FACULDADE DE MEDICINA
UNIVERSIDADE DO PORTO

MESTRADO INTEGRADO EM MEDICINA

2009/2010

Isabel Nogueira Miranda Pinto

Mastectomia e comunicação de más notícias: aspectos relevantes da literatura

Abril, 2010

FACULDADE DE MEDICINA
UNIVERSIDADE DO PORTO

Isabel Nogueira Miranda Pinto

Mastectomia e comunicação de más notícias: aspectos relevantes da literatura

Mestrado Integrado em Medicina

Área: Psicologia Médica

Revista: Psycho-Oncology

Trabalho efectuado sob a Orientação de:

Professora Doutora Irene Maria Palmares Dias Carvalho

Abril, 2010

U.PORTO
FMUP FACULDADE DE MEDICINA UNIVERSIDADE DO PORTO
UNIDADE CURRICULAR
PROJECTO DE OPÇÃO
DISSERTAÇÃO/MONOGRAFIA/RELATÓRIO DE ESTÁGIO

Projecto de Opção do 6º ano - DECLARAÇÃO DE REPRODUÇÃO

Nome: Isabel Nogueira Miranda Pinto

Endereço electrónico: m04147@med.up.pt; i.nm.pinto@gmail.com

Título da Monografia:

Mastectomia e comunicação de más notícias: aspectos relevantes da literatura

Nome completo do Orientador:

Irene Maria Palmares Dias Carvalho

Ano de conclusão: 2010

Designação da área do projecto de opção:

Psicologia Médica

É autorizada a reprodução integral desta Monografia apenas para efeitos de investigação, mediante declaração escrita do interessado, que a tal se compromete.

Faculdade de Medicina da Universidade do Porto, 19/04/2010

Assinatura: Isabel Nogueira Miranda Pinto

U.PORTO
FMUP FACULDADE DE MEDICINA UNIVERSIDADE DO PORTO
UNIDADE CURRICULAR
PROJECTO DE OPÇÃO
DISSERTAÇÃO/MONOGRAFIA/RELATÓRIO DE ESTÁGIO

Projecto de Opção do 6º ano - DECLARAÇÃO DE INTEGRIDADE

Eu, Isabel Noguira Miranda Pinto, abaixo assinado, nº mecanográfico 040801147, aluno do 6º ano do Mestrado Integrado em Medicina, na Faculdade de Medicina da Universidade do Porto, declaro ter actuado com absoluta integridade na elaboração deste projecto de opção.

Neste sentido, confirmo que NÃO incorri em plágio (acto pelo qual um indivíduo, mesmo por omissão, assume a autoria de um determinado trabalho intelectual, ou partes dele). Mais declaro que todas as frases que retirei de trabalhos anteriores pertencentes a outros autores, foram referenciadas, ou redigidas com novas palavras, tendo colocado, neste caso, a citação da fonte bibliográfica.

Faculdade de Medicina da Universidade do Porto, 19/04/2010

Assinatura: Isabel Noguira Miranda Pinto

Mastectomy and communication of bad news: relevant aspects in the literature

[Mastectomia e comunicação de más notícias: aspectos relevantes da literatura]

Isabel Pinto[1*], M.D., M.A. Candidate
Irene Carvalho[2], Ph.D.

[1] School of Medicine, University of Oporto, Portugal
[2] Department of Medical Psychology, School of Medicine, University of Oporto, Portugal

[*] Correspondence to:
Isabel Pinto
Rua Miguel Torga, nº 97
4405-880 Vila Nova de Gaia, Portugal
E-mail: i.nm.pinto@gmail.com
Contact nr: +351919264772

Abstract

Objective: The goal of this study is to conduct a literature review on mastectomy in the context of general protocols for breaking bad news. Suggesting a mastectomy while discussing breast cancer treatments can be additional bad news. This study aims to identify sensitive dimensions of patients' emotional and social experiences when confronted with this surgical option.

Methods: Articles were identified in Pubmed, Web of science, Scopus and PsycINFO, from inception to December 2009. Included articles referred to general guidelines for breaking bad news, mastectomy experiences and those that associate the communication of bad news to mastectomy or to breast cancer in general.

Results: Forty articles resulted from the review. Studies concerned with the integration of guidelines for communicating bad news in breast cancer focus primarily on the diagnostic moment. Mastectomy as a treatment option is overlooked. Mastectomy patients experience several difficulties, namely concerning body image, mood changes and post-operative physical symptoms. Sexuality, marital stability and life patterns may also be disrupted. The importance attributed to physical appearance, age, pre-operative expectations and preparation, quality of sexual/marital relationship, coping mechanisms, time since surgery, availability of support, need for additional medical treatments and the possibility of breast reconstruction are pertinent aspects that influence the impact of mastectomy.

Conclusions: Familiarization with this knowledge allows preparation of the physician on the specificities of this situation to present women with the possibility of mastectomy, improving general protocols for breaking bad news, and support them throughout this emotionally threatening experience.

Keywords

Mastectomy; Breast cancer; Bad news; Psychosocial adaptation; Review

Resumo

Objectivo: O presente estudo faz uma revisão da literatura acerca da mastectomia no âmbito dos protocolos gerais de comunicação de más notícias, pois a mastectomia como tratamento do cancro da mama pode ser considerada uma má notícia adicional. Este estudo procura identificar áreas sensíveis da vivência emocional e social da mulher perante a possibilidade desta cirurgia.

