# CHAPTER 3 INFORMATION SEEKING BEHAVIOR AND COPING STYLE OF WOMEN CHOOSING FOR EITHER IMPLANT OR DIEP FLAP BREAST RECONSTRUCTION

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## Abstract

***Background*** High satisfaction rates have been reported after autologous breast reconstruction. Yet, most mastectomy patients receive implant reconstructions (ImBR). Independent and active decision-makers have shown mainly to choose for autologous reconstructions such as the DIEP flap (DiepBR). To further explore the decision-making to opt for either ImBR or DiepBR, we investigated patient knowledge, informational resources used, effect of plastic surgeons' advice, coping style and personal independence.

***Methods*** A total of 153 women who were planned for DiepBR or ImBR preoperatively completed a study-specific and standardized validated psychological questionnaire. Analyses were aimed at information seeking behavior, personal independence and coping styles associated with autonomous decision-making regarding reconstruction.

***Results*** DiepBR women reported different informational resources to be very important and they were more active information seekers, compared to ImBR women. ImBR women found their physician's advice to be more important in their decision-making than DiepBR women. Actively seeking for information regarding BR was positively correlated with active coping, sensitivity to others and the decision for DiepBR.

***Conclusions*** Women opting for DiepBR were more active and independent in their decision-making regarding the type of BR. Women opting for ImBR seemed less well-informed and more dependent on their physician in their decision compared to women opting for DiepBR. To undergo a complex type of BR, active and independent information seeking may be required. However, clinical and logistic characteristics need to be considered as some patients were limited in their reconstruction options.

## Introduction

The number of patients opting for breast reconstruction (BR) increases [1-3]. In general, three types of BR are possible: BR using implants, autologous tissue, or a combination of both. In particular, an increasing number of patients choose microsurgical BR methods with autologous tissue, such as the Deep Inferior Epigastric artery Perforator (DIEP) flap in which the lower abdomen is used to reconstruct a breast [4;5]. These patients report higher satisfaction rates compared to women with implant BR [6-9]. However, the majority of patients opting for BR still receives implant BR [10-14].

Previous studies have shown that women who chose BR compared to those not opting for BR tended to be younger, better educated, more often Caucasian, wealthier and more often married or in a relationship [15-18]. The decision for the type of BR can be influenced by different factors such as surgeon's preferences and expertise, treatment characteristics (therapeutic or prophylactic indication for mastectomy, timing of BR) and patient characteristics [16;19-24]. Up to now only a few studies have specifically focused on the decision-making regarding the *type* of BR and personal processes involved [4;22;25]. Recently, a study showed that women who underwent microsurgical BR were likely to be older, independent and active decision-makers compared to women who underwent non-microsurgical BR [25].

Previous studies regarding BR have shown that a lack of information and unrealistic expectations regarding the outcome were associated with regret or low satisfaction rates with the end result of BR [9;20;26-28]. However, these studies were conducted after BR. Hence, the level of satisfaction with the result may have biased the recall of information provision. Others investigated coping style post-operatively and its relationship to regret post-surgery. They found that a passive coping style was correlated with post-decisional regret following BR [28]. Currently, no studies have explored the relationship between coping styles and the decision for the type of BR pre-operatively. An active coping style and personal independency regarding BR decision-making can result in women who actively seek for information. Consequently, they have the opportunity to form realistic expectations regarding the outcome, which ultimately may increase patient satisfaction and reduce regret.

In the present study information seeking behavior was explored pre-operatively in relation to coping styles and independent decision-making in women opting for either implant or DIEP flap breast reconstruction.

## Patients and Methods

### *Patients*

This study is part of a multi-centred prospective follow-up study on the psychological impact of two types of BR. Participants were women who opted for reconstruction after unilateral therapeutic mastectomy or after unilateral therapeutic mastectomy combined with contralateral prophylactic mastectomy (CPM). Reconstructions were either implant or DIEP flap based. All patients consented to participate in the study.

Exclusion criteria were a BR in the past and not being able to understand and speak the Dutch language sufficiently. Women who did not consent or who did not react two weeks after the invitation were considered as non-respondents. Patients were approached between December 2007 and May 2010 at the Leiden University Medical Center (LUMC), Erasmus Medical Center Rotterdam (EMCR), Daniel den Hoed Cancer Center, Haga Teaching Hospital (Haga), Rijnland Hospital Leiderdorp, the Lange Land Hospital, Hospital Walcheren, Oosterschelde Hospital and at the Hospital Zorgsaam. Ethics approval was obtained from all participating hospitals.

