A Qualitative Assessment of the Journey to Delayed Breast Reconstruction

Une évaluation qualitative du parcours vers une reconstruction mammaire tardive

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Abstract

Background: Canada has low immediate breast reconstruction (IBR) rates compared to the United States and Europe. Breast cancer survivors live with mastectomy defects sometimes for years, and this represents an area for improvement in cancer care. **Purpose:** This study qualitatively assessed (1) information provided about breast reconstruction at the time of cancer diagnosis among women seeking delayed breast reconstruction (DBR) and (2) referral practices for plastic surgery consultation for DBR. **Methods:** Fifty-two consecutive patients seen in consultation for DBR at a single Canadian tertiary care centre completed questionnaires regarding their experience in seeking breast reconstruction. Seven semi-structured interviews were conducted to further explore themes identified through questionnaires. Questionnaire responses and interview transcripts were analyzed for recurring themes using standard qualitative techniques. **Results:** A significant portion of women (43%) was interested in reconstruction prior to mastectomy, yet IBR was infrequently discussed (14%) or discouraged by their oncologic surgeons (33%). Common patient reasons for not pursuing IBR were referring physician objection and not having adequate knowledge. Women expressed wanting to discuss reconstruction at the time of cancer diagnosis. Half of the patients had attended another consultation, but the initial plastic surgeon either did not offer procedures for which these women were candidates or had prohibitively long surgical wait times. **Conclusion:** Lack of information about reconstructive options at the time of cancer diagnosis and perceived access barriers to plastic surgeons may contribute to underutilization of IBR in Canada. Access to breast reconstruction can be improved by reducing inefficiencies in plastic surgery referrals.

Résumé

Historique : Le taux de reconstructions mammaires immédiates (RMI) est faible au Canada par rapport aux États-Unis et à l'Europe. Les survivantes du cancer du sein vivent parfois avec une mastectomie pendant des années, ce qui représente un secteur à améliorer dans les soins du cancer. **Objectif :** La présente étude était une analyse qualitative 1) de l'information transmise au sujet de la reconstruction mammaire au moment du diagnostic de cancer chez les femmes qui souhaitent une reconstruction mammaire tardive (RMT) et 2) des pratiques d'orientation vers une consultation en chirurgie plastique en vue d'une RMT. **Méthodologie :** Cinquante-deux patientes consécutives vues en consultation pour subir une RMT dans un seul centre canadien de soins tertiaires ont rempli des questionnaires sur leur expérience dans l'obtention d'une reconstruction mammaire. Les chercheurs ont organisé sept entrevues semi-structurées pour explorer les thèmes colligés grâce aux questionnaires. Ils ont utilisé des techniques qualitatives standards pour analyser les réponses aux questionnaires et les entrevues transcrites et relever des thèmes récurrents. **Résultats :** Avant la mastectomie, une forte proportion de femmes (43 %) souhaitait subir une reconstruction, mais leur chirurgien oncologue abordait rarement la RMI (14 %) ou la déconseillait (33 %). Les raisons fréquentes pour ne pas demander une RMI étaient l'objection du médecin traitant et le manque de connaissances suffisantes. Les femmes

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indiquaient vouloir parler de reconstruction au moment de leur diagnostic de cancer. La moitié des patientes avait participé à une autre consultation, mais le premier plasticien n'avait pas offert d'interventions auxquelles ces femmes étaient candidates ou présentait une trop longue liste d'attente avant l'opération. **Conclusion :** Le manque d'information sur les possibilités de reconstruction au moment du diagnostic de cancer et les obstacles perçus à l'accès aux plasticiens peuvent contribuer à une sous-utilisation de la RMI au Canada. Pour améliorer l'accès à la reconstruction mammaire, on peut réduire les inefficacités en matière de demande de consultation auprès des plasticiens

Keywords

breast cancer, immediate breast reconstruction, delayed breast reconstruction, access barriers

Background

Immediate breast reconstruction (IBR) can offer patients with breast cancer significant quality-of-life benefits¹ with equal oncologic safety^{2,3} when compared to delayed reconstructive options. For reasons that are not fully understood, the use of IBR in Canada has historically been low when compared to the United States and Europe.^{4,5} Efforts to measure and understand breast reconstruction utilization in Canada have been limited. Current knowledge is based largely on retrospective reviews of administrative databases, combining all mastectomy patients without considering whether a woman is interested in reconstruction.⁶ Little is known about the actual barriers encountered by Canadian women who are interested in, and actively pursuing reconstruction.

