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LYMPHEDEMA TREATMENT CERTIFIED PHYSICAL THERAPISTS' AWARENESS OF AND PRACTICE PATTERNS FOR SIDE EFFECT RISK REDUCTION AFTER BREAST CANCER TREATMENTS

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ABSTRACT

Background: Lymphedema and other side effects (SEs) of breast cancer (BC) treatments are a clinical condition; hence, input based on clinical experience is highly relevant for deciding on intervention.

Purpose: To evaluate lymphedema treatment certified physical therapists' (CLT) awareness of SEs after BC treatments and their recommendations for risk-reduction.

Methods: In a mixed model qualitative study, a convenience sample of 20 CLTs with at least 5-years' experience were interviewed by phone call. Topics discussed were SEs after BC treatments and recommendations for risk reduction. The authors analyzed the data separately and then discussed the interpretation of similarities and differences.

Results: The most frequently mentioned SEs were arm lymphedema, breast swelling, pain, and shoulder movement limitation. General SEs, such as stress and anxiety, were also mentioned. There was consensus on the need for education about lymphedema, infection prevention, and physical activity, but not on the optimal timing to provide instruction, or for a preliminary session with a CLT.

Conclusions: The participants wereaware of and knowledgeable about common SEs after BC surgery and preventive interventions, in keeping with "best practice" recommendations. However, remaining controversies raise the need for a practical guideline for SEs risk reduction after BC surgery.

Keywords: Breast cancer, treatment, side effects, risk-reduction

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INTRODUCTION

Breast cancer (BC) prevalence in Israel is 28,823,with a yearly incidence of about 5000 cases [1]. A wide variety of side effects (SEs) related to BC treatments may occur any time after surgery and treatment [2,3]. These SEs are associated not only with physical discomfort, but also with reduced quality of life and, might cause distress and anxiety [4]. Upper quadrant morbidities, such as lymphedema and movement restrictions [3], and general SEs, such as cancer-related fatigue (CRF), and anxiety are common and makethe return to routine life difficult [5,6]. There is evidence that women report more treatment-related SEs than that recorded in their medical files [7,8].

Incidence- Up to 56% of the women reported at least one upper-body symptom [3]. The cumulative incidence of arm lymphedema was 13.5% at two years of follow-up, 30.2% at five years, and 41.1% at ten years [2,9]. The incidence of axillary web syndrome (AWS) is about 47%, with the most frequent onset occurring one to eight weeks post-surgery [10]. Seroma inspiration was reported at 20% after intra-operativeradiation therapy (IORT) + whole breast radiation (WBR) [11]. Risk factors for upper quadrant SEs are related to the initial surgery performed, the radiation therapy protocol [12], and patients' characteristics [2].

Risk reduction- Despite the frequency and implications of SEs, risk reduction instruction, and prophylactic treatment cover arm lymphedema [13-16]. However, the focus of professional literature has shifted in recent years from arm lymphedema alone [9,13] to upper quadrant lymphedema [17], upper-body morbidity [3], and additional wide-ranging general SEs [5,18] as is reflected in publications on the benefits of multidisciplinary teamwork in the management of breast cancer [19-21].

There is evidence that risk for some SEs can be reduced throughout both initial and later recovery periods [13-16]. For example, preoperative assessment enabled early diagnosis and treatment of lymphedema [13,14]. In two randomized control trials, initial physical therapy (PT) with or without the use of compression garments was effective in the prevention of secondary lymphedema, during the first year after ALND [16]. There is a strong consensus that physical activity (PA) [5,22], and PT which includes exercise to maintain and improve shoulder range of motion, infection prevention, and early recognition of swelling [22], are effective interventions for lymphedema risk reduction. Also recommended are arm compression while performingresistance exercises [25], and during flights [16,29] despite controversial scientific evidence regarding effectiveness [30,31].

Breast swelling, seroma, and AWS are considered self-limiting conditions, but in some cases they became chronic. To the best of our knowledge, prevention has not been studied, and treatment studies are rare. The conclusion of a literature review was that PT might have a useful role in the treatment of AWS, but risk reduction was not mentioned [24].

Few publications have focused on aprotocol for instruction provision. Questions such as, should all patients be instructed, what is the optimal time to provide instruction, and for an initial visit with CLT, has been rarely discussed. For example, in one study, researchers suggested that all patients should be instructed regarding lymphedema prevention [32], whereas a different study indicated that only patients who are at high risk of developing lymphedemas should receive prevention instruction [18]. Stout et al. (2008) claimed that the preferred time to give instract is before surgery [14], and later recommended prospective surveillance conducted during periodical follow-ups with a CLT [18].

In Israel, physical therapists undergo post-graduate training in lymphedema treatment in the Foldi (in the past), Vodder, and Casley Smith methods of treatment (ongoing) [34-36]. Basic and refresher training includes SEs such as AWS, seroma, shoulder rehabilitation, breast swelling, weakness, pain fibrotic scarring and quality of life sequelae. Many of these SEs can be effectively treated whereas lymphedema is a chronic condition, which can only be managed [32,33]. Scant attention, if any is paid to general SEs.

Lymphedema treatment is included in the basket of health services provided by law via the four health management organizations (HMOs), which cover the entire population. It is provided by the HMOs' PT clinics and also outsourced to private PT clinics. However, there is a lack of uniformity of awareness for risk reduction instruction. This, combined with waiting periodsfor an appointment with the