fine, it was fast. It’s not as long as some women do. Okay, I just put pressure, that’s logical. And the [naming chairman self-help], of course, too.” (ID no. 67)*

The role of medical experts concerning instrumental support is to connect MBCP with providers, to select a rehab center, or to offer medical and cosmetics support:

*“So fortunately, she is a doctor herself, an internist. She’s working with a health insurance company as a consultant doctor has since contact with rehab clinics. WITHOUT her, I wouldn’t have done it that way.” (ID no. 77)*

On the opposite side, some MBCP state that they do not need any instrumental support:

*“I didn’t have any physical limitations. I was immediately completely active in life again. I think that’s a bit different between people. There are many who, I say in quotation marks, who care for their illness and are affected by their illness. And for me is actually [...] I’ve felt no impact because after the surgery, after three, four days you have no pain anymore.” (ID no. 87)*

### *Social Support Scale*

Scores for the availability of social support range from 1 to 5 within the two subscales of emotional and informational support. The mean of emotional support is 4.39 (4.49) and of informational support is 4.42 (4.41) (Table 4).

### *Types of Used Social Support*

The participants (N=27) can be divided into different types concerning their usage of social support resources within the dimensions of social support (emotional, informational, instrumental). Table 5 presents this mixed-method matrix.<sup>3</sup> Sociodemographic and disease-related characteristics of the types in total are presented in Table 6.<sup>4</sup>

**Table 4.** Availability of Social Support of Male Breast Cancer Patients (N=100)

<i>Subscale social support</i>	<i>N (N)</i>	<i>Range</i>	<i>Min (Min)</i>	<i>Max (Max)</i>	<i>Mean (Mean)</i>	<i>SD (SD)</i>
<i>Emotional support score</i>	98 (25)	1-5	1 (1)	5 (5)	4.39 (4.49)	.841 (.459)
<i>Instrumental support score</i>	96 (25)	1-5	1 (1)	5 (5)	4.42 (4.41)	1.008 (1.043)

<sup>a</sup> Notes: Reference of the subscales: Moser et al. (2012)

Three different types can be identified: Type 1 does not use any social support during the breast cancer disease. Nevertheless, the added group score of the mMOS-SS support scale identifies that the participants within this group mostly have someone who offers them emotional (mean = 4.4) and instrumental support (mean = 4.5). With an average age of 78 years, it is the oldest type and consists of two participants. Concerning aspects of disease, both participants within this type have breast cancer for the first time and have just received cancer care in the form of surgery (100%) or surgery and hormone therapy (50%; Table 6). Concerning their occupational situation, the men within this type are certified sick or are retired.

The second type uses different resources of social support from one to three categories of social support during the process of disease. They use a minimum of two resources for support and the number of used supports falls between those of the two other types. The total score of the social support scale indicates that they mostly have someone who offers them social support, but the mean value of support is the lowest among the groups (mean emotional support = 4.2, mean instrumental support = 4.4). With 17 participants, it is the biggest type, with a younger age on average compared to Type 1, 66.6 years. Regarding aspects of the disease, these men have breast cancer for the first time (94.2%) or are experiencing a relapse (5.8%). In cancer care, the treatment is wide spread, as some men had only surgery, while others also had chemotherapy



(52.9%), adjuvant radiation (58.8%), hormone therapy (94.2%), and rehabilitation (58.82%). Most men within this group are not working (retired 52.9% or certified sick 23.5%).

The third type receives social support from two or all three categories of social support. This type uses the most different resources of support and has the highest amount of used support. The availability of social support has the highest mean value of the types (mean emotional support = 4.7, mean instrumental support = 4.8). There are eight men within this type. It is the youngest type with an average age of 57.5 years. All participants within this group have breast cancer for the first time (87.5%) or are experiencing a relapse (12.5%) and are being given a high amount of cancer care on average, as most of the participants received several steps of cancer treatment (chemotherapy 87.5%, adjuvant radiation 75.0%, hormone therapy 100.0%) Regarding the occupational situation, half of men within this group are working (full time 37.5%, part time 12.5%) and the other half does not (retired 25.0% or certified sick 25.0%).





## Discussion

The aim of this study was to determine the social support of MBCP within their social environment: What resources do they use? Within which dimensions do they receive support? Are there different types in MBCP concerning the heterogeneity of used resources?

### *Resources*

MBCP use a variation of resources for social support. Within their closer and wider social environment, they “use” their partner, family, friends, colleagues, other BCP, and medical experts. Concerning the partner, most participants have a partner, who is the key source of social support for some of them. This is congruent with the findings of Iredale et al. (2006) and France et al. (2000), who state that MBCP mostly use their partner and female friends for social support. Regarding medical experts within the social environment, they are of particular importance for social support, as they involve a trust-based relationship and provide information. As Ernstmann et al. (2017) report, a close and trusting relationship between patient and provider leads to patient enablement for oncology patients. Furthermore, if there is a medical expert within the social environment, the access and availability is much easier than contacting an unknown professional within the cancer care system. Because of this double role of medical experts, it might be easier for them to explain difficult medical topics to the patients, as they can also speak on a personal level, not only the professional one. In addition, medical experts are very important because of the rareness of the disease. Often, there is not very much information available for MBCP about the disease and many men do not know about breast cancer in men before they get the disease.

Whether the working environment can be used as a source of support depends on the occupation and the atmosphere within the working place of the individual participant and if it is established there or possible to talk about personal problems. As former studies report, social support within the working environment can improve health of employees (Jung et al., 2012; Liukkonen, Virtanen, Kivimäki, Pentti, & Vahtera, 2004). Regarding other BCP, most participants have contact with female BCP, while contact with MBCP is quite rare. This might be connected with the rareness of the disease. In social surroundings as well as within the cancer care system, MBCP often only meet

female BCP. Furthermore, the majority of the participants do not want to have contact with a support group. That is congruent with the results of Pituskin et al. (2007). Concerning rare diseases, support groups are often the only option to meet other patients – in this case MBCP. There is a specific support group for men, but it is not clear how well known this support group is for MBCP. Within the interviews, some men stated that they did not know about a male-specific support group for breast cancer, although it can be found on the internet. Maybe the knowledge of the existence of this support group would increase the interest of some MBCP to have contact with a support group. As former studies report, MBCP would prefer support groups only for men (Brain, Williams, Iredale, France, & Gray, 2006; da Silva, 2016; Farrell et al., 2014; Iredale et al., 2006). Patients who experienced a male breast cancer (telephone) support group recommend it to other patients for coping with the disease (Farrell et al., 2014). It needs to be taken into account that some participants state that they do not want personal contact with other BCP because they are afraid of depressive talks and do not want to be confronted with the disease anymore. So, it might also be an issue of coping whether someone wants to attend a support group or not. As a study by Batenburg and Das (2014) reported, (female) BCP who cope with their emotions more actively have more benefit from a support (online) Sgroup than patients who cope less actively with their emotions.