*Implant BR*

All 96 patients who were planned for implant BR (usually preceded by tissue expansion) were invited to participate in the study. Fifteen women did not respond, 10 patients declined and 71 women consented to participate (74.0%).

*DIEP flap BR*

All 101 women who were scheduled for a DIEP flap BR were asked to take part in the study. Seven women did not respond, 12 patients declined and 82 women consented to participate (81.2%).

***Procedure***

In the preoperative phase, an invitation letter explaining the procedure and purpose of the study, an informed consent, and a prepaid envelope were sent to all women on the BR waiting lists of the participating hospitals. A reminder letter was sent if patients did not respond within two weeks. They were contacted by phone if surgery was planned on short term. Patients, who returned informed consent, received a questionnaire including a range of demographic, clinical and psychosocial items which they were requested to fill in preoperatively. Patient reported clinical data were confirmed by medical records.

***Questionnaires***

Demographic information (e.g. age, having a partner or children (at home), educational level), and clinical data (e.g. indication for mastectomy, body mass index (BMI)) were collected. The latter were confirmed by checking medical records.

*Information provision*

Preoperative information seeking behavior concerning BR was measured with a study specific-questionnaire. Fourteen questions were developed to investigate the following aspects (Table 3): a) knowledge regarding BR options (items 1,2); b) different informational resources (items 3-8); c) general quality of information (items 9,10); d) activity level of information seeking (item 12) and e) independency of decision-making (items 11,13,14).

Questions 1 and 2 could be answered with “yes” or “no”. Items 3 to 8 were rated on a five-point Likert scale ranging from 1 “not at all” to 5 “very much”, where a higher score

indicates a greater use of the concerning resource. Questions 9 to 14 were rated on a five-point Likert scale ranging from 1 “totally disagree” to 5 “totally agree”.

*Autonomy*

The Autonomy Connectedness Scale – 30 (ACS-30) [29] was used to assess different aspects of personal independence or autonomy and is a shortened version of the original questionnaire containing 50 items [30]. The ACS-30 consists of three subscales: Self-Awareness (SA, 7 items); Sensitivity to Others (SO, 17 items) and Capacity for Managing New Situations (CMNS, 6 items). Items can be scored on a 5-point scale from 1 “disagree” to 5 “agree”. Reported reliability and validity of the ACS-30 are good [29]. The concept of autonomy is used in this study to indicate the extent to which women are capable of making an independent decision concerning BR.

*Coping*

The Utrecht Coping List (UCL) [31] was used to assess seven coping strategies: Active Coping (AC, 7 items); Palliative Reaction Pattern (PL, 8 items); Avoidance and Awaiting (AA, 8 items); Seeking Social Support (SS, 6 items); Passive Reaction Pattern (PS, 7 items); Expressing Emotions (EE, 3 items) and Comforting Thoughts (CT, 5 items). Answers could be rated on a 4-point scale from 1 “seldom or never” to 4 “very often”. A higher score reflects more use of the concerning coping strategy. The validity and reliability of the UCL have been found to be good [32-34].

***Statistical analyses***

Differences between implant and DIEP flap BR for dichotomous variables were analyzed with Fisher’s exact tests. Normally distributed continuous variables were analyzed using Student’s t test, not normally distributed and ordinal variables with Mann-Whitney tests. Categorical variables were tested with Chi square tests. Missing values were replaced by the mean score of the concerning series. To explore determinants of active information seeking, backwards hierarchical regression analysis was used. ACS and UCL subscales were compared to the normal Dutch population with Student’s t-tests. Data were analysed with the statistical package SPSS 16.0 (SPSS Inc., Chicago). Two-sided p-values $< .05$ were considered statistically significant.

## Results

***Non-respondents***

Ninety-three percent of the non-respondents (n = 44) underwent unilateral therapeutic mastectomy compared to 80% of the respondents (n = 153), of which 20% underwent therapeutic mastectomy combined with CPM ($p = 0.04$). Non-respondents and respondents did not significantly differ in age and timing of BR ($p = 0.50$ and $p = 0.35$, respectively). We assume the respondents are a representative sample of the total patient group.

***Demographic and clinical characteristics***

More women who chose implant BR were planned for reconstruction after therapeutic mastectomy combined with CPM. Women opting for DIEP flap BR had a higher BMI and their mean time interval between mastectomy and reconstruction was longer compared to women choosing implant BR. The patient groups did not differ in age, having a partner and/or children (at home), educational level and hereditary risk for developing BC (Table 1).