Métodos: As bases de dados Pubmed, Web of science, Scopus e PsycINFO foram pesquisadas, desde o começo da indexação até Dezembro de 2009. Seleccionaram-se os estudos relativos a protocolos gerais de comunicação de más notícias, à comunicação de más notícias associada à mastectomia ou ao cancro da mama e à vivência de mulheres mastectomizadas.

Resultados: Foram incluídos 40 artigos. Os estudos sobre protocolos de comunicação de más notícias no cancro da mama focam o momento do diagnóstico em detrimento do tratamento. Perante a mastectomia, as doentes experienciam diversas dificuldades, desde alterações da imagem corporal e do humor a sintomas físicos pós-operatórios. A sexualidade, estabilidade marital e diversos padrões de vida poderão, também, ser afectados. A importância atribuída à aparência física, idade, expectativas e preparação pré-operatórias, qualidade do relacionamento sexual prévio, mecanismos de *coping*, tempo decorrido após a cirurgia, apoio disponível, tratamentos adicionais e reconstrução mamária, são aspectos determinantes no impacto da mastectomia.

Conclusões: Este conhecimento permite familiarização com especificidades da mastectomia e preparação do médico para as abordar quando apresenta esta hipótese terapêutica, complementando os protocolos gerais de comunicação de más notícias. Contribui, ainda, para a melhoria do apoio oferecido a estas doentes.

Introduction

Breast cancer is the most frequently diagnosed cancer in women [1]. It jeopardizes not only women's physical health but also the emotional balance [2], since breasts are closely associated with femininity, sexuality and self-esteem [3]. Additionally, patients have to face demanding treatments [2]. The current surgical choices are breast-conserving therapy (BCT) and mastectomy, alone or with reconstruction. BCT is the standard of care for most patients as it has similar survival and is believed to be less psychologically traumatic [4]. Nevertheless, mastectomy is still largely performed [5].

Breaking bad news such as a cancer diagnosis is part of physicians' practice. Bad news can be defined as "any news that drastically and negatively alters the patient's view of her or his future" [6]. Guidelines for breaking bad news stem from clinical experience and intend to be useful in different daily clinical situations and adequately address patients' needs [6,7]. From 1995 to 2009, only 1.6% of the published studies in the field of breaking bad news provided evidence-based information [8]. Three important examples of guidelines [7,9-13] are summarized in Table 1 (adapted from Fallowfield [14]).

In the context of breast cancer, in addition to the disturbing diagnosis news, when mastectomy is the suggested treatment, the patient will probably experience additional stress thinking about mastectomy's future implications. Therefore suggesting a mastectomy is itself another potential bad news that requires as much attention as the diagnostic moment. Familiarity with probable physical, psychological and social effects of surgery can enhance doctors' competencies to anticipate patients' concerns and to help deal with them [15]. Research indicates that patient preparation for the likely outcomes of surgery can reduce fears, namely because it may increase the sense of control over the disease [2]. However, many patients do not express their doubts unless directly invited [16]. Doctor's preparation to address mastectomy-related issues is thus crucial.

This study conducts a review of the literature on mastectomy in women with breast cancer with the goal of identifying and systematizing sensitive aspects of patients' emotional and social experiences when confronted with this surgical option. By focusing on how women deal with mastectomy, including experienced difficulties and opportunities for successful coping, this study aims to contribute knowledge to an area that has been only marginally addressed as part of the treatment plan in the

communication of bad news protocols. A better understanding of the specificities involved in this domain contributes to a more adequate communication when doctors suggest mastectomy to breast cancer patients.

Methods

Search and selection processes

Searched databases included Pubmed, Web of Science, Scopus and PsycINFO. The latter was used to complement the others on the important psychological and social dimensions involved.

A first search was conducted in all databases in order to identify articles connecting the communication of bad news with mastectomy, from inception to December 2009 (query "(bad news) AND mastectomy"). To ensure the inclusion of the maximum number of studies, a second broader search was conducted in all databases, with the same time frame, in order to study the communication of bad news in breast cancer (query "(bad news) AND (breast cancer)"). A third search was conducted in PsycINFO for further articles about psychological and social aspects involved in the experiences of mastectomy, from inception to December 2009 (query "mastectomy"). To ensure the completeness of this third search, Pubmed was also inspected (query "mastectomy AND (body image OR sexuality OR quality of life OR psychological aspects)"). Since this was a complementary search, we restricted it to recent findings (January 2004 to December 2009). Finally, pertinent reading suggestions by authors were included.

Included articles referred to women, most used protocols for breaking bad news, communication of bad news in mastectomy and in breast cancer, and mastectomy experiences. Considered languages were English, Spanish and Portuguese. Excluded articles were those whose scope is not directly related with the goals of the present review (e.g. comparison of mastectomy with BCT, breast cancer during pregnancy, prophylactic mastectomy, ethical subjects about cancer diagnosis and workshops about breaking bad news).

Data analysis

Each study was characterized according to study design, population evaluated and type of instruments used. The databases were also compared concerning content. Secondly, articles were reviewed for content and their main results and clinical

implications were analysed. Data were arranged in tables for facility of analysis and presentation of results.