### *Dimensions*

The availability of social support is generally high for MBCP as the social support scale demonstrates. Qualitative and quantitative data identify that emotional support is the most used and most available resource for the participants. It is mostly provided within the closer social environment such as family and friends, but also by other BCP and colleagues who can spend emotional support to the patients. This usage of different resources is in contrast to the results of Pituskin et al. (2007), as they reported that there is no emotional support outside the family. Maybe family means privacy. This private atmosphere and trust can also be created within other social relationships such as other BCP or colleagues. But not every patient wants to be emotionally supported; there are also men who avoid emotional support. It can be assumed this avoidance is an aspect of gender, as Quincey, Williamson, and Winstanley (2016) discussed:

Expressing emotions is seen as a feminine characteristic (Moynihan, 2002) and especially men following “traditional hegemonic masculinities” do not want to assume a “feminine” practice of coping (Quincey et al., 2016).

The necessity of informational support might be related to the low informational level of male breast cancer. As it is information based, this dimension is more focused on experts of (male) breast cancer who can provide information on the disease, such as persons with a medical background (medical experts) or people who have personal experiences with the disease, such as other BCP. Thaxton, Emshoff, and Guessous (2005) support those results, as they identified that for prostate patients, men benefit from the information exchange of support groups. MBCP differ in the level of information needs, as there are MBCP who do not want to receive too much information. This might also be associated with an avoiding coping style (Brain et al., 2006).

Within instrumental support, there is the largest variance, as some men receive instrumental support and others do not. Qualitative data reveal that instrumental support is less used by MBCP. This might be explained by the fact that some of the participants were in an early stage of the disease and they do not yet feel the need for instrumental support. If instrumental support is used, it is mostly focused on the private surroundings, such as the partner. Friends provide it, but men do not make use of it very often. Nevertheless, the majority of the participants state that instrumental support is available for them if needed (quantitative data).

### *Typification*

The three types of social support usage demonstrate the variance of social support between MBCP. Since the types differ in age, occupational situation and received cancer therapy, there might be an association between age, occupational situation, severity of the disease, and social support. Concerning age, the older the patients are, the less (resources of) support they use. Therefore, Meléndez, Mayordomo, Sancho, and Tomás (2012) reported that coping strategies in problem solving and social support seeking decrease with age. Reasons for this might be that the resources of support become less, as the family gets smaller (death of partner and other family members, children move out) and the social contact points often decrease (e.g., no

colleagues in retirement). In addition, studies report that life satisfaction increases with age (starting from middle age; Wolff & Tesch-Römer, 2017). Even with health restrictions, life satisfaction can be high in old age (Staudinger, 2000). This could be another reason for less support seeking of elderly MBCP. Nevertheless, all patients within this group (and within other groups as well) state that they have the availability of social support if they needed it (emotional, emotional/ informational, and instrumental). Another reason might be the image of masculinity of this generation of men, as they do not want to talk about personal problems and emotions. As Mendélez et al. (2012) identify, older men especially use a more problem-solving coping style, which is less emotional than the coping style women of this age use. Furthermore, women look more intensively for social support. With increasing age and beginning retirement, one is not any longer within a working environment, which is why the occupational situation might have an influence on the availability of the resource of other colleagues.

Regarding severity of disease, there are indications that patients who receive a higher amount of therapies often use more resources of social support. As a disease gets more serious, more topics and worries arise that need to be handled or coped with by the patients. For example, they cannot do daily routines anymore and therefore they need (instrumental) support from others. Corbin and Strauss (1991) state in their trajectory model that more social support is needed especially in severe cases of chronic disease within phases of transition (e.g., from stable to instable phase).

Furthermore, the use of social support also depends on one's need of support and coping style. As Type 1 demonstrates, the patients mostly have the availability to use social support, but they do not use it during their breast cancer journey. Quincey et al. (2016) state that some MBCP stay away from several coping strategies to protect their masculinity, as the disease is feminized itself. It can be assumed that patients from this sample who totally reject social support want to protect their masculinity, as seeking social support is associated with a female coping style, since women are more socialized for seeking support (Moynihan, 2002; Quincey et al., 2016). Also, this avoidance of social support may cause stigmatization, as some MBCP want to hide their diagnosis (Midding et al., 2018).

### *Reflection and Study Limitations*

Reflecting the relationship between interviewer and participants of this study, taking part in the study, and doing a personal interview was also some kind of social support (especially emotional support) for some of the participants. This was confirmed by statements of the patients or by concluding their behavior within or after the interview as a feeling of "There is someone who is interested in me and my worries." It can be concluded that social support is missing somehow for some MBCP.

Within this study, it was not possible to differentiate between actual and personally felt support, as suggested in the literature (Schwarzer, 1996). The support could only be measured by a personal estimation of the participants. For a measurement and a comparison of the actual and personal felt support, an observation would have been necessary.

### *Practical Implications and Further Research*

As the partner and the close social environment (family and friends) play an important role for the social support of many MBCP, it should be included more in cancer care. Currently, relatives of cancer patients can be involved in the discharge management in the hospital or rehabilitation stay in Germany (Deutsche Vereinigung für Soziale Arbeit im Gesundheitswesen, 2013).

As the specific support group for MBCP in Germany is not known to all patients, health-care professionals should provide the patients with this information. As support groups provide a lot of informational and emotional support, they can be useful for patients who look for that kind of support. Furthermore, social support groups can be recommended to MBCP who are confronted with the disease and are willing to talk about the disease and share experiences with other MBCP.

Following the results of this explorative cross-sectional study, they can be considered within longitudinal studies or interventional designs to find out what effect social support or support groups have for coping with the disease or for life satisfaction of MBCP.

Previous research identifies that social support by health-care providers can be an important resource for cancer patients (e.g., (Dunkel-Schetter, 1984). In the future,



social support from health-care professionals needs to be examined, as it can be assumed that they are also an important resource of support for MBCP.