**Table 1. Participants characteristics**

| | **Implant group** | **DIEP flap group** | ***p* Value*** |
|---|---|---|---|
| | **n = 71 (%)** | **n = 82 (%)** | |
| Mean age at time of breast reconstruction (sd\ | 49.07 (9.95) | 49.40 (7.96) | 0.82** |
| Partner | 62 (87.3) | 65 (79.3) | 0.20 |
| Children | 62 (87.3) | 70 (85.4) | 0.82 |
| Children at home | 42 (59.2) | 43 (52.4) | 0.42 |
| Education | | | |
| low | 15 (21.1) | 16 (19.5) | |
| intermediate | 27 (38.0) | 28 (34.1) | 0.54¶ |
| high | 29 (40.8) | 38 (46.3) | |
| Inherited predisposition for BC[a] | 21 (29.6) | 17 (20.7) | 0.26 |
| Unilateral therapeutic mastectomy | 45 (63.4) | 77 (93.9) | < 0.001 |
| Therapeutic mastectomy with CPM | 26 (36.6) | 5 (6.1) | |
| Mean BMI (sd) | 24.0 (4.07) | 27.7 (3.64) | < 0.001** |
| Mean time since mastectomy in years (sd) | 1.43 (3.55) | 3.15 (2.58) | < 0.001¶ |

[a]: BRCA1/BRCA2/familial risk; BC: breast cancer; CPM: contralateral prophylactic mastectomy; BMI: body mass index; DIEP: Deep Inferior Epigastric artery Perforator; sd: standard deviation; * Fisher's exact test unless otherwise indicated; ** Student's t-test; ¶ Mann-Whitney test.

***Informational resources and information provision***

Initially, 38% of the women in the implant group were not aware of the possibility of breast reconstruction using autologous tissue compared to 17% of the women opting for DIEP flap BR ($p = 0.006$, Table 2).

For both groups the physician/plastic surgeon was the most important resource; however, women opting for implant BR rated their doctor as more important in their decision-making than women choosing for DIEP flap BR (Table 2, items 3 and 14, $p < 0.004$). Items 6 to 8 in Table 2 show that women who opted for DIEP flap BR rated a book, paper, magazine, internet and television as more important resources compared to women choosing implant BR ($p < 0.015$).

**Table 2. Knowledge and information seeking behavior in the decision-making process of implant and DIEP flap BR patients**

| | Implant group | DIEP-flap group | p Value* |
|---|---|---|---|
| | n = 71 | n = 82 | |
| *Knowledge* | n (%) | n (%) | |
| 1. "Before my decision I knew about the existence of BR with autologous tissue" | 44 (62.0) | 67 (82.7) | 0.006** |
| 2. "Before my decision I knew about the existence of implant BR" | 67 (94.4) | 78 (98.7) | 0.19** |
| *Use of information resources (range 1-5: not at all – very much)* | M (sd) | M (sd) | |
| 3. physician/plastic surgeon | 4.2 (.9) | 3.5 (1.2) | < 0.001 |
| 4. significant other/family/friend/colleague | 2.5 (1.3) | 2.2 (1.3) | 0.12 |
| 5. information leaflet | 2.4 (1.3) | 2.2 (1.2) | 0.36 |
| 6. book/paper/magazine | 1.4 (.7) | 1.9 (1.1) | 0.005 |
| 7. internet | 2.4 (1.5) | 2.9 (1.4) | 0.015 |
| 8. television | 1.4 (.7) | 1.8 (1.1) | 0.015 |
| *Information and decision-making (range 1-5: totally disagree – totally agree)* | | | |
| 9. "Information concerning my type of BR was well available" | 4.3 (1.1) | 4.0 (.8) | 0.001 |
| 10. "Information concerning my type of BR was understandable" | 4.3 (.5) | 4.1 (.5) | 0.02 |
| 11. "I totally support my decision for this type of BR" | 4.6 (.6) | 4.6 (.6) | 1.00 |
| 12. "I actively sought information about this type of BR" | 3.7 (1.2) | 4.2 (1.0) | 0.003 |
| 13. "I have the feeling the choice for this type of BR was not my own decision" | 1.6 (.9) | 1.3 (.6) | 0.07 |
| 14. "In the decision-making process for this type of BR I was affected by my physician/plastic surgeon" | 2.7 (1.4) | 2.0 (1.1) | 0.004 |

BR: breast reconstruction; DIEP: Deep Inferior Epigastric artery Perforator; SD: standard deviation * Mann-Whitney test, unless otherwise indicated; **: Fisher's exact test

Information concerning DIEP flap BR was less readily available (p = 0.001) and less clear (p = .022) than information regarding implant BR. Women opting for DIEP flap BR more actively sought for information (p = 0.003).