Results

The database review yielded 1,018 articles, and nine additional studies were suggested by authors. According to inclusion/exclusion criteria, 40 articles were finally included in the review. This process is summarized in Figure 1.

1. Characterization of the databases and included articles

From the 40 included articles, one [16] was identified through Search 1 (which yielded only six articles), nine through Search 2 [11,12,17-23], 21 through Search 3 [2-5,15,24-39], and the remaining nine [6-10,13,14,40,41] through authors' suggestions. On the other hand, nine (Pubmed n=2 [11,22]; additional studies n=7 [6-10,13,14]) concern general guidelines for breaking bad news; 24 (Pubmed n=14 [4,5,16,24-34]; PsycINFO n=8 [2,3,15,35-39]; additional studies n=2 [40,41]) concern mastectomy experiences, of which only one (Pubmed [16]) links the communication of bad news with mastectomy; and eight (Pubmed n=6 [12,16-18,21,23]; Scopus n=2 [19,20]) concern the communication of bad news in breast cancer in general. Web of Science is not mentioned because its relevant articles were repeated in the other databases.

An increasing concern, particularly from Radiology [17-19,21], about the integration of guidelines for breaking bad news in the specific field of breast cancer can be noticed [12,16-23]. However the main focus of these works is the diagnostic moment, not mastectomy.

In turn, the 24 articles about mastectomy are predominantly observational studies (n=13 [3,25-28,32-34,36-39,40]) and reviews (n=9 [2,4,5,15,16,24,29,30,35]). Only one randomized experience [33] was found. The observational studies were conducted with women selected from clinics and hospitals through convenience sampling methods and have varied sample sizes (n=4 to n=494 participants). They are based on self-report questionnaires administered in person (n=6 [3,25,26,33,37,40]) or by mail (n=3 [27,28,36]), interviews (n=3 [34,38,39]) and combined modalities (n=1 [32]). Most of the reviews focus on theory and lack methodological explanations.

2. Themes on experiences of mastectomy

When confronted with the possibility of mastectomy after cancer diagnosis, women may be assaulted by many fears and concerns. Those most common in the literature are: fear of death [5,15,30,31,], recurrence [15,25,30,31,], rejection (social or in intimate relationships) [5,26,31,35] and sexual dysfunction [30,31]; concern about body image disruption [15,30,31,], a sense of loss (as breast loss may be lived as a mutilation or even castration) [5,15], need for further treatments [15], difficulties in marital communication and persistent anxiety [30]. The following analyses about experiences of mastectomy validate these fears.

Body image is the most studied area of mastectomy's impact, followed by mood and post-surgery physical symptoms. The number of articles (and percentage) per database that address these and other identified themes is presented in Table 2. The next subsections refer to these pertinent themes documented in the literature concerning women's experiences of mastectomy. They are interrelated and the organization scheme adopted is for facility of presentation.

2.1 Body image, sexuality and marital stability

Identity, femininity and self-confidence are closely related to body image. Therefore body image disturbances are commonly reported after mastectomy [3,29,30] because surgery breaks the breast's symbolism of womanhood [31]. In a study, 47.4% of women experienced negative changes in body image [40]. These radical changes in body image may in turn, lead to sexual problems [25,26]. Research reports that 50.0% of women continue to have difficulties in sexual life after breast cancer treatment [31]. Problems can persist even after 5 years [27]. Karabulut and Erci found, in a sample group of 123 women, that after treatment, sexual desire was low and women needed much support concerning femininity and body image [25].

Women may find it very difficult to look in the mirror and face the scar [2,31,39,40], touch it [40] or show it to the spouse [2,5,15,39,40]. They may feel less whole [28], become more self-conscious [2,31], have a sense of loss of femininity and sexual attractiveness [2,25,31], see their professional outlook affected [3] and perceive their partners to be repulsed by their new body images [25,28,31]. Studies found that some husbands felt ashamed of their wives' less attractive bodies [25,28], and others even rejected them [39]. Thus, it is expected that some women believe that after mastectomy they will have some maladjustment in intimate relationships [25,26]. Avci

et al found that women in their sample had a moderate level of marital adjustment, concluding that mastectomy affects marital stability little or not at all [26]. However this was not observed in other studies which reported that mastectomy women tend to have more marital problems [31,39]. On extreme, mastectomy has been reported as a frequent cause for divorce [25].

2.2 Mood

The changes in physical appearance may also affect mood and self-esteem, eventually leading to depression [3,25,26,29,39]. A study reported that up to 45.0% of early breast cancer patients felt anxious or depressive (does not mention if it is before or after surgery) [31]. Avci *et al* found that after mastectomy 44.1% of the women in the sample felt sad about their body image, 32.2% felt like they were becoming depressed and 23.7% ignored it [26]. Maluf found that 31.6% of the interviewed women were depressive and two had already thought about suicide [40]. These mood changes may not only cause sexual problems, worsening depression itself and patient's general quality of life, but also affect intra-familial relationships and the prognosis, by leading to less effective coping strategies [26]. There is also evidence of a significant association between depression and cancer pain probably because they share common neurobiological pathways [28]. Skrzypulec *et al* concluded that the level of depression after mastectomy depends on the intensity of post-traumatic stress [27]. Depression may continue after physical recovery from surgery, a point that should not be neglected [15].

