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# **Research Article**

# Reported Experience of Women Who Received a New Self-management Physical Therapy Instruction before Breast Cancer Surgery - A Case Series

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## Abstract

**Objective:** The need to provide information and instruction for patients post breast cancer (BC) surgery is highly supported Several studies have shown pre-surgery instruction to be beneficial. However, as information about the experience of patients receiving pre-surgery instruction is limited, this case series aims to describe the experience of nine individual women who received newly developed, updated, self-management physical therapy (PT) instruction before BC surgery.

**Methods:** Participant interviews were conducted by telephone using a list of questions prepared in advance about their personal experience. Medical files provided demographic and medical data. Interviews were performed by one physical therapist, transcribed, and analysed by two co-authors. Similarities and differences between transcripts were summarized.

**Results:** Most participants found the instruction content to be easily understood and beneficial. They also expressed the value of receiving instruction before BC surgery. Nine felt that the instruction should be routinely provided. Criticism was mainly for lack of instruction regarding pain control, dealing with exercise fear avoidance, and that women unfamiliar with self-management and independent exercise may benefit less.

**Conclusion:** Most participants found the new instruction understandable and beneficial when provided pre-surgery. However, this may not be suitable practice for all women as some may need personalized post-surgery instruction. Therefore, in addition to pre-surgical instruction provision, a post BC surgery PT visit would identify those requiring individualized instruction. Information about outpatient PT services

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should be added to pre-surgery instruction. Future studies should examine content and provision timing in a large sample of participants.

**Keywords:** breast cancer surgery, physical therapy, instruction, self-management

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### 1 INTRODUCTION

The need to provide information and instruction to patients post breast cancer (BC) surgery is highly supported<sup>[1-5]</sup>. Several studies have shown that pre-surgery instruction is also beneficial<sup>[3]</sup>. However, information about the experience of patients receiving instruction is limited<sup>[6,7]</sup>. Recently, new recommendations for professionals providing individual patient instruction and self-management instruction for women after BC surgery were developed in Israel and made available on-line<sup>[8,9]</sup>. The need for this project was based on a literature review, a survey assessing instruction alignment with current evidence among physical therapists certified in lymphedema treatment (PTCLT)<sup>[9]</sup>, and the existing instructions in Israeli medical centers (unpublished material) which exposed the need to provide information to women who had undergone BC surgery<sup>[3,4,6,10-13]</sup>. Most medical centers in Israel do provide physical therapy (PT) instruction one day after surgery, however, it is not unifrom in terms of content and receiving population.

The new body of instruction, developed as self-management material, addresses patients in the first person and uses everyday language<sup>[8]</sup>. It includes general recommendations for good health and risk reduction for side-effects after BC surgery such as regular physical activity, hygiene, and routine medical follow-up. Exercise prescription, according to recovery stage, is illustrated by color photographs and differentiates between women at high or low risk for side effects (post axillary / sentinel lymph node dissection; ALND / SLND). In addition, the information is translated from Hebrew into Arabic, Russian and English, which are the most used second languages in Israel. These were sent on-line to PT departments in all medical centers, to all PTCLTs in the country and uploaded onto the web sites of the Israel Physiotherapy Society<sup>[14]</sup>. The English version for women after ALND is available here as a supplement. In addition, a video instruction for younger women was produced by the Stop-Cancer Association and is freely available on YouTube<sup>[15]</sup>. The potential contribution of online material to people with cancer was recently evaluated and found to be high<sup>[16]</sup>.

Further examination of the literature exposes a dilemma regarding the best timing for information provision. While all women require movement instruction after BC surgery, the majority are not receptive to learning new educational material immediately after surgery<sup>[6,10,11]</sup>. Pre-surgery instruction is limited despite evidence about its contribution and that distress levels before BC surgery may be higher than after<sup>[3,17,18]</sup>. Thus, to further enhance instruction provision efficacy for women undergoing BC surgery, there is a need to examine provision timing as a factor.