Women in both groups indicated they supported their decision, although there was a trend that women in the implant group had the feeling the choice for their type of BR had not entirely been their own (p = 0.07).

***Autonomy and coping styles***

Women from both BR groups did not significantly differ in self-awareness, the extent to which they are sensitive to others and their capacity to manage new situations. Their use of coping styles was also not significantly different (Table 3).

**Table 3. Mean Autonomy and Coping styles subscale scores of implant and DIEP flap BR patients**

| | Implant group | DIEP-flap group | p Value* |
|---|---|---|---|
| | n = 71 | n = 82 | |
| | M (sd) | M (sd) | |
| Autonomy (ACS-30) | | | |
| Self-awareness | 3.9 (.7) | 3.9 (.7) | 0.88** |
| Sensitivity to others | 3.6 (.5) | 3.5 (.6) | 0.16 |
| Capacity to manage new situations | 3.1 (1.1) | 3.2 (.9) | 0.96 |
| Coping styles (UCL) | | | |
| Active coping | 19.8 (3.4) | 20.0 (2.9) | 0.64 |
| Palliative reaction pattern | 18.8 (3.5) | 18.5 (3.3) | 0.40 |
| Avoidance and awaiting | 15.7 (3.1) | 15.5 (2.6) | 0.76 |
| Seeking social support | 15.9 (3.5) | 15.7 (3.8) | 0.71 |
| Passive reaction pattern | 10.6 (2.7) | 10.8 (2.5) | 0.70** |
| Expressing emotions | 6.3 (1.4) | 6.5 (1.7) | 0.58** |
| Comforting thoughts | 13.6 (2.3) | 13.4 (2.4) | 0.56 |

Higher scores indicate more self-awareness, sensitivity to others, capacity to mange new situations, and more use of the coping styles. * Student t-test unless otherwise indicated; ** Mann-Whitney test; DIEP: Deep Inferior Epigastric artery Perforator; SD: standard deviation; ACS-30: Autonomy Connectedness Scale - 30; UCL: Utrecht Coping List

Comparing the ACS subscales with the normal population, our patients had significantly lower scores on the ACS subscale "Sensitivity to Others" ($t_{(241)} = 4.44$; $p < 0.001$) [29], meaning they are less sensitive to others opinions, whishes and needs and are less likely to adapt to another person's believes or preferences. They scored higher on the UCL subscales "Palliative Reaction Pattern" ($t_{(379)} = -2.99$; $p = 0.003$), "Seeking Social Support" ($t_{(289)} = -4.01$; $p < 0.001$) and "Comforting Thoughts" ($t_{(351)} = -5.77$; $p < 0.001$), indicating our patients more often try to relax, share their worries with others and try to have positive thoughts when they need to adapt to demanding situations, compared to the healthy population.

**Determinants of active information seeking**

Patients who scored higher on the Active Coping Scale, more actively sought for information regarding BR ($p = 0.02$). In addition, women opting for DIEP flap BR were more active information seekers ($p = 0.003$). Finally, we found a tendency towards a higher score on the

autonomy scale "Sensitivity to Others", which was almost significantly associated with active information seeking (p = 0.053, Table 4), indicating that women who are more sensitive to others, tend to seek more actively for information regarding BR.

**Table 4. Determinants for actively searching for information regarding BR (item 12) after 9 steps**

| | B | Std. Error | Beta | t | Sig. |
|---|---|---|---|---|---|
| Constant | 0.71 | 0.92 | | 0.76 | 0.45 |
| Choosing implant (1) or DIEP flap BR (2) | 0.53 | 0.17 | 0.24 | 3.02 | 0.003 |
| Sensitivity to others (ACS-30) | 0.32 | 0.16 | 0.16 | 1.95 | 0.05 |
| Active coping (UCL) | 0.07 | 0.03 | 0.19 | 2.36 | 0.02 |

BR: breast reconstruction; ACS-30: Autonomy Connectedness Scale; UCL: Utrecht Coping List; B: regression weight; Beta: standardized regression weight.

## Discussion

In this study we explored information seeking behavior with regard to type of breast reconstruction in women, who were scheduled for either implant or DIEP flap BR after mastectomy.

Understandably, most women with therapeutic mastectomy combined with CPM were scheduled for implant BR (84%). Immediate bilateral BR with more complex reconstruction techniques like the DIEP flap method, is more difficult to schedule due to logistic problems because of limited availability and longer operation times resulting in long waiting lists. In addition, bilateral DIEP flap BR requires abdominal tissue for two flaps, which could have been a limitation for women with a lower BMI.