Anxiety is also a common reaction to mastectomy [3,15]. Farooqi found that pre-surgical anxiety was significantly higher than post-surgical anxiety, arguing that patients anticipate physical or psychological damage and fear the unknown. Oppositely no statistically significant difference was found in depression levels, although higher levels existed before surgery. However, the author suggests that after surgery, depression levels can increase due to body image changes [3].

2.3. Life patterns

After surgery women may experience difficulties such as insomnia, recurrent nightmares, loss of appetite, trouble returning to household affairs or to work, inability to concentrate and diminished physical activity [15]. As mentioned earlier, mastectomy is also associated with divorce [25], a major life change. Patients may also feel differences when returning to active sexual life. Some women may reinvent new ways

of expressing their sexuality in a positive way. Others avoid social contact, fear rejection and hide the scar during the sexual act [39]. Couples may need to learn new positions for sleeping and lovemaking to avoid discomfort [15]. Sometimes a different style of clothing has to be adopted. This can decrease the woman's self-esteem and harm interpersonal relationships [5] or, conversely, it can help to feel comfortable by hiding the scar [2,34,39]. Using prosthesis also promotes reintegration in society [34]. To sum up, mastectomy may alter previous life patterns such as sexual activity, marital life and clothing.

2.4 Post-surgery physical symptoms

After mastectomy patients may experience unpleasant physical symptoms like pain [5,25,28,38], lymphedema [2,5,25,34,38], limited arm movements [2,38] and phantom breast syndrome (PBS) [15,28,32,34,38]. If lymphedema occurs, more time is necessary to return to full activity [5]. In 1980, the incidence levels of PBS after mastectomy reported in the literature ranged from 23.0% to 52.7% [15]. Recently, a study found that 22.9% of the sample experienced PBS and that it was associated with younger age and higher scores of depressive symptoms [32]. Another investigation found that 17.4% of women still experienced PBS six years after mastectomy. Finally, post-mastectomy pain may also decrease physical and sexual functioning [28].

3. Variables that influence the impact of mastectomy

In 1980, Meyerowitz [15] focused on the impact of breast cancer's treatment and the variables that influence the intensity and duration of that impact. This well organized review and its findings remain current. We reviewed it and added recent findings. Availability of support was the most cited influence, followed by coping mechanisms and additional medical treatments. Curiously, coping mechanisms were mainly addressed in PsycINFO articles and pre-operative preparation and expectations were exclusively found in this database. A comparison of the different databases included concerning these different variables is presented in Table 3.

3.1 Importance of physical appearance

Mastectomy is extremely devastating for women whose self-esteem is based on beauty and physical attributes [3,29,15]. These women may have a poorer psychosocial adjustment after surgery [28]. Accordingly, women who demonstrate a positive self-

image (beyond physical appearance) before surgery are less likely to develop a poor self-image after it [29].

3.2 Age

Ganz considers that younger age is a risk factor for psychosocial distress after breast cancer diagnosis and treatment [30]. Sexual motif is among the most cited reasons in the literature [15,25,31], namely because of decreased sexual interest among elderly women, associated with biological changes. Higher physical beauty expectations in youth constitute another explanation [25].

A study found that it is indeed more difficult for younger women to adjust to treatment changes because they have more concerns about body image, partner relationships [30], sexual functioning and simultaneous less adaptive coping mechanisms [29]. Skrzypulec *et al* also found that younger women experience more physical symptoms. However they did not find a statistically significant correlation between age and perception of body image or sexual satisfaction [27]. Nevertheless some authors suggest that younger women should have extra emotional support [29].

3.3. Pre-operative expectations and preparation

Studies indicate that a doctor-patient discussion before surgery may bring patient's expectations closer to reality [15] and reduce fears and concerns [2,15,39]. Research has further suggested that even physical discomfort may be less disturbing if women are expecting it, supporting such pre-surgical meetings [15].

3.4. Quality of sexual/marital relationship

Research indicates that the better the sexual relationship before surgery, the better the sexual satisfaction after it [15,26]. Greater marital satisfaction can decrease pain by encouraging acceptance, helping to find useful coping methods and providing direct or instrumental support [28] (e.g. transportation to appointments, preparation of meals and help with other daily activities [30]). Strong and positive marital adjustment also contributes to low hopelessness levels [26].

3.5. Patients' coping mechanisms

In 1980, coping mechanisms were not widely studied like nowadays. Denial is the most analysed mechanism in Meyerowitz's review. It is useful as long as it does not

interfere with necessary treatments [15]. Recent studies contributed to a greater understanding of this mechanism.

Some authors suggest that, for most women, approach-oriented coping and focusing on realistic expectations can be very useful [30]. Others concluded that more experienced stress, more use of avoidance strategies, less focus on the positive or less use of social support are significantly associated with more physical symptoms. Conversely, having a more positive look on the situation by doing more problem solving efforts and a more positive reappraisal of events is associated with decreased stress and more use of social support (which in turn is associated with less depressive symptoms) [37]. Comparing the situation to the loss of an arm may also bring relief. Some women tend to turn into themselves and take care of their own needs as a coping mechanism. They try to stand out in different ways and be recognized as unique (despite being mutilated) [39].

Literature consulted demonstrated that most breast cancer survivors adapt gradually and successfully to mastectomy [2,15,37,38]. However, some patients may not find positive coping strategies without help [2,15,30].