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Please contact the corresponding author for additional research materials and further information.

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### **Notes**

1. „Qualitative content analysis defines itself [...] as an approach of empirical, methodological controlled analysis of texts within their context of communication, following content analytical rules and step by step models, without rash quantification” (Mayring, 2000). The text is interpreted following the research question in the form of categories. Within the analysis, the categories were established and revised (Mayring, 2000).
2. The term “colleagues” includes all people within the working environment of a person (e.g., coworkers, supervisors, students).
3. For typification, the interviews were analyzed for the usage of social support. A score including three factors was created: a) number of used resources, b) number of mentioned support types within the interviews, and c) the number of used categories for social support (emotional, informational,

instrumental). The values of those aspects were added for every participant and divided by three. As the maximum total value reached by the participants is 5.0, it represents the total maximum. Dependent on the total value, participants were scaled into three different types: Type 1 total value = 0, Type 2 = 1.0-3.0, and Type 3 3.1-5.0.

4. When comparing the percentage quotations of sociodemographic or disease-related characteristics among types, it needs to be taken into account that the three types do not have the same size.

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### 3.3 Male Breast Cancer Patients' Perspectives on Their Health Care Situation: A Mixed Methods Study

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**Abstract**

Male breast cancer is rare. No information was available on how male breast cancer patients (MBCPs) experience the health care they receive in Germany in a setting that is tailored to women. The aim of this study was to explore the health care situation of MBCPs from their perspectives.

The study follows a mixed methods design, combining quantitative data from a standardized written questionnaire with qualitative data from personal interviews. Descriptive statistics (quantitative data) and qualitative content analysis (qualitative data) were used for data analysis.

Questionnaires completed by 100 and personal interviews of 27 MBCPs were analyzed. Several men reported mainly positive experiences while others experienced shortcomings. These included delays in diagnosis, health care provider uncertainty about treatment (tamoxifen, radiation therapy), experiences of stigmatization, and issues of continuity of care including unclear responsibilities for aftercare and access challenges to breast-cancer-specific care in gynecology settings.

The awareness of male breast cancer needs to be increased among the public, health care providers and researchers in order to avoid delays in diagnosis and reduce stigmatization and uncertainty about treatment. Health care structures ensuring access to gynecology care and clear responsibilities for aftercare need to be established.

## Introduction

Breast cancer in men is rare. It has been estimated that about 1% of all breast cancer diagnoses are established in men [1,2]. For the U.S., 2550 new cases of male breast cancer (MBC) and 480 deaths due to the disease were estimated for 2018 [3]. In Germany, 650 new cases of MBC and 134 MBC-related deaths occurred in 2014 [4]. The average age of diagnosis is higher in men than in women (71 vs. 64 in Germany) [4]. Studies indicate that age-adjusted incidence rates have increased over recent years [1,5,6], while overall mortality has significantly decreased [7,8]. Giordano [1] has recently summarized current knowledge on epidemiological, pathological, clinical and treatment-related data for MBC.

Female breast cancer (FBC) receives much public attention, and breast cancer centers offer well-established structures for routine care that are specifically tailored to female medical and psychosocial needs. In contrast, there is little public awareness of MBC [9], and specifics regarding the treatment and needs of male breast cancer patients (MBCPs) are rarely known. Although a section on the treatment of MBC has recently been included in breast cancer clinical guidelines in Germany [10], due to the lack of clinical studies, treatment is still mainly based on the knowledge obtained from treating FBC [1,7,11–13].

Several studies conclude that there are differences in health care provision for FBCPs versus MBCPs. These include, for example, a later stage at diagnosis and a worse overall survival of MBCPs compared to FBCPs as well as different behavior of health care providers' (HCPs) when dealing with MBCPs compared to FBCPs [14,15]. Due to the rareness of the disease, HCPs may have never been confronted with an MBCP [12]. Lack of HCP knowledge and experiences may affect MBCPs' experiences and uncertainties throughout their cancer journeys. Yet, only a few studies have investigated the psychosocial burden and experiences of MBCPs. MBCPs report experiences of stigmatization [16] and problems regarding their sexual identity and body image [15,17]. Many MBCPs perceive the health care situation as specialized to women, especially in terms of information provision [18–20]. Moreover, MBCPs were found to not participate in supportive measures [19,21]. A qualitative study found that MBCPs have a need for increased public and provider awareness, more gender-

specific information and the inclusion of MBCPs in research [21]. Kowalski et al. [22] found a higher health-related quality of life in MBCPs than in FBCPs but lower scores in the subscales covering aspects of “role functioning”, indicating the need for early psychosocial interventions. Several studies recommend adapting health care provision to the needs of MBCPs [9,20,21,23–25].

Nevertheless, to the best of our current knowledge, there is no study specifically investigating the entire process of MBC care in Germany. Based on this background the N-MALE study (male breast cancer: patients’ needs in prevention, diagnosis, treatment, rehabilitation and follow-up care) was initiated. First results of the N-MALE study found health care disparities between different states in Germany in terms of access difficulties to gynecology treatment and MBCPs experiencing stigmatization [16, 26]. In this study, the main results of the N-MALE study are presented. It was aimed to determine the following: How do MBCPs experience the health care situation with respect to every step in the cancer care process from diagnosis to treatment (surgery, chemotherapy, radiation therapy, [anti-]hormone therapy), rehabilitation and aftercare?

## **Materials and Methods**

### *Study Design*

The N-MALE study was conducted between 2016 and 2018 and funded by the German Cancer Aid. A cross-sectional mixed-methods observational design was applied combining quantitative data from a standardized postal survey and qualitative data gathered in personal interviews. A mixed methods approach was chosen since the combination of quantitative and qualitative methods can be used for a comprehensive analysis of the research question: quantitative data allow a comprehensive assessment of factual experiences of a larger sample size. The qualitative approach allows an exploratory assessment of the experiences of MBCPs in Germany and was applied in view of the lack of knowledge in this area. Qualitative data assessment further allows to get a deep insight into MBCPs’ experiences. Moreover, using both types of data enables a reciprocal validation of results. The Ethics Committee of the Medical Faculty of the University of Bonn has given approval for the study. Midding et

al. [16] reported detailed information on the methods used in the N-MALE study (open access publication).