We found that 38% of women who had decided for implant BR were initially not aware of the option to reconstruct breasts with autologous tissue. The option of DIEP flap BR may not have been discussed with or offered to the patient because of insufficient abdominal tissue, due to logistic issues or the absence of required surgical expertise [35]. In addition, some women may have decided in favour of implant BR before they had their first consultation with the plastic surgeon. Information by the plastic surgeon on alternative options for BR may, therefore, not have altered their final decision.

Women in the implant group rated most information resources as less important than women in the DIEP flap group. Most women in the implant BR group had limited time to search for BR methods and perhaps less time to consult different resources as their time between mastectomy and BR was more often immediate or shorter compared to DIEP flap BR patients. Dealing with the diagnosis may have been their main priority in stead of focusing on BR. Women opting for DIEP flap BR may have had more opportunity to think about their reconstruction options and to consult different resources. Eventually, this could have led to the decision to opt for a more complex BR method. We did not ask *why* they had a prolonged time between mastectomy and reconstruction.

The reconstructive surgeon was the most important resource for both groups. For women who opted for implant BR, their surgeon was of greater influence on their decision. We speculate that women scheduled for immediate BR, given the time pressure and expected higher distress, may have relied more on the surgeon than women who had more time to consider alternative BR options. In addition, plastic surgeons may have suggested to undergo implant BR in these cases as it is a relatively simple, obtainable and cheaper method. Obviously, their professional advice may also have been based on other patient-related factors.

Patients reported that information regarding DIEP flap BR was less clear and less readily available than information about implant BR. An explanation could be that DIEP flap BR is generally less obtainable and a more complex BR technique compared to the more commonly performed implant BR.

Active seeking for information about BR was associated with the decision to opt for DIEP flap BR and with an active coping style. In accordance with previous findings, patients who had chosen microsurgical DIEP flap BR were active information seekers compared to women who had opted for implant BR [25]. Active information seeking is obviously required to be comprehensively informed about reconstruction options as information regarding DIEP flap BR may generally not have been actively offered by all physicians and/or institutions. On the other hand, patients who were engaged to their decision for DIEP flap BR, may have searched more actively for information.

The study-specific questionnaire showed that women in the DIEP flap group were more independent in their decision for BR compared to women choosing implants, which is in concordance with the findings of the study of Matros et al. [25]. Although data from the autonomy questionnaire ACS-30 were not significantly correlated with the decision for the type of BR, the patients in our study were more independent in their decision-making compared to a healthy sample of Dutch women.

Furthermore, when comparing our patients' coping styles, we found they scored higher on the subscales "Palliative Reaction Pattern", "Seeking Social Support" and "Comforting Thoughts" than the normal Dutch population. These findings indicate that women choosing BR generally try to distract themselves more when they are worried, seek social support and think positive, compared to healthy women. This is in accordance with previous studies that have shown that women with early-stage BC and BC survivors often have more adaptive coping styles compared to healthy women, which is positively correlated with quality of life aspects and personal growth [36-39].

A limitation of the present study could be that more women planned for CPM chose to participate in our study compared to women with unilateral therapeutic mastectomy. Women with CPM were mostly diagnosed with BC in the past, and therefore, at the time of inclusion could possibly focus on BR and study participation, instead of having BC treatment as their priority. We do not think this affected the representation of our population, although we have to keep in mind participants may have been more committed to their decision regarding BR.

Inevitably, our study was limited by selection bias, as patients could not be randomized to the BR type they received. In addition, not all participating hospitals offered both BR types described. However, DIEP flap BR was carried out in one of the academic centers as well as in one of the general hospitals, suggesting it was offered to different populations. Although one could argue the present study should have been carried out in a selection of patients that had been offered identical reconstruction options, we believe a large group of patients from multiple centers is representative for the Dutch patient population as information provision regarding BR is currently not standardized in our country. This is probably true for other countries as information regarding BR seems not yet standardized [4;40].

In conclusion, women opting for DIEP flap BR were more active and independent in their decision-making regarding the type of BR. Women opting for implant BR seemed less well-informed and more dependent on their surgeon. Possibly the pool of women who had implant BR and who were mainly influenced by their surgeon, could have been convinced to have a DIEP flap BR. However, although the decision regarding the type of BR is ultimately the patient's, factors such as patient suitability for a procedure, risk factors and timing of BR play a role in reaching this final decision.

During patient consultation regarding treatment options by (reconstructive) surgeons, it is necessary to verify if the patient is aware of all her reconstruction possibilities, including the opportunity to delay BR. In addition, it is important to specifically ask for her own preferences and expectations, to increase the chance that she will receive the reconstruction that suits best with her needs and wishes that will eventually improve satisfaction [41].

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