3.6. Time since surgery

Despite not well investigated in 1980, the negative impact of mastectomy was believed to decrease over time [2]. Recently some authors suggested that time since surgery plays a role in patient reports (especially concerning mood) [28] while others found that it did not significantly affect the symptoms or the functional status of women after mastectomy [27].

3.7. Availability of support

In Meyerowitz's review it was suggested that patients who have support experience less psychological distress. The three major sources of support identified were: the medical team, spouse and family and other mastectomy patients [15]. Recent findings widen these sources of support. The lack of support is a risk factor for the development of anxiety and depression [3] which may have a negative impact on sexuality or physical symptoms, as pointed out earlier.

3.7.1. Professional health team

Doctors' [15,16] and nurses' [2,5,15,25,26,27,31,] attitudes may have a remarkable impact in the emotional state of the patient. Research stresses the

importance of an emphatic doctor-patient relationship [39]. Doctors can provide support and guidance [15] in order to reduce patients' anxiety and fears [3,15,26,27,29,] and help in the pursuit of hope [26]. To this end, taking time to answer questions can make a great difference [25]. Psychologists can not only help maximize the patient's control over the treatment, but also help the medical team to deal with the overwhelmed breast cancer patient [2,40].

3.7.2. Spouse and family

As pointed out earlier, emotional support from the spouse is crucial to maintain healthy sexual and romantic life, gain courage to show the scar [31], increase body image self-acceptance [28,33], reduce pain and improve mood [26,28]. Including them in post-mastectomy reunions can thus be beneficial for the patient and also help their own emotional state [3,15]. The mere presence of the partner during the diagnostic consultation is associated with better long-term adjustment [28].

3.7.3. Social support

Women with greater social support tend to have better coping strategies and self-esteem and longer survival [27]. Research suggests that social networks protect marital stability [26] and foster a faster rehabilitation after surgery [3]. Many forms of social support are mentioned in the literature: friends, clergy, work colleagues, social workers, community resources [30], independent support groups [5,27,30] and volunteers that have undergone mastectomy [15,30]. Supportive groups usually integrate a multidisciplinary team and aim to promote self-esteem and quality of life [5].

3.8. Additional medical treatments

Additional medical treatments often decrease quality of life [15]. Radiation treatments may alter the appearance of the skin [34]. Side effects of chemotherapy may also disturb the patient's sense of attractiveness as well as sexual life [5,15,25,30,34,35,37,39,]: increased fatigue [25,31], decreased libido [25,31,35], mood disturbances [25], early menopause [25,31,34,35], hair loss [5,31,39], pallor [31], weight gain [31,34], nausea and vomiting [31], dyspareunia [31,35] and vaginal irritation [31]. However, some authors found no significant difference about feeling sexually attractive in women who had mastectomy alone or with chemotherapy [37].

3.9. Breast reconstruction

This aspect was not contemplated in Meyerowitz's review in 1980 [15]. Discussing it may create a positive view of the future related to body image and also transmit the feeling that the doctor believes in the patient's survival, minimizing the psychological stress before mastectomy [16]. However, a recent review found that breast reconstruction can either improve or worsen or even have no effect in women's quality of life after mastectomy [24].

Reported reasons for having breast reconstruction are: unnecessary external breast prosthesis, larger variety of clothes available [16] and feeling whole and sensual again [16,38,39]. On the other hand, reasons women provide for not having breast reconstruction are: older age, lack of information, concern about costs, fear of recurrence and additional surgery, uncertainty about the outcome, negative attitudes within society toward reconstruction [16] and conviction that reconstruction denies women's strength (feminist perspective) [41].

Discussion

This study sought to review existing literature on experiences of mastectomy in order to investigate and systematize current knowledge on important aspects involved in patients' lives and the direction of mastectomy's impact on those aspects. Knowledge on this subject can add specificity to the general area of dealing with bad news in cancer, especially during the discussion of treatment.

The initial search for mastectomy within the context of breaking bad news in breast cancer yielded only one result, reflecting the lack of scientific information on this domain. As previously referred, studies focus on the diagnostic moment and the important topic of treatment discussion is systematically overlooked. Subsequent searches were conducted to find research to bridge this gap.

This review resulted in the main fears and concerns that women feel when faced with the possibility of mastectomy, previously presented. These concerns stem generally from the disruption that mastectomy can bring to patients' lives. Within such potential disruption, the most explored area of mastectomy's consequences is body image. Depression and post-op physical symptoms are also given relevance, but other less explored aspects also emerge as important and should be considered in encounters with mastectomy patients. These include changes in life patterns, an area in which healthcare providers can help, if discussed (e.g. sleep disturbances can be medicated,

advice on adequate physical exercise or external prosthesis use can be given as well as guidance to develop positive coping mechanisms so that clothing changes have less impact).

Sexuality, a potentially affected area, tends to be overlooked in clinical encounters, as literature indicates [25,31,39]. Comfortableness on the part of the healthcare provider to discuss this matter is crucial, namely to help deal with sexual dysfunction after surgery [25,31].

In general, research consensually points out that patients may experience great difficulty in accepting their new body image, feel less feminine and sexually attractive, have difficulties with sexual life, get sad or even depressed and face uncomfortable physical symptoms after surgery (like lymphedema and limited arm movements). Doubts still remain concerning depression after mastectomy. Doctors should expect that only certain patients will get depressed. There is also less consensus about marital stability. Some studies suggest that marital problems increase after mastectomy (e.g. due to rejection of physical contact), while others indicate that marital stability is little affected.