### *Sample*

MBCPs were recruited throughout the country via German breast cancer center hospitals, via the self-help network for MBCPs 'Männer mit Brustkrebs e.V.' and public notices in the media between 2016 and 2017. Inclusion criteria for survey participation were the availability of a written declaration of consent and a confirmed diagnosis of breast cancer (C50.x or D05.x). Additional exclusion criteria for personal interviews were determined as aspects that impede setting up an interview and included speech or comprehension problems, deafness, advanced cancer, psychosis, dementia, and related issues like pain, and difficulties in concentrating. Data from the postal questionnaire were used for the sampling of MBCPs for personal interviews. The sampling for personal interviews was established following the theoretical sampling approach by Glaser and Strauss [27]. This approach aims to identify and include signifying and contrasting cases (e.g., in terms of sociodemographic and disease-related characteristics). Detailed information about sampling criteria used in this study is described elsewhere [16]. Interviews were conducted in a reciprocal process of data collection and data analysis until theoretical saturation was achieved.

### *Quantitative Data: Measures and Analyses*

The written questionnaire included validated instruments assessing psychosocial and medical aspects of care and self-generated factual items (open and closed questions). They included questions about HCPs being involved in the diagnostic process and aftercare (multiple choice answer categories and open answer possibility), types of treatment received and the location of treatment (e.g. hospital that is connected to a breast cancer center or not), management between interfaces (e.g. recommendation for rehabilitation measures) and questions about the dates of the first consultation of a physician due to symptoms related to breast cancer and a first suspicion of breast cancer by a physician. A time span was calculated (date of the first suspicion of breast cancer by a physician up to the date of the first consultation of a physician due to symptoms related to breast cancer). Socio-demographic data were collected with factual single items. The questionnaire was pilot-tested in four pretests with MBCPs.

SPSS version 24 (IBM SPSS Statistics, 2016) was used for descriptive statistical analysis.

### *Qualitative Data: Measures and Analyses*

A semi-structured interview guideline was developed by the interdisciplinary research team, based on Helfferich [28]. The interdisciplinary research team developed and pilot-tested the guideline with 3 MBCPs. It included both open questions on every health care setting along the cancer care continuum and a thematic guidance note with pre-set thematic areas and an opportunity for follow-up questions. Interviews were conducted face-to-face and lasted between 1 and 2 h. Interviews were audiotaped and transcribed in accordance with standardized transcription practices [29]. Two scientists of the research team at the University Hospital of Bonn analyzed the transcripts of the interviews following the method of summary qualitative content analysis [30]. Coding was inductive and deductive in order to summarize themes that are of importance for MBCPs in the process of cancer care. Results were discussed in a research workshop at the University Hospital of Bonn. MAXQDA Standard 12 (VERBI Software, 2016) software was used for data analysis.

## **Results**

### *Sample Characteristics*

124 MBCPs wished to participate in the study. 3 of these MBCPs were excluded because they did not meet inclusion criteria. Reasons for drop out included death or a wish to withdrawn participation because of bad health. 4 MBCPs participated in pretests of the written questionnaire and were therefore excluded from further data collection. 117 MBCPs were thereby eligible for participation and received a postal questionnaire. 103 MBCPs returned a questionnaire to the research team (response rate 88.0%). Reasons for nonresponse included death of the participant, change of health situation or withdrawal from participation. In addition, 3 questionnaires had an amount of missing values of  $\geq 30\%$  and were excluded from further analysis. Thereby data of 100 MBCPs were included for data analysis (cleared response rate=85.5%). Personal interviews were conducted with 27 of these patients. Table 1 gives an

overview of the sample characteristics of both the quantitative and the qualitative sample.

### *Experiences of MBCPs over the Course of the Disease*

Below, quantitative and qualitative results are reported in separate sections along all steps of cancer care (diagnosis, treatment, rehabilitation and aftercare).

### *Results of Quantitative Data Analysis*

Table 2 summarizes the results, showing how often which HCPs were involved in the diagnostic process. Primary care (70.7%) and breast cancer centers (75.8%) were the most prevalent HCPs in the diagnostic process. Figure 1 shows the results concerning the time span (in days) between the first consultation of a physician due to symptoms related to breast cancer and a first suspicion of breast cancer by a physician. The mean value was 44.9 days and the median was 0 days (SD=186.4; min-max=0-1388 days). In most cases (62.8%), the physicians assumed that symptoms might be related to breast cancer during the first consultation. 89 (94.7%) men were treated in breast cancer center hospitals and 5 (5.3%) men were treated in hospitals not connected to a breast cancer center (missing values n=6). Results show that 39 of the 56 MBCPs who had chemotherapy (73.6%; n=3 missing values) and 36 of the 65 MBCPs who had radiation therapy (57.1%, n=2 missing values) received it at the same hospital where they underwent surgery. 53 men (54.6%) participated in a rehabilitation measure (2 outpatient; 51 inpatient). Rehabilitation was recommended by primary care physicians (n=9), outpatient gynecologists (n=1), treating hospitals (n=32) (e.g., social counselling service, physicians), outpatient oncologists (n=6) and others (n=1 health insurance company, n=3 personal initiative). 81 MBCPs indicated that they received aftercare. Table 3 provides an overview of the HCPs involved in aftercare. Aftercare mostly took place in the same hospital where the surgery had been conducted (59.5%), followed by outpatient gynecology (23.4%).