As a result of only a minority of Canadian women receiving IBR, many breast cancer survivors are left waiting for delayed breast reconstruction (DBR). One retrospective study conducted in Ontario reported that patients seeking DBR waited on average, 3 times as long from referral for consultation to the day of surgery than patients undergoing IBR between 2001 and 2004.⁷ The current provincial surgical wait time database only captures the period between a patient signing up for an operation and undergoing surgery.⁸ This however is only one small part of a patient's journey to DBR. Wait times for DBR consultation (from the time of referral to the day of plastic surgery consultation) and the number of different plastic surgery consultations a patient has attended prior to surgery are not recorded. In our institution's experience, many women that are interested in pursuing DBR live with mastectomy defects for years before accessing breast reconstruction resources, representing an area for investigation and improvement in current breast cancer care.

This study was conducted to (1) qualitatively examine how patients currently awaiting DBR were informed about reconstruction at the time of cancer diagnosis and (2) explore the referral practices to plastic surgeons for DBR consultation experienced by these patients. In contrast to prior studies, we specifically examined barriers actually encountered throughout the journey to DBR.

Methods

This was a study of consecutive patients seen in consultation for DBR at a single tertiary care referral centre over a 1-year period. Following review by the institutional research ethics board, women aged 18 to 75 who were fluent in English, had

undergone unilateral or bilateral mastectomy, and been referred for plastic surgery consultation for DBR were eligible for study enrollment. Patients were excluded if they had undergone previous breast reconstruction surgery.

This study had 2 phases. In phase 1, participants completed a questionnaire exploring their experience in learning about breast reconstruction and their decision to attend a consultation for DBR. The single-page questionnaire consisted of seven short answer and multiple-choice items. Responses were tabulated, coded, and reviewed for recurring ideas and themes according to standard qualitative techniques until data saturation was achieved. Another member of the research team with experience in qualitative methods (LS) verified the results.

Phase 2 consisted of semi-structured interviews to further explore patient experiences in becoming informed and making decisions about breast reconstruction. A random sample of patients who completed questionnaires in phase 1 were approached regarding interview participation. A researcher who had no involvement in their clinical care conducted the interviews at the end of their initial consultation. The interviews followed a predetermined interview guide (Appendix A). Interview transcripts were reviewed and coded for recurring ideas and themes independently by 2 researchers using constant comparative method. Interviews were conducted continued until data saturation was reached.

Results

A total of 52 patients completed the questionnaire, and 7 semi-structured interviews were conducted. Table A1 displays patient demographics and disease characteristics. All women had previously undergone mastectomy secondary to a diagnosis of breast cancer.

Phase 1: Questionnaire

Timing of interest in breast reconstruction. The timing of interest in breast reconstruction was distributed in a bimodal pattern. Forty-three percent of study participants reported that they were interested in reconstruction prior to undergoing mastectomy (Figure B1). These patients reported wanting reconstruction either "as soon as they [general surgeon] told me I needed a mastectomy." A second group of patients reported becoming interested in reconstruction only after a period of living with the mastectomy defect.

Patient education at the time of breast cancer diagnosis. The majority of participants reported that IBR was not discussed as an option at the time of breast cancer diagnosis (Figure B2).

I wasn't told anything.

Other patients reported that they were advised that reconstruction is best deferred until after all cancer treatment is completed, and no other information about reconstruction was provided.

She [general surgeon] said to deal with it after all my treatment if I wanted to.

The majority of patients felt that information about reconstructive options, and specifically IBR, would have been helpful at the time of diagnosis (Figure B3). These patients wanted to know "that it [IBR] was a possibility" and the "advantages/disadvantages to having it [reconstruction] done at this stage."

Reasons for delaying reconstruction. Among study participants, the most commonly cited reasons for not pursuing IBR were (1) the potential or expected need for radiation, (2) physician advice to defer reconstruction, and (3) lack of knowledge about IBR (Figure B4).

Multiple consultations. Out of 51 patients, 25 (49%) reported that they had seen at least one other plastic surgeon prior to being seen at our institution (Figure B5). Many of these patients were referred to, and seen by another plastic surgeon that could not offer the breast reconstruction procedures that the patients were candidates for.

Phase 2: Interviews

Two key themes were identified as reasons patients to choose DBR instead of IBR: (1) information and (2) perceived access barriers (Table A2).

Information. General information about breast reconstruction. Women felt that the amount of information they received about breast reconstruction at the time of cancer diagnosis was inadequate. Patients believed they were uninformed or misinformed about their reconstructive options when they made the decision to undergo mastectomy.

There wasn't anything done. And the information I did get was misinformation.