This review also resulted in the identification of several variables that can influence the impact of mastectomy. In general, women whose self-esteem is based on physical attributes, who are younger, who were not psychologically prepared for the surgery, whose sexual life or marital relationship was already problematic before the surgery and who need additional treatments (e.g. chemotherapy) tend to have more difficulties adapting to mastectomy. On the other hand, certain coping mechanisms (e.g. moderate denial, avoiding stress, problem-solving approaches, positive reappraisal, focusing on the positive and on realistic expectations), more time elapsed since surgery, availability of support and the possibility of breast reconstruction may help women overcome mastectomy. Still, some inconclusive findings remain concerning the influence of age, time since surgery, additional treatments and breast reconstruction on women's adjustment. Women may expect surgery to perfectly recreate the previous breast and, as this may not happen, they can be disappointed. It is also possible that the other aspects (e.g., presence or absence of adequate coping mechanisms or previous preparation for surgery) play a bigger role in this adjustment.

Literature suggests that counselling [25], rehabilitation and psychotherapy may be very helpful [3], even after the end of treatment [27]. They should consider issues on body image, sexuality and interpersonal relationships [31], and previously prepare the

patient for the possibility of additional medical treatments [5]. Sex therapy alone [2] or a combination of couple therapy and sex therapy can significantly improve women's body image perception as well as sexual and marital life [33]. Sex therapy may be beneficial for some patients [2] and a combination of couple therapy and sex therapy can significantly improve women's body image perception as well as sexual and marital life [33]. Information on available support groups should be provided, and [30] the possibility of breast reconstruction should be offered to all women [16].

One of the strengths of this work is its exclusive focus on the neglected area of the impact of mastectomy and the incorporation of the findings into the discussion of breast cancer treatment. It also has some limitations. Language restriction and the exclusion of the articles that compared BCT with mastectomy probably caused the loss of some important information. A small number of articles was included. This included studies varied in strategies used for data collection and analysis, and sample size and characteristics, which limits comparisons due to heterogeneity. Small/medium sample sizes, using non randomized observational design, lack of control groups and the use of self-report measures limits the existing literature. The tenuous line between mastectomy's psychological consequences and those from the experience of breast cancer itself can somehow confuse certain results about mastectomy (e.g. about mood). Despite these limitations, the findings in this review highlight the various aspects in the literature associated with the experiences of mastectomy, its implications in a woman's life and the consequent importance of support since the pre-operative period.

Future research could assess if the discussion of the identified sensitive subjects before mastectomy contributed to better adjustment after surgery. Women's opinions about strategies to reduce the identified fears and concerns before surgery could be assessed. The usefulness of counselling, psychotherapies and support groups should be tested in order to further implementation in breast cancer treatment plans, namely when mastectomy is performed. Finally, more studies are needed to clarify the role of breast reconstruction and also some other non consensual areas such as marital stability.

Conclusions

The knowledge of the presented information contributes to doctors' expertise on the potential problems that mastectomy patients may experience, leading to better doctor-patient communication and to more adequate support offered to the mastectomy patient.

Acknowledgements

The authors wish to thank to Professors: Beth Meyerowitz, Robert Sanson-Fisher, Lesley Fallowfield, Ian Kudel, José Manuel García Arroyo, Lesley Stirling, Neziha Karabulut, Mira Crouch, Inger-Lise Nesvold, Louise Houlcroft, Michael Linver and Heather McKenzie for their contribution to make this study possible.

References

[1] American Cancer Society. Cancer Facts & Figures 2009. American Cancer Society: Atlanta, 2009.

[2] Meyerowitz BE. The impact of mastectomy on the lives of women. *Prof Psychol* 1981; 12(1):118-127.

[3] Farooqi YN. Depression and Anxiety in Mastectomy Cases. *Illness, Crisis, & Loss* 2005; 13(3):267-276.

[4] Pockaj BA, Degnim AC, Boughey JC, Gray RJ, McLaughlin SA, Dueck AC, Perez EA, Halyard MY, Frost MH, Cheville AL, Sloan JA. Quality of life after breast cancer surgery: what have we learned and where should we go next? *J Surg Oncol* 2009; 99(7):447-455.

[5] Pereira SG, Rosenhein DP, Bulhosa MS, Lunardi VL, Filho WD. Vivências de cuidados da mulher mastectomizada: uma pesquisa bibliográfica. [The experience of mastectomized woman: a bibliographic research]. *Rev Bras Enferm* 2006; 59(6):791-5.

[6] Buckman R. How to break bad news: a guide for health care professionals. The Johns Hopkins University Press: Baltimore, MD, 1992.

[7] Girgis A, Sanson-Fisher RW. Breaking bad news: consensus guidelines for medical practicioners. *J Clin Oncol* 1995; 13(9):2449-2456

[8] Paul CL, Clinton-McHarg T, Sanson-Fisher RW, Douglas H, Webb G. Are we there yet? The state of the evidence base for guidelines on breaking bad news to cancer patients. *Eur J Cancer* 2009; 45(17):2960-2966.

[9] Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKES – A six-step protocol for delivering bad news: application to the patient with cancer. *Oncologist* 2000; 5(4):302-311.