**Table 1.** Sociodemographic and disease-related sample characteristics

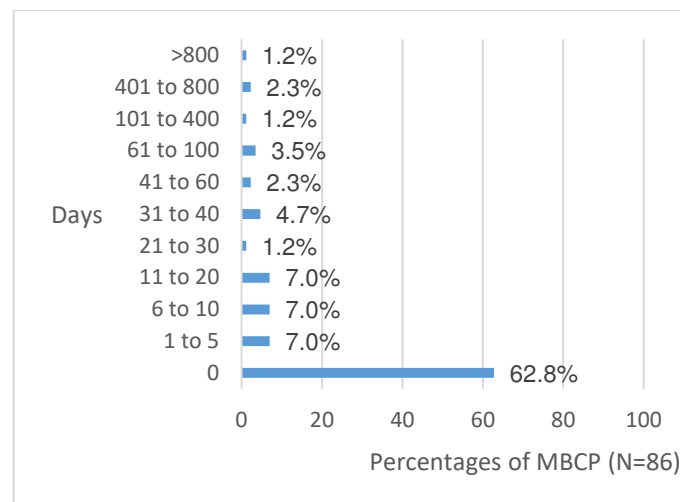
	N (N)	% (%)	Mean (mean)	Min (min)	Max (max)
<i>Sociodemographic characteristics</i>					
Age in years (missing 2 [1])			66.91 (64.8)	39 (42)	89 (89)
Living with a partner (missing: 6 [3])					
Yes	82 (19)	87.2 (79.2)			
No	12 (5)	12.8 (20.8)			
Children (missing 6 [1])					
Yes	79 (20)	84.0 (76.9)			
No	15 (6)	16.0 (23.1)			
Education (multiple answers) (missing 2 [1])					
No school-leaving certificate	2 (0)	2.0 (0.0)			
Lower school-leaving certificate	41 (11)	41.8 (42.3)			
Intermediate school-leaving certificate	27 (8)	27.6 (30.8)			
General or subject-specific university entrance qualification	35 (11)	35.7 (42.3)			
<i>Disease-related characteristics</i>					
Types of treatment received (multiple answers possible) (missing 0 [0])					
Surgery	97 (27)	97.0 (100)			
Chemotherapy	56 (16)	56.0 (59.3)			
Radiation therapy	65 (16)	65.0 (59.3)			
(Anti-)Hormone therapy	75 (22)	75.0 (81.5)			
I don't know	2 (1)	2.0 (3.7)			
First diagnosis (missing 4 [2])					
Yes	92 (24)	95.8 (96.0)			
No	4 (1)	4.2 (4.0)			
Time since first diagnosis (in years)(missing 5 [1])			3.61 (4.1)	<1 (<1)	20 (17)

Quantitative sample n=100; data of the qualitative sample (n=27) in brackets.

**Table 2.** Health care providers involved in the process of diagnosis

Medical disciplines (n=100)	Yes		No		Missing n
	n	%	n	%	
Primary care	70	70.7	29	29.3	1
Outpatient gynecology	20	20.2	79	79.8	1
Mammography center	43	43.0	57	57.0	0
Breast cancer center	75	75.8	24	24.2	1
Other (open answers: dermatology, urology, surgery, hospital, radiation center, wife, personal initiative)	19	19.2	80	80.2	1

More than one answer possible



**Figure 1.** Time span (in days) between the first consultation of a physician due to symptoms related to breast cancer and the first suspicion of breast cancer by a physician

**Table 3.** Health care professionals involved in aftercare (n=81)

	Yes		No		Missing n
	n	%	n	%	
Primary care	13	16.9	64	83.1	4
Gynecology (outpatient)	18	23.4	59	76.6	4
Treating hospital (surgery)	47	59.5	32	40.5	2
Other hospital	4	5.2	73	94.8	4
Oncology (outpatient)	19	24.1	60	75.9	2
Other	2	2.6	74	97.4	5

More than one answer possible

### *Results of the Qualitative Data Analysis*

Concerning the diagnostic phase, MBCPs reported that they went to see their primary care physician because they or their spouses noticed symptoms like lumps, a bleeding nipple or pain in the breast. The physicians' reactions differed. Some primary care physicians responded quickly and thoroughly and soon expressed the necessity for further examination or even directly suspected breast cancer. Consequently, they immediately referred the men to gynecology, mammography or radiology centers:

"Well, my primary care physician already suspected that it could be breast cancer, and therefore, first mammography". (ID 12)

Other men reported that their primary care physicians did not express any suspicion that the symptoms might indicate breast cancer. Either they referred the men to



physicians who do not provide breast cancer care (e.g., dermatologists) or they recommended a wait-and-see approach. Some of these misjudgments resulted in delays in the diagnosis. In some cases, the diagnosis was established as late as months or years after the first symptoms arose and partly due to the personal initiative of patients and their spouses:

“Since April 2009, I have been annoying my primary care physician with it and he did not RECOGNIZE it as such.” (ID 17) (diagnosis in 2013 at a clinic due to personal initiative)

Some gynecologists misjudged the situation as well:

“(…) the physician who did the surgery at (name of the place) breast cancer center, she hasn’t done ANYTHING BUT breast cancer in women for 20 years. And of course ALWAYS with imaging performed before the examination. And I … before that, I was at a SPECIALIST practice for women that offers screening. And BOTH of them got it wrong. Both didn’t quite laugh at me but smiled about me when I asked ‘Could it also be breast cancer?’” (ID 87)

Furthermore, men reported access difficulties to gynecology care in the diagnostic phase (and aftercare, see below). Outpatient gynecology practices and hospital gynecology departments including breast cancer centers rejected MBCPs due to billing issues related to treating men:

“(…) the secretary from the gynecology department called and said: ‘(…) Well, you are a man; we cannot treat that here at the gynecology department at the HOSPITAL.’ (…) And I thought, well I will call a local outpatient gynecologist. They also directly told me: ‘We do not treat men in general.’ (…) So I slowly started to get nervous.” (ID 77)

In the treatment phase - during hospital stay - some men were satisfied overall and did not report any situations differing from routine care. Men felt safe with providers and well informed. Some men reported that they felt in a “special position” during the hospital stay, with the perception of this “special position” differing between men. Several men perceived it in a positive way: They experienced a high level of attention by HCPs, in some cases even leading to the perception that they received more

comprehensive treatment (e.g., having a conversation with the chief physician, staying in a single room, more physicians being involved in treatment).

"(...) especially since I did not have to worry. 'Hopefully they did everything right.' (...) The surgeon said: 'So many eyes were watching,' and he said: 'Then, you CANNOT possibly do anything wrong.'" (ID 17)

In contrast, other men did not feel comfortable with their "special position", e.g. because a single room had to be arranged for a man at the gynecology department:

"Then the women were split up in all these other rooms and I suddenly had a four-bed room for myself. They made an insane effort there" (ID 23)

Others experienced stigmatization during the hospital stay which is described elsewhere [16].

Men did not report any positive or negative experiences that were attributable to being an MBCP during chemotherapy. With regard to radiation therapy, differences from routine care were identified in terms of the indication for radiation therapy for MBCPs. Men criticized that physicians were unsure whether radiation therapy was indicated:

"(...) I had gotten some information myself and I had only read that, in women, if the surgery is not breast conserving, radiation therapy is not carried out after chemo. He (the physician from radiology) was of the opinion that you had to hit it with radiation too. (...) And then the chief of the department came and said to me, I looked at your documents again and I do not think that we should do it. Said you should treat men and women the same and you do not do it in women." (ID 12)

Treatment with tamoxifen ([anti-] hormone therapy) was associated with side effects and uncertainty. Side effects included sweating, hot flushes, aching muscles, joint pain, tingling fingers, sleep disorders, memory loss, sexual dysfunctions, etc. Some men stopped taking tamoxifen due to side effects, while others did not experience any. Men reported HCP uncertainty concerning the side effects, effectiveness and administration period of tamoxifen.