Information about IBR. When asked specifically about IBR, participants said they did not consider IBR because they did not know that it was an option prior to undergoing mastectomy.

They said not to worry about reconstruction. But I didn't know there could be an immediate.

Well there wasn't an option so I didn't even consider it.

Timing of information. Reconstruction was sometimes not discussed with patients until after mastectomy. Information about breast reconstruction was provided too late for women to make an informed decision about surgery. Participants wanted information about the available breast reconstruction options to be discussed at the time of diagnosis.

My surgeon... said we'll take the breast out and then later when everything settles down, we'll talk about reconstructive surgery.

It would have been better to have known those options earlier on... You're left in the dark right up until you finally get that meeting with the doctor [plastic surgeon].

He should tell me... [that] you have [the] choice to do a reconstruction. And if you want, I can refer you to see the plastic surgeon. At least he should ask me. At least he should give me the choice.

Although the final treatment decision may have been the same, interviewees felt that they would have been more certain of their decision had information about reconstruction been provided prior to mastectomy.

Information source. Participants believed that their cancer care team should have offered information about breast reconstruction. Having just received a breast cancer diagnosis, they were not equipped to ask the questions needed to become informed about breast reconstruction. However, women did not feel that a plastic surgeon specifically was needed to provide this information.

When you really don't know that much about it, it's hard to figure out what you would ask... You have no idea what kind of reconstruction; they don't go into that at all.

I didn't ask the doctor [general surgeon] because... I'm not sure about my case... maybe I would die at that time.

The idea [reconstruction] should be mentioned to them by like the doctor or the nurse, whoever they work closely with.

Perceived access barriers. Availability of plastic surgeons. When IBR was discussed, patients were often discouraged from pursuing it, with the inability to access plastic surgeons in a timely manner being one of the most commonly cited reasons. Women were told IBR was not possible without causing undue delay to their cancer treatment.

There just wasn't a doctor available that quick. You could not have it [reconstruction] done at the same time as your mastectomy.

[The general surgeon] did mention reconstruction but that there was a long waiting list. It would not happen for a long time... Only in the States [is IBR available], not here in Canada.

Multiple plastic surgery consultations. Women were referred for multiple plastic surgery consultations primarily because the previous plastic surgeon either did not offer autologous or free-flap reconstruction or had a longer surgical wait time.

She [plastic surgeon] believed that I will use the muscle of my back and it's difficult for her and I should go to specialist.

He's great, except the surgery keeps getting referred [deferred], moved back.

Discussion

The objective of this study was to explore the patient experience of becoming informed about breast reconstruction and the path to DBR. Through patient questionnaires and interviews, 3 key themes were identified: (1) lack of knowledge and underutilization of reconstruction, (2) multidisciplinary collaboration, and (3) inefficient referral practices.

Lack of Knowledge and Underutilization of Reconstruction

We found that breast reconstruction, particularly IBR, remains infrequently discussed before mastectomy decision-making. This gap in patient care has been identified in prior studies and appears to continue in Canada. A population study from the United States found that only 33% of patients had a general surgeon that discussed reconstruction prior to surgical treatment.⁷ Another US survey also found that women who had only recently undergone mastectomy lacked knowledge about breast reconstruction, answering only 37.9% of knowledge questions correctly.⁹ This lack of information was 1 key reason cited by women in our study for not receiving IBR.

Multidisciplinary Collaboration

Many patients in our study voiced a need for designated oncology-trained healthcare professionals to provide information about reconstruction to all women diagnosed with breast cancer. As one of the first point of contact in breast cancer care, general surgeons play a key role initiating the discussion about reconstruction. A recent study found that being referred for plastic surgery consultation greatly increased a patient's likelihood of receiving reconstruction.¹⁰ Another US study evaluating the role of surgeons in the delivery of breast cancer treatment found that general surgeons accounted for 26% of the variation in whether a patient received breast reconstruction. Reconstruction rates ranged from 6% to 84% based on general surgeon factors alone, with propensity to refer patients to a plastic surgeon before definitive surgery decision accounting for the largest amount of between-surgeon variation in immediate reconstruction.¹¹

Improvements in access to breast reconstruction can be made through collaboration between plastic surgeons and the multidisciplinary cancer care team. General surgeons and breast cancer nurses, for instance, can help patients make more informed treatment decisions by providing newly diagnosed patients with breast cancer with accurate information about reconstruction. Studies from the United States show that women treated by general surgeons who practice within an organizational framework that facilitates multidisciplinary care that includes plastic surgeons were more likely to undergo

reconstruction. High propensity to refer patients for reconstruction was associated with working in a cancer centre. Low-referral surgeons perceived more access barriers and lower patient priority for reconstruction.¹² Collaboration between members of the multidisciplinary care team could greatly improve patient access to breast reconstruction.