[10] Buckman RA. Breaking bad news: the S-P-I-K-E-S strategy. *Community Oncol* 2005; 2(2):138-142.

[11] Girgis A, Sanson-Fisher RW. Breaking bad news. 1: Current best advice for clinicians. *Behav Med* 1998; 24(2):53-9.

[12] Girgis A, Sanson-Fisher RW, Schofield MJ. Is there consensus between breast cancer patients and providers on guidelines for breaking bad news? *Behav Med* 1999; 25(2):69-77.

[13] Rabow MW, McPhee SJ. Beyond breaking bad news: how to help patients who suffer. *West J Med* 1999; 171(4):260-263.

[14] Fallowfield L, Jenkins V. Communicating sad, bad, and difficult news in medicine. *Lancet* 2004; 363(9405):312-19.

[15] Meyerowitz BE. Psychosocial correlates of breast cancer and its treatments. *Psychol Bull* 1980; 87(1):108-131.

[16] Parker PA, Aaron J, Baile WF. Breast cancer: unique communication challenges and strategies to address them. *Breast J* 2009; 15(1):69-75.

[17] Adler DD, Riba MB, Eggly S. Breaking bad news in the breast imaging setting. *Acad Radiol* 2009; 16(2):130-5.

[18] Brem RF, Sanchez JL, Rapelyea JA. Breaking bad news in breast imaging: a critical component of patient care. *Acad Radiol* 2009; 16(2):121-2.

[19] Linver MN. Delivering bad news: A vital skill for professionals involved in breast cancer care. *Breast Cancer Online* 2009; 12(2):art. no. e3.

[20] Azu MC, Jean S, Piotrowski J, O'Hea B. Effective methods for disclosing breast cancer diagnosis. *Am J Surg* 2007; 194(4):488-490.

[21] Harvey JA, Cohen MA, Brenin DR, Nicholson BT, Adams RB. Breaking bad news: a primer for radiologists in breast imaging. *J Am Coll Radiol* 2007; 4(11):800-8.

[22] Mager WM, Andrykowski MA. Communication in the cancer 'bad news' consultation: patient perceptions and psychological adjustment. *Psychooncology* 2002; 11(1):35-46.

[23] Maguire GP. Breaking bad news: explaining cancer diagnosis and prognosis. *Med J Aust* 1999; 171(6):288-9.

[24] Lee C, Sunu C, Pignone M. Patient-reported outcomes of breast reconstruction after mastectomy: a systematic review. *J Am Coll Surg* 2009; 209(1):123-33.

[25] Karabulut N, Erci B. Sexual desire and satisfaction in sexual life affecting factors in breast cancer survivors after mastectomy. *J Psychosoc Oncol* 2009; 27(3):332-43.

[26] Avci IA, Okanli A, Karabulutlu E, Bilgili N. Women's marital adjustment and hopelessness levels after mastectomy. *Eur J Oncol Nurs* 2009 ; 13(4):299-303.

[27] Skrzypulec V, Tobor E, Drosdzol A, Nowosielski K. Biopsychosocial functioning of women after mastectomy. *J Clin Nurs* 2009; 18(4):613-9.

[28] Kudel I, Edwards R, Raja S, Haythornthwaite J, Heinberg LJ. The association of perceived partner-related social support with self-reported outcomes in women post-mastectomy. *J Health Psychol* 2008; 13(8):1030-9.

[29] Helms RL, O'Hea EL, Corso M. Body image issues in women with breast cancer. *Psychol Health Med* 2008; 13(3):313-25.

[30] Ganz PA. Psychological and social aspects of breast cancer. *Oncology (Williston Park)* 2008; 22(6):642-6, 650; discussion 650, 653.

[31] Sheppard LA, Ely S. Breast cancer and sexuality. *Breast J* 2008; 14(2):176-81.

[32] Spyropoulou AC, Papageorgiou C, Markopoulos C, Christodoulou GN, Soldatos KR. Depressive symptomatology correlates with phantom breast syndrome in mastectomized women. *Eur Arch Psychiatry Clin Neurosci* 2008; 258(3):165-70.

[33] Kalaitzi C, Papadopoulos VP, Michas K, Vlasis K, Skandalakis P, Filippou D. Combined brief psychosexual intervention after mastectomy: effects on sexuality, body image, and psychological well-being. *J Surg Oncol* 2007; 96(3):235-40.

[34] Thomas-MacLean R. Beyond dichotomies of health and illness: life after breast cancer. *Nurs Inq* 2005; 12(3):200-9.

[35] Silva LC. Câncer de mama e sofrimento psicológico: aspectos relacionados ao feminino. [Breast cancer and psychological suffering: Female-related aspects]. *Psicologia em Estudo* 2008; 13(2):231-237.

[36] Karademas EC, Argyropoulou K, Karvelis S. Psychological symptoms of breast cancer survivors: a comparison with matched healthy controls and the association with cancer-related stress and coping. *J Psychosoc Oncol* 2007; 25(3):59-74

[37] Beckjord E, Compas BE. Sexual quality of life in women with newly diagnosed breast cancer. *J Psychosoc Oncol* 2007; 25(2):19-36

[38] Ferreira MLSM, Mamede MV. Representação do corpo na relação consigo mesma após mastectomia. [Body representation in the relation with the self after mastectomy]. *Revista Latino-Americana de Enfermagem* 2003; 11(3):299-304.

[39] Duarte TP, Andrade AN. Enfrentando a mastectomia: análise dos relatos de mulheres mastectomizadas sobre questões ligadas à sexualidade. [Facing mastectomy: analysis of the discourse of mastectomized women about questions of sexuality]. *Estudos de Psicologia* 2003; 8(1):155-163.

[40] Maluf MF. Mastectomia radical e sexualidade feminina [Radical mastectomy and feminine sexuality]. LMP - Livraria Médica Paulista Editora: São Paulo, 2006.

[41] Lorde A. The Cancer Journals. Aunt Lute Books: San Francisco, CA, 1980.

Tables

Table 1*. Examples of guidelines

Author	Guidelines
Baile *et al* [9], Robert Buckman [10]	SPIKES: Setting up the interview, assessing the patient's Perception, obtaining the patient's Invitation, giving Knowledge and information to the patient, addressing the patient's Emotions with empathic responses, Strategy and Summary
Girgis and Sanson-Fisher [7,11,12]	Ensure privacy and adequate time, assess understanding, provide information simply and honestly, encourage patients to express feelings, give a broad time frame, arrange review, discuss treatment options, offer assistance to tell others, provide information about support services, document information given
Michael Rabow [13]	ABCDE: Advance preparation, Build a therapeutic relationship, Communicate well, Deal with patients' and families' reactions, Encourage and validate emotions

*(adapted from Fallowfield [14])

Table 2. Frequency and percentage of articles that address identified themes per database.

	Impact of mastectomy					
Database	Body image	Sexuality	Marital stability	Mood	Life patterns	Post-surgery symptoms
Pubmed n=14	8 (57%)	3 (21%)	3 (21%)	5 (36%)	3 (21%)	5 (36%)
PsycINFO n=8	4 (50%)	3 (38%)	1 (13%)	3 (38%)	3 (38%)	3 (38%)
Additional studies n=2	1 (50%)	1 (50%)		1 (50%)		
TOTAL n=24	13 (54%)	7 (29%)	4 (17%)	9 (38%)	6 (25%)	8 (33%)

Table 3. Frequency and percentage of articles that address identified variables per database.

	Variables that influence the impact of mastectomy								
Database	Phys*	Age	Pre-op*	Sex*	Coping	Time*	Support	Add treat*	Reconst*
Pubmed n=14	3 (21%)	5 (36%)		2 (14%)	1 (7%)	2 (14%)	10 (71%)	4 (29%)	2 (14%)
PsycINFO n=8	2 (25%)	1 (13%)	4 (50%)	1 (13%)	6 (75%)	1 (13%)	4 (50%)	4 (50%)	2 (25%)
Additional studies n=2					1 (50%)		1 (50%)		
TOTAL n=24	5 (21%)	6 (25%)	4 (17%)	3 (13%)	8 (33%)	3 (13%)	15 (63%)	8 (33%)	4 (17%)

* Phys: physical appearance; Pre-op: pre-operative expectations/preparation; Sex: sexual/marital relationship; Time: time since surgery; Add treat: additional treatments; Reconst: breast reconstruction

Figures

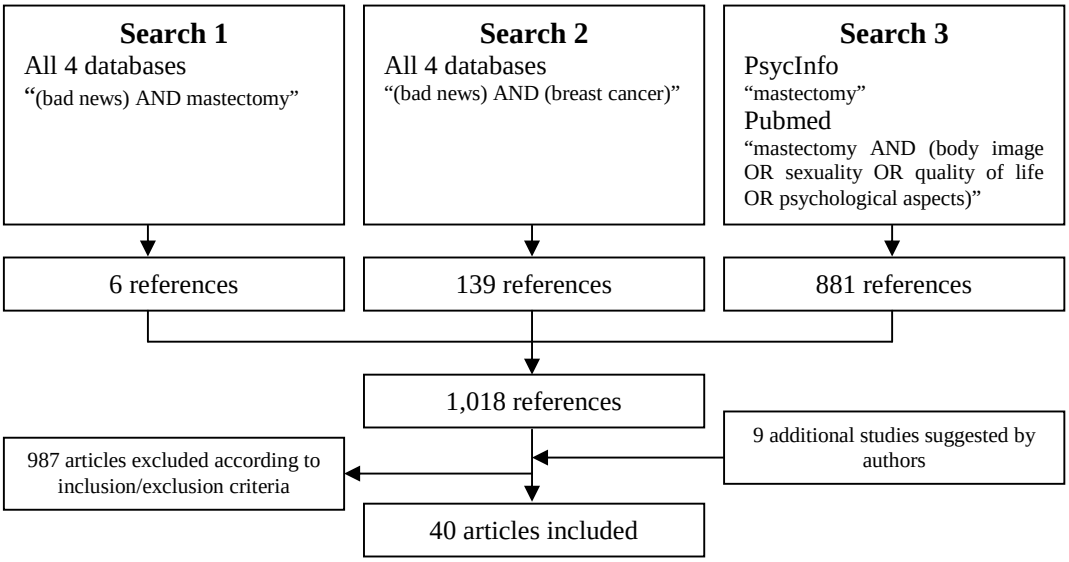

Figure 1. Process of identification of the articles included in the review. Numbers reflect totals after exclusion of repeated articles.