"(...) no one could tell me what the side effects were, of tamoxifen." (ID 18)

One of the main aspects men reported about the rehabilitation phase was their experience of being the only man around women and how the staff dealt with this. Positive experiences included the opportunity to exchange experiences with female and male (breast cancer) patients as well as positive reactions of female patients:

“And for this, I was just glad, just to hear, how are the WOMEN? How do THEY deal with tamoxifen? Do they also take tamoxifen or do they have anything ELSE? Do they ALSO have the side effects, err, like I have? And, err, I have to say quite honestly, I was VERY glad that I was in a group, just to exchange experiences.” (ID 18)

One man reported being the only man in a group of women and felt like women were thinking:

“This person, it’s a man, but it’s actually just an affected person.” (ID 22)

In contrast to these experiences, other men felt exotic and excluded from group therapies for women by the clinical staff:

„No. (-) At the water aerobics, I was also the only one. Because they said (-) they do not want, that the women with breast cancer, that there is a, a man. Because some women (-) may not want that (-), yes. I say: "OKAY", I say: (-) "So I'm alone in the swimming pool.” (ID 44).

Positive experiences during after care included trust in physicians, regular examinations and comprehensive instructions about self-examination of the breast. Aftercare was perceived as routine investigations by some men:

“And then the aftercare examination is a process like going to the TÜV (routine car inspection). So routine, (-) nothing more.” (ID 42)

After care was also connected to negative experiences such as an unclear distribution of responsibilities: Some HCPs did not know who was responsible for aftercare, e.g., the breast cancer center did not give any information about where aftercare could take place:

“Because somehow nobody really knew, or it was different for everyone.” (ID 15)

Other HCPs did not feel responsible:

“I have survived the cancer now, the surgery, survived the chemo and survived the radiation and now I have no doctor who does the aftercare.” (ID 18)

Moreover, instructions for after care were lacking. Some MBCPs did not receive any instructions about self-examination of the breast or how often they have to see a physician for aftercare. In this context, men reported that their personal initiative was important. MBCPs independently looked for physicians for aftercare; they had to figure out how often aftercare was necessary and asked for instructions for self-examination of the breast:

„(...) I always ask for it (instructions for self-examination) but she said ‘No, we don’t need it.’” (ID 16)

Access challenges as reported above in the “diagnosis” section were also prevalent during aftercare [26].

### **Discussion/Conclusion**

The aim of this study was to explore the health care situation of MBCPs in Germany from the patients’ perspectives. Results from the analyses of the quantitative and qualitative data of our large and diverse sample of MBCPs show that several aspects of care are well integrated into existing structures of general breast cancer care. However, also shortcomings in several phases of cancer care were identified that are quite similar to those known from other rare diseases [31].

Results from quantitative data analysis reveal that in two thirds of cases, physicians suspected a breast cancer at the first consultation. Qualitative data support these results as several men reported a fast reaction of physicians. However, results from qualitative data analysis also reveal delays in diagnosis which were mainly caused by HCPs’ misinterpretation of breast cancer symptoms and access challenges to gynecology care. France et al. [23] also found delays in diagnosis in MBCPs that likely reflect that some HCPs are unfamiliar with the clinical picture of MBC. Thomas [9] found that HCPs never talked about the topic of MBC with their male patients even if they had a positive family history of breast cancer. Considering these results and the fact that primary care was involved in the diagnostic process in 70% of our sample, the importance of primary care as a first point of contact in prevention and patient

education is clearly underlined. Moreover, partners and spouses seem to play an important role in noticing breast cancer symptoms in our sample, an observation that is congruent with other findings [19,32] and emphasizes the importance to increase public attention for MBC. As results from quantitative data analysis show, most men were treated (surgery, chemotherapy, radiation therapy) in hospitals connected to a breast cancer center. Qualitative data analysis reveals that MBCPs mainly felt safe with the providers. Some MBCPs even felt that they received special attention due to the rarity of their disease, partly even making them feel safer and more comprehensively treated than female patients. Other MBCPs in turn experienced uncertainty: HCPs were partly unsure whether radiation therapy after mastectomy was indicated in men. This result may be explained by the debate about this indication [11]. Stigmatization was a further theme of importance during the main treatment phase (hospital stay) [16]. Qualitative data analysis further shows that HCPs and MBCPs were unsure about tamoxifen treatment. Some men felt left alone and not informed about tamoxifen. Adjuvant treatment with tamoxifen is considered the gold standard and is associated with an overall better survival in comparison to treatment with aromatase inhibitors [33,34]. Uncertainty about tamoxifen treatment in men might contribute to non-adherence, which is in turn associated with worse medical outcomes, such as shorter time to recurrence (in FBCPs) [35]. Results by Oke et al. [36] support this assumption. They found a high percentage of 61% of elderly MBCPs not continuously taking tamoxifen up to the recommended 5 years. As shown in quantitative data analysis, about a half of the MBCPs participated in an inpatient rehabilitation measure, a slightly lower number compared to FBCPs [37]. Some men reported to feel welcomed by other female patients. Others reported experiences of stigmatization (e.g., exclusion from group therapies). Stigmatization was more often caused by HCP uncertainty than by other patients. Detailed information about stigmatization experiences of our sample of MBCPs is reported elsewhere [16]. Aftercare mostly took place in the same hospital where the surgery had been conducted as shown in quantitative data analysis. However, MBCPs reported in the personal interviews that responsibilities for aftercare were unclear. Some MBCPs even had to insist in order to find a provider who felt responsible for aftercare and figure out on their own how often aftercare examinations were necessary. Moreover, access

challenges to gynecology care occurred as also found during the diagnostic phase. These shortcomings can keep MBCPs from receiving a timely diagnosis or continuous specialized treatment, which in turn may seriously affect patient prognosis and survival [19,38]. Quincey et al. [39] also found MBCPs to be dissatisfied with the lack of specific structures for their aftercare and treatment.