Inefficient Referral Practices

Many women attend multiple consultations for DBR because the previous surgeon either did not offer the procedure she was eligible for or had prohibitively long surgical wait times. Plastic surgery consultations are a scarce health resource, and this redundancy further limits patient access to breast reconstruction care.

General surgeons, oncologists, and family doctors are key members of the team caring for patients with breast cancer and are also the gatekeepers for breast reconstruction referrals. These physicians, however, make referral decisions individually and often without key information about surgeon scope of practice, wait times, or alternate providers. Wait times from referral to consultation for breast reconstruction are currently not measured. Ontario surgical wait times also vary widely depending on geographic location, and information is incomplete for some locations.⁸

In order to improve the current referral practices, up-to-date information regarding location, scope of practice, wait time for consultation and surgery for Canadian reconstructive surgeons is needed. In recognition of this, the province of Ontario has recently implemented wait 1, an expansion of the wait times information system that will capture time from referral to consultation.¹³ This is 1 crucial step towards developing a coherent and efficient referral system. Development of an additional centralized mechanism for directing referrals to plastic surgeons appropriate for individual patients may further increase the efficiency by reducing the number of plastic surgery consultations needed per patient. Such an integrated referral system could also provide a complete list of surgeons accepting referrals for DBR consultation, better match patient and surgeon factors, balance wait times between surgeons, and allow more women to access breast reconstruction consultation in a timely manner.

Limitations

Our study was conducted at a single tertiary care cancer centre that offers microsurgical oncology reconstruction, and therefore more likely to include patients with challenging surgical issues. As IBR eligibility criteria vary between centres, our study may represent patient who were previously considered unsuitable for reconstruction in other institutions. Most of our patients also required postoperative radiation treatment, which is considered by some practitioners to be a contraindication for IBR. The general surgeons in our institution have developed a close collaboration with the senior authors (LS, JL) and routinely refer women for timely consideration of IBR. All of the patients in this study who had discussed IBR prior to mastectomy were referred from within our institution. Therefore, the

frequency in which IBR was discussed in our study population may be higher than in jurisdictions where general surgeons and plastic surgeons do not collaborate or where IBR is not available. Most women were also referred from the Greater Toronto area, which is relatively well-served compared to other jurisdictions in Ontario and Canada. In underserved areas, access to plastic surgeons and reconstructive procedures may be more restricted and IBR utilization may be lower. Finally, a number of the questionnaire and interview questions relied on participant recall and therefore subject to bias.

Conclusion

This study suggests that the lack of timely information about reconstructive options and perceived access barriers to plastic surgeons contribute to the underutilization of IBR in Canada. Patients in our study wanted breast reconstruction discussed by the multidisciplinary cancer care team as part of the treatment decision-making process. Current inefficiencies in the use of plastic surgery referrals further restrict access to breast reconstruction.

Appendix A

Table A1. Patient characteristics (n = 52)

Average age	51 years	
Mastectomy laterality		
Unilateral	46	88%
Bilateral	6	12%
Reconstruction laterality		
Unilateral	38	73%
Bilateral	14	27%
Mastectomy indication		
Breast cancer	43	83%
Prophylactic	0	0%
Breast cancer + prophylactic	9	17%
Radiation treatment		
Yes	41	79%
No	11	21%
Chemotherapy		
Yes	45	87%
No	7	13%
Average time since mastectomy	23 months	
Average time since completion of adjuvant radiation therapy	13 months	

Table A2. Summary of Major Interview Themes and Subthemes.

Theme	Subtheme
Information	General information about breast reconstruction
	Information about IBR
	Timing of information
	Information source
Perceived access barriers	Availability of plastic surgeons
	Multiple plastic surgery consultations

Appendix B

Figure B1. Patient questionnaire responses to the question “At what point did you become interested in breast reconstruction?”

Figure B2. Patient questionnaire responses to the question “Were you told about immediate breast reconstruction (IBR) at the time of your breast cancer diagnosis?”

Figure B3. Patient questionnaire responses to the question “What information about immediate breast reconstruction (IBR) would have been helpful at the time of your diagnosis?”

Figure B4. Patient questionnaire responses to the question “What contributed to your decision not to have immediate breast reconstruction (IBR)?”

Figure B5. Patient questionnaire responses to the question “Have you seen another plastic surgeon about breast reconstruction?”

Declaration of Conflicting Interests

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