Patient experience plays a major role in the evaluation of educational programs. Therefore, this case series aims to describe women's individual experience to pre-surgery self-management instruction. This study will be a primary step to evaluate women's experience and, with additional studies, may be instrumental in deciding future clinical practice.

### 2 MATERIALS AND METHODS

### 2.1 Study Design and Participants

This case series includes a convenience sample of nine middle-age to older women who underwent initial BC surgery in one large medical center in Israel. Those diagnosed with other cancers or not fluent in Hebrew were excluded. Participants received the new self-management PT instruction (printed) from a nurse coordinator a few days before surgery.

# 2.2 Data Collection

Participants were recruited and interviewed between 2021 and 2022. They were interviewed by telephone using a pre-prepared list of 19 questions about their personal experience (Supplementary List 1). The questions were devised by the research team (HSC - a physical therapist clinician with over 12 years' experience in oncology rehabilitation, TJ - a physical therapist, PhD in Public Health; RP - physical therapist with over 40 years of experience, certified in lymphedema treatment and a Casley-Smith Clinical Instructor in Lymphedema Treatment).

The list of questions (Q) included 15 closed (yes / no) and four open-ended questions (Supplementary Table 1). Interviewees were encouraged to add comments after each answer. The interview topics were related to post-surgery recovery (Q 1-3), instruction provision and clarity (Q 4-8), instruction performance and contribution (Q 9-15), physical activity (Q 16,17) and additional comments (Q 18,19).

Participant demographic and medical backgrounds were obtained from their medical files.

2.3 Procedure

A nurse coordinator, working in the breast surgery department, recruited the participants a few days prior to surgery, requested signed consent, provided a printed copy of the the new self-management PT post BC surgery instruction, and an explanation of its purpose. After discharge, a physical therapist at the same medical centre, sent the participants an email with the study information and scheduled a time for a telephone interview<sup>[19]</sup>. The interview design followed a deductive approach based on the belief that pre-surgery information would be an effective means to improve the experience of coping with post-surgery rehabilitation and had a predetermined framework for the analysis<sup>[20]</sup>. The interviewer typed the answers during the phone call and sent them to the interviewee for confirmation of accuracy. Transcripts were sent to two authors (Jacob T and Peleg R) for analysis. They each summarized answers to open questions under the main themes. Possible relationships to participants' background were identified and discussed.

### 2.4 Ethical Approval Statement

The study was approved by the Ethics Committee of the Medical Center (No. RMB-0200-21).

### **3 RESULTS**

## 3.1 Participant (P) Characteristics

Participants' ages ranged from 43 to 81 years, all were married, and, other than one, had completed at least high school. Regular exercise was reported by six (P.1-4,6,7) with walking being the most popular physical activity. Eight were discharged the day after surgery (P.1-5,7-9) (Table 1). Four participants underwent lumpectomy with SLND (P. 5,7-9) and five had lumpectomy with ALND.

### 3.2 Experience of Post-surgery Health and Functioning

Six participants reported their health to be good (P.1-3,9) or very good (P.4,5) and three reported moderate or poor health (P.6-8). Two had resumed to their usual activities (P.2,5), four had partially resumed (P.1,3,4,9) and three felt they could barely function (P.6-8). Limited arm use was reported by five participants (Table 2).

### 3.3 Instruction Provision and Clarity

Six participants read the instructions before surgery (P.1-5,9) and three on the day following surgery (P.6-8). Details of answers are presented in Table 3. All participants expressed the value of offering this information to patients before or after BC surgery. Seven (P.1-5,7,9) expressed satisfaction with the benefit they gained from the instructions and said that the instructions and pictures were very clear. Three mentioned re-reading it several times (P.2-4). The exercises were described as "suitable" by participant

4 and as "clear" by participants 6, 8 and 9 despite reports of pain preventing complete exercise performance.

Participant 1 said that the instructions helped her understand what arm activity was recommended despite surgical wound healing complications. She felt almost back to normal, and her hand was fine. Her awareness as a nurse working in BC surgical ward prompted her to comment that post-surgical instructions for different types of breast reconstruction surgeries would be a valuable addition.

The instructions were clear for participant 2, and she performed all the exercises routinely. She appreciated the work that had been invested in writing the instructions and felt that the exercises were very helpful to her. However, she underwent surgery for the first time in her life and expressed fear of general anesthesia and a need for information about pre- and post-surgery procedures. In addition, she would have liked information about exercise during radiation therapy. She also criticized the lack of a post-surgical reminder to follow the instructions and their importance for successful arm rehabilitation and return to normal life. Participants 1 and 2 remarked that the instructions did not cover all their pre-surgery requirements such as what to bring to the hospital.

Participant 3 kept her instruction booklet close at hand for reference when necessary. She preferred mat exercises with printed instructions, as provided in this study, to the inconvenience of reading online text off a screen while exercising. Participant 4 mentioned that her previous participation in gym classes made it easy to understand exercise instruction. Participant 6 said that despite the surgery, treatment demands, and emotional turmoil, she understood the information clearly. However, she mentioned that fear of pain caused her to limit her arm movements. She added that post discharge outpatient PT for post-surgical advice and post BC surgery rehabilitation is also necessary. An insight from participant 7 was that the instruction timing was less relevant for efficacy than patient compliance with exercise performance. Participant 8 said that she felt the exercises were too aggressive for her pain level. She expressed doubt concerning feasibility of exercise soon after surgery due to pain. She had difficulty performing the exercises as instructed and mentioned disliking exercise in general. She also expressed frustration that no staff members were available to provide predischarge information. The lack of additional post-surgical PT was considered a weakness also by participant 2 Selected quotations of participants' answers are presented in Table 4.

### **4 DISCUSSION**

This case series is a preliminary study on the experience of nine individual women who were provided with newly developed self-management PT instruction a few days

**Table 1. Participants Background Characteristics** 

Participant	Age (Y)	Family Status	Children (N)	Education	Regular Physical Activity before Surgery	Type of Physical Activity before Surgery	Hospitalization (Days)	Time from Surgery to Interview (Days)
1	55	Married	3	Master's degree	Yes	Walking, Pilates	1	12
2	58	Divorced		High school + Certification studies	Yes	Walking	1	5
3	72	Married	3	Master degree	Yes	Walking & swimming	1	16
4	81	Married	4	High school + Certification studies	Yes	Gardening Walking and gym in the past	1	11
5	69	Married		11 grades	No		1	27
6	45	Married	3	High school	Yes	Walking	2	35
7	55	Divorced	3	High school	Yes	Walking	1	15
8	74	Married	2	Above High school	No		1	18
9	43	Married	3	High school	No		1	17
Total	Average (SD): 61.3 (13.3) Range: 43-81	Married - 7 Divorced - 2			Yes - 6 No - 3			Average (SD): 17 (8.9) Range: 5-35

Table 2. Participant Breast Cancer Surgery Characteristics, Health Status and Daily Activity

Participant	Operated Side	BC Surgery	Lymph Nodes Dissection	General Perception of Health at Interview	Return to Usual Activities	Limited Arm Use
1	R	Lumpectomy	5	Good	Partial	None
2	L	Lumpectomy Chemotherapy prior surgery	6	Good	Almost 100% from the beginning, with caution, according to the instructions, not to cause any harm	None, except some pain and swelling
3	R	Lumpectomy	7	Good	Partial	Yes
4	R	Lumpectomy	3	Excellent	About 80%. Warned by family to be careful with the arm	None
5	L	Lumpectomy	Sentinel	Very good	Completely	None
6	L	Lumpectomy	7	Bad, still painful, weak	Not yet	Yes
7	L	Lumpectomy	Sentinel	Moderate, still pain at axilla and at operation site	Hardly, difficulty to cook, clean the house, very tired	Yes
8	L	Lumpectomy	Sentinel	Bad, still painful, weak, discomfort	No	Yes
9	R	Lumpectomy	Sentinel	Good	About 50%	Yes

before their BC surgery. The timing was chosen after previous studies showed that women undergoing BC surgery are not attentive to new information immediately after surgery<sup>[10,11]</sup>, and that pre-surgery instruction may be preferable<sup>[3,17,18]</sup>. As the instructions are a 'self-management' intervention, no additional PT guidance was provided.

Participants received printed instructions to eliminate computer illiteracy as a limitation. The information provided was perceived as easily understood and helpful by seven of the nine participants who differed in age and in time after surgery when interviewed. Some differences in participant characteristics and experience deserve attention.

Table 3. Participant Answers to Questions Relating to the Instructions

Participant	When Did You Read the Instructions?	What Would be the Best Time to Read the Instructions	Are the Instructions Clear?	Did You Follow the Instructions' Recommendations?	Did the Instructions Help You?	Did You Receive Additional Instructions?
1	Immediately after receiving them	Pre-surgery	Very clear	Yes	Yes, very much	Only from family
2	Before and after surgery and at home	Pre-surgery	Very clear	Yes	Yes, very much	No
3	Before and after surgery	Pre-surgery	Very clear	Yes	Yes, very much	No
4	Immediately after receiving them and after surgery	Don't remember if pre- or post- surgery	Very clear	Yes	Yes, very much	Yes, my sister is a nurse and provided more explanations.
5	Before surgery	Pre-surgery	Clear	Yes	Yes, very much	No
6	After surgery	Pre-surgery	Clear	Yes	Partly, the arm is still restricted	
7	After surgery	Not important as long as you do the exercises	Clear	Partly after surgery and then stopped	It helped	Yes, provided by a physician
8	After surgery	Do not know	Clear but difficult to follow at that time	Do not know if I did it correctly. Did not receive in person guidance.	No	No
9	Before surgery	Pre-surgery, Important to read and be prepared	Clear	Yes	Partly	No

# **4.1 Instruction Suitability to Individual Needs and Requirement for Additional Guidance**

Although all participants stated that the instruction content was clear, some mentioned pain, fear avoidance and difficulty understanding the exercise instructions as reasons for limited exercise performance. Two who had reported difficulty in performing exercises also reported additional health problems and that they had not returned to their usual activities two weeks after surgery. These participants may have benefitted from more than a self-care program. Women with past exercise experience may have found the post-surgery exercise instructions more easily understandable. Thus, pre-surgery enquiry into previous physical activity habits may be helpful for post-surgery rehabilitation planning.

The fact that instruction content was clear for all participants may be related to their level of education. Women with less education, fear avoidance, pain and poor comprehension of the instructions may also have limited exercise performance after BC surgery. They would benefit if they were identified before their surgery and provided with additional post-surgery PT.

# **4.2 Timing for Instruction Provision**

Seven participants stated their preference for pre-surgery instruction. They expressed the importance of being able to

prepare for their immediate post-surgery period. This is in line with evidence that offering information immediately after surgery is not always helpful<sup>[6,10]</sup>, and that there are benefits to individual<sup>[3,17]</sup>, or group<sup>[18]</sup> pre-surgery provision. The pre-surgery period is a tense time for most women with BC and early information may help relieve some of their distress. This is supported by several previous studies published on women's need for information<sup>[1-5]</sup>. Provision of pre-surgical information may be easily integrated into existing services, so would be feasible logistically and financially. It seems that the main barriers for providing pre-surgery PT instructions can be overcome by improving awareness amongst staff and patients of evidence supporting the need for new protocols. In this case series, participants who did not support pre-surgery instruction provision expressed less relevance to the timing than to defacto information provision and that women' compliance with exercise performance is the deciding factor for efficacy. However, the question remains if instruction timing influences compliance.

It would also seem that routine post-surgery PT for some women, before discharge, in addition to provision of pre-surgery instructions, would still be necessary for those identified as potentially having difficulty with self-management and needing referral to outpatient PT services.

Table 4. Selected Quotation of Participants' Answers to Open Ended Questions

Questions	Participant	Answers
When do you think is the best time to receive instructions	1	Pre-surgery because there are instructions that should be carried out immediately on the first day after surgery. There is important information that should be provided before the operation.
	2	For women like me who are under great stress, instruction should be given before surgery. It is also important to talk about the instruction, before discharge, rather than just provide it. I could easily have forgotten about the booklet without a reminder. A physiotherapist should have come but did not. The surgeon discharged me and that was it. How can this be? It doesn't make sense. Especially as there is so much awareness about breast cancer.
	3	In my opinion, before surgery. My level of anxiety was low, I had previous experience with my family, so I was not very anxious and that's why I read the instruction I was given before the operation.  It is more effective to read before, so you know when to start exercise and to know what awaits you after surgery. I was very interested to read about getting back to movement and so the instruction was very important to me.
	4	I think that before the surgery is best. So, one will know what to expect.
	5	Before the operation is best. So, one will know what to do afterwards.
	6	Before surgery is best. I think that long before the surgery one should get the exercise instruction to prepare.
	7	It is not important when you receive the instruction, what matters is what you do with the information.
	8	After surgery is best. On Fridays, there are no doctors' visits, no social worker or doctor available. I don't think this is the way to treat a patient after surgery. I felt as if I had been thrown out. After my discharge, I had to go to the HMO to get answers to my questions.
	9	It is better to read and prepare before the operation; to be prepared.
What do you think about the clarity of the instructions?	1	I read all the instruction pages, the pictures are very nice, easy to understand and illustrate the exercises well.  The presentation itself is very nice, very pleasing to the eye. Very helpful for those who need to read it. Arranged with bullet points about what to do at each stage, easy for people to follow the instructions.
	2	Very clear instruction, no problem with that.
	3	Very good. Very simple and effective. I still have the booklet next to the TV, I look at it from time to time and do the exercises. I think it is excellent.
	4	The explanation is clear, especially for those who have done physical activity before (like me). The exercises are suitable for anyone who can lie on the floor.
	5	It was clear, just fine.
	6	I am doing so many tests, there is so much that needs to be read. The head sometimes doesn't work anymore, it's very difficult after surgery. But the instructions are totally clear.
	7	It was clear.
	8	It is difficult to do the exercises required one day after surgery. Certainly not these exercises. The surgical area is very sensitive. Sport and I are not friends. In order to do an exercise, I need to check if I can do it.  The explanations were not appropriate, I was in too much pain.
	9	The instructions were clear.
Personal progress	1	The instruction sheets were very helpful, even for me as a professional. At a time like this the instruction was very helpful. I constantly worked on breathing exercises, and on performing the other exercises and instructions given. I can see that this is very thorough instruction. The instruction sheets helped me understand what normal movement was and what was not, for my arm. Feels like I'm almost back to myself.
	2	I just made sure every time to see that I was at the right pace, and the range of motion adjusted according to your booklet. I have no movement limitation now.
	6	I do what I can, not less than necessary, or put it off till the next day. I am trying to embrace my arm in a good way, and hope that I won't suffer pain. I'm afraid of pain.
	7	The instruction was effective and as soon as I felt that the hand was returning to normal function, I stopped using it.
	9	It fits, but not 100%, I still have pain and it's hard to do all the exercises.

Additional comments	1	It would be better to have versions for different reconstruction surgeries as well as mastectomy and lumpectomy. It may be useful to combine the instruction with that provided by nurses, to reduce the number of instruction sheets and to avoid duplication (The patient is a nurse working in a plastic surgery department).
	2	I understand that this is a physical therapy booklet. But maybe you will work with nurses and add the instruction that I did not receive from the nurse before surgery. For example, what to bring to the hospital before surgery. Additional instruction after radiation is needed.
	3	It is very good to get the booklet separately.  Making a booklet out of the instruction sheets is my recommendation. From my experience during the COVID-19 virus lockdowns, doing lessons through the computer and the TV caused me neck discomfort. Some people my age prefer printed materials. When I lie on the mattress to exercise using the booklet, I don't have to raise my head to look at the computer screen.
	6	I want to know where to do physiotherapy. I want professional advice. Physiotherapy is very important to me. Now it's still fresh, but I'm afraid that the hand won't function like the right hand. We must do physiotherapy, which causes pain, like tight muscles. There is a change in the hand, I believe that with exercises it will be released. I need someone to guide me at least once a week.

### **4.3 Additional Comments**

The new instruction, developed for immediate postoperative recovery from BC surgery, may be useful when provided before BC surgery but, as expressed by participants 1 and 2, periods of adjuvant BC treatments also require relevant patient instruction. Shoulder and trunk range of movement may be challenged by additional radiotherapy or late onset surgical side effects and suitable exercises may help relieve some of these complications<sup>[21]</sup>. It follows that more information needs to be added to the existing instructions. In addition, individualized PT would be required for patients with later side effects for which self-management would be insufficient, such as issues related to radiation scarring, fibrosis, and post breast reconstruction surgeries. A comment by one participant that regular individualized PT is necessary after BC surgery is supported by studies recommending routine PT or nurse surveillance in outpatient clinics<sup>[22]</sup>. In Israel, most women post BC surgery remain under surveillance by physicians (oncologists and surgeons) only. Based on the authors' experiences, physician follow up is for cancer recurrence, shoulder range of motion and lymphedema but overlooks other side effects such as functional difficulties, pain, and Axillary Web Syndrome. Ideally, post BC surgery followup should include assessment for all side effects, inability to return to usual activities and quality of life issues and referral for treatment as necessary<sup>[5]</sup>.

### 4.4 Limitations

This is a case series and therefore limited to the experience of a small incidental group of participants who were interviewed as individuals. Different perceptions may emerge from a larger representative group of women. However, the participants did present a wide range of functional issues after BC surgery and experiences relating to instruction provision. Another limitation is that the report of participants' functional status was subjective. Future studies should also include objective measurements. In addition, the focus of this case series was on the contribution of a new post BC surgery self-management PT instruction to women before BC surgery.

A study comparing the contributions of existing post BC surgery instruction to the new instruction would also provide useful information for clinical practice.

### 4.5 Implications for Clinical Practice

A newly developed self-management instruction for women after BC surgery was offered to nine women awaiting BC surgery. Many found it clear and helpful. PT visits may still be necessary for all patients before discharge. This would provide a reminder to follow the instruction provided pre-surgery and additional guidance for those who need it. Furthermore, it is an opportunity to identify the needs and provide information about outpatient PT services. Future studies are suggested: to determine if a pre-surgery PT session is warranted to identify patients not suitable for self-management program, to identify which women are likely to require post-surgery PT and to formulate additional rehabilitation information and instructions for women undergoing breast reconstruction and adjuvant cancer treatments.

### **5 CONCLUSION**

Most women perceived new self-management PT post BC surgery instructions as understandable and effective when provided pre-surgery. However, some need additional personalized post-surgery instruction. Providers should consider factors such as educational level, familiarity with exercise and possible fear avoidance when deciding on pre-surgery or both pre- and post-surgery instruction. A PT visit may be justified for all women post BC surgery to identify those needing additional guidance and outpatient PT services. Future studies should examine these issues in a more representative sample using different options for instruction provision.

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Not applicable.

### **Conflicts of Interest**

The authors declared that they have no conflict of interest.

### **Author Contribution**

Cohen HS was responsible for conceptualizing, interviewing, writing reviews, and editing. Peleg R was responsible for conceptualization, transcription analysis, writing reviews, and editing. Bracha J was responsible for writing reviews and editing. Ifargan R was responsible for participant recruitment. Jacob T was responsible for conceptualization, transcription analysis, writing the first draft, writing reviews, and editing, as well as supervision. All authors read and approved the submitted version.

### **Abbreviation List**

BC, Breast cancer

P, Participant

PT, Physical therapy

PTCLT, Physical therapists certified in lymphedema treatment

Q, Questions

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