All in all and in contrast to patients with other rare diseases, MBCPs are likely to benefit from the extensive knowledge and existing structures for general breast cancer care. However, shortcomings and insecurities exist, especially during the diagnostic phase and aftercare.

This study has several strengths and limitations. Strengths include the comparatively large sample size of 100 MBCPs, the high response rate (quantitative data), the diverse sample (qualitative data) and the combined analysis of these data, applying a mixed methods design. Limitations of the study include differences between participants in terms of their years since diagnosis. Some participants received their diagnosis several years ago. Hence, there is some risk of recall bias, and the health care situation for MBC might have changed over recent years. Other MBCPs were only recently diagnosed and received their main treatment during the study period. Since their treatment had not been completed, it is not possible to draw any conclusions about whether all participants received the recommended treatment (e.g., aftercare, rehabilitation measures). Moreover, further research may be necessary to see whether the findings translate to other health care systems since health care in Germany is characterized by a separation of the inpatient and outpatient sector. However, a rare disease such as MBC is likely to be associated with HCP uncertainty and missing health care structures in several health care systems.

In order to reduce negative experiences and thereby improve the health care situation for MBCPs, we recommend the following approaches:

- 1) Awareness of MBC among the public as well as within the health care system should be increased in order to avoid delays in diagnosis and reduce stigmatization [16,17,23,40]. Especially primary care providers need to be trained regarding the clinical picture of MBC in order to initiate treatment

processes at an early time. Palpation results at the male breast always require further investigation [41].

- 2) Breast cancer research should include men, especially regarding differences in tamoxifen treatment between men and women and the indication of radiation therapy in men.
- 3) Information material tailored to MBCPs' needs should be developed and provided.
- 4) Responsibilities of providers for aftercare need to be clarified and transitions between different steps in the cancer care continuum need to be clearly managed.
- 5) Unrestricted and comprehensive access to gynecology care for MBCPs has to be ensured [26].

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### **Statement of Ethics**

The Ethics Committee of the Medical Faculty of the University of Bonn has given approval for the study.

### **Disclosure Statement**

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## 4. Discussion

MBCP are a vulnerable group within a care system tailored to women's needs, and there are health inequities (differences in morbidity and mortality) between FBCP and MBCP. Within this cumulative dissertation, three original articles are used to find out what could cause health inequities for MBCP in Germany, and how they can be reduced. Therefore, areas of health burdens (stigmatization), coping resources (social support), and provision of health care (cancer care) are considered.

In the first publication, stigmatization as an indicator for a difference in health burden is regarded. MBCP experience stigmatization as the feeling of "being the only rooster in the yard", gender-discrimination in cancer care, or ignorance of MBC, since the disease is nearly unknown in private and professional surroundings. Aspects of physical changes caused by BC, like scars on the breast or loss of hair, can also have a stigmatizing effect, as they make the disease visible to others. This can affect social interactions, as the person with BC may be perceived as an ill person who may no longer be able to fulfill their social role expectations (Parsons & Turner, 2005; Reuter, 2015). Stigmatization varies with age and number of treatment methods received: younger men and MBCP who have undergone more treatment methods are more stigmatized. These patients have more interfaces to experience stigmatization: first, within working environment, since younger MBCP are mostly working in comparison to older retired patients; second, patients who undergo more treatment methods pass different stages of cancer care system, where stigmatization could take place. Not least, most stigmatization is experienced in working environment and cancer care system. To reduce stigmatization, the participants wish for increased awareness of MBC in the cancer care system and in public, as shown in the literature as well (Iredale et al., 2006; Pituskin et al., 2007; White et al., 2011), and for equality of men and woman in cancer therapy.

The second publication is dedicated to social support of MBCP and the difference in coping resources. Results indicate that the availability of social support is high among MBCP. The partner is a key resource for many MBCP, which is congruent to other research (France et al., 2000; Iredale et al., 2006). Emotional support is mostly received and provided in closer social environments. The second most used support

is informational support, which is often provided from persons who are experts of the disease. Since there is little information on MBC, and patients have unmet information needs (Bootsma et al., 2020), this kind of support is important for many patients. Other patients avoiding too much information on the disease. Contact with other (male) BC patients plays a key role in gaining information and emotional support. A MBC-specific support group can be helpful for patients who are willing to talk about the disease and experiences with other men. Nguyen et al. (2020) came to similar results. MBCP support groups are not known to all participants. Participants use less instrumental support, and support is mostly provided by partners or close family. The use of social support depends on age, occupation, and severity of disease. The older the patients and the less severe the disease, the less social support MBCP use. This is congruent to previous findings (Kümpers & Alisch, 2018), as social contacts outside the family become fewer with age. Some participants do not use social support at all. Avoiding social support might be related to dissociating from “feminine” coping practices, as women are more likely to seek support (Moynihan, 2002; Quincey, Williamson, & Winstanley, 2016).

The third publication refers to a patient perspective on health care situation to show differences in the provision of health care. Shortcomings that are similar amongst rare diseases in general (e.g., just a few specialists, poor information, or uncertainties in drug treatment) can be identified (Eidt et al., 2009).<sup>6</sup> The results indicate that primary care is the first contact for 70% of MBCP in patient education and prevention. Partners and spouses have a central role in the first health care process, as they often observe BC symptoms. Within the process of cancer care, MBCP reported different experiences. Positive experiences concentrated on fast reaction of physicians when it comes to diagnosis and trust in physicians. Shortcomings were experienced especially during the diagnosis and aftercare phases, and included delays in diagnosis by physician’s misinterpretation of symptoms or access challenges to gynecological care within diagnosis and aftercare.<sup>7</sup> Nguyen et al. (2020) also report challenges in gynecological care. The access to gynecological care is regulated inconsistently in

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<sup>6</sup> Even if MBC is not officially a rare disease, it can be categorized due to its rarity and shortcomings similar to rare diseases.

<sup>7</sup> Gynecologists are important specialists for MBCP, since BC is located in the gynecological department (Halbach, Midding, Wesselmann, Würstlein, & Ernstmann, 2018).

Germany (caused of different billing possibilities with health insurance companies in federal states) (Halbach, Midding, Wesselmann, Würstlein, & Ernstmann, 2018). Due to issues of continuity of care and unclear responsibilities within aftercare, patients' initiatives were necessary. Furthermore, some patients experienced their own and their HCP's uncertainty about treatment with tamoxifen, although it is considered the gold standard for overall survival (compared to treatment with aromatase inhibitors) (Fentiman, 2016; Massarweh & Choi, 2016). Sixty-one percent of elderly MBCP shorten the recommended duration of tamoxifen intake (Oke, Niu, Chavez-MacGregor, Zhao, & Giordano, 2018).

Embedded in the medical sociological model of health inequity by Mielck (2005), the three publications clarify that there are differences within the considered areas: health burdens (stigmatization), coping resources (social support), and provision of health care (cancer care). Differences can be seen between female and MBCP in the form of stigmatization due to the lack of knowledge on MBC and feminization of BC, trivialization of physical and mental changes in MBCP, difficulties in accessing gynecological care, inconsistent follow-up regulations, and uncertainty in medication, especially tamoxifen. These differences indicate that gender seems to influence BC treatment. Nguyen et al. (2020) come to similar results. Among MBCP, the age of the patients and the number of treatment steps taken are different with regard to the degree of stigmatization and the use of social support. Consequently, horizontal social inequality, from factors such as gender and age, seems to have an effect on the health inequity of MBCP. Within cancer care, differences can be found particularly in the areas of diagnosis and follow-up care. Those are determined by the correct interpretation of BC symptoms by the treating doctor and the regulation of care at the attending hospital. These differences provide indications of how health inequities of MBCP can be reduced. The scope for further research and implications for health care practice are discussed after the main strengths and limitations of this work are presented.

#### 4.1 Strengths and Limitations

A key strength of this dissertation project is in the methodological approach: It has a mixed methods design, in which qualitative and quantitative data was combined in order to analyze the data in depth with a broad framework (Carell, 2005; Flick, 1992)

to describe results from an extensive perspective. The broad perspective is attained due to purposeful sampling regarding qualitative data. Purposeful sampling was successful, as significant cases could be selected. For the analysis of subjective perspectives, qualitative methods in health services research are regarded as the gold standard and are increasingly used (Karbach et al., 2012; Meyer & Flick, 2011). For the quantitative data, 100 participants was a comparatively large sample of MBCP when considering the incidence of 710 (ZfKD, 2019) cases in Germany per year. Even the response rate was high (85.5% cleared response rate), and affected persons showed a lot of interest in the N-MALE study. Furthermore, an interdisciplinary team of people from the fields of senology, psychosomatics, health sciences, nursing, and self-help was involved in the study. Different perspectives were taken into account when planning, implementing, evaluating, and interpreting the data.

One limitation may be whether the research questions can be answered for MBCP in Germany in a representative manner. The patients surveyed as part of the N-MALE study are well educated and were highly motivated to participate in the study. In order to include MBCP who do not take part in studies for health, educational, or motivational reasons, one could use, for example, routine data from statutory health insurance. Another limitation is focusing on disease related-data that was given by the patients and therefore can be prone to error. Patients of this study were at different stages of disease. They differ in time since diagnosis; some were recently diagnosed with BC and other were diagnosed several years ago. That causes a risk of recall bias, and the health care situation might have changed during this time. Concerning the recently diagnosed participants, it cannot be guaranteed that they received the recommended treatment. Since qualitative data was used and the quantitative sample of 100 participants is too small for that, correlation analysis with typical factors of social inequity like differences in education, occupational status, and income were not made. Furthermore, correlation analysis was not part of the N-MALE study. The three factors influencing social inequity discussed above are just a few aspects to consider in order to reduce health inequities in MBCP. As indicated in Mielck's model, there are other factors taken into account, such as differences in health-related and illness behavior. This would go beyond the scope of this work and can be part of further studies.

#### 4.2 Implications to Improve the Health Care Situation of Male Breast Cancer Patients

From the three publications, the following implications arise for health care practice, further research, and medical sociology in order to reduce health inequities and improve the health care situation of the vulnerable group of MBCP.

As it is most effective to reduce health inequity by focusing on real-life areas (Lampert & Mielck, 2008), there is a need of more publicity about MBC in public and among HCPs to raise awareness of the disease and its symptoms, to prevent stigmatization, and to accelerate diagnosis. In particular, information about MBC should be part of trainings for health care professionals. As Ernstmann and Kowalski (2019) show, the central results of the N-MALE study and the central implications for MBCP are validated by Nguyen et al. (2020). Since MBCP are often diagnosed at a later stage of disease than women (Giordano, 2018), it is important to speed up the process of diagnosis to increase the possibility that the cancer can be cured and to reduce mortality of MBCP. In addition, access to gynecological care should be improved and standardized to facilitate diagnosis and aftercare, and clear responsibilities for aftercare should be defined. Within the health care structure, partners and those in the patient's close social environment should be more included within cancer care, as they are a key resource of social support for MBCP. There is a need for equality of men and woman in BC care, including gender-neutral communication and information material, as also demanded by Co et al. (2020). Furthermore, body image problems (e.g., scars on the breast or the feeling of emasculation) should be taken more seriously by HCPs, as they can be traumatic for patients. Since the MBCP-specific support group in Germany (Netzwerk Männer mit Brustkrebs e.V.) is not known to all MBCP, HCPs should inform patients about this opportunity to receive information about the disease and share experiences.

Within further research, a context analysis including typical factors of social inequality like differences in education, occupational status, and income with a bigger sample of MBCP (e.g., routine data from the statutory health insurance) needs to be done in order to be able to make more universal statements concerning health inequity of MBCP. In addition, the morbidity and mortality of MBCP should be considered to be able to make broader statements about health inequities of MBCP.



Furthermore, it could be of interest to have a closer look at vertical inequalities and their influence on health inequities (e.g., occupational status and stigma). Since health care systems differ between countries, research should be extended to other health care systems to examine the generalizability of the results. Prospective long-term clinical studies on the effects of tamoxifen in MBCP are necessary to give MBCP and HCPs more security in drug treatment.

MBC is a special form of rare disease; the gender difference makes it rare, since BC is one of the most common oncological diseases in women. Therein are central advantages and disadvantages for those affected: Compared to patients with other rare diseases, MBCP can benefit from the extensive knowledge and the existing structures of (female) BC care. At the same time, however, there is a risk in research and practice of trivializing MBC as an independent disease and equalizing the needs of FBCP and MBCP. This cumulative dissertation shows the importance of gender in the subject of illness, which is highly relevant in terms of medical sociology. Special attention should be paid to this in medical-sociological research in order to focus more on central gender differences in diseases and, ultimately, to convert them within the reality of cancer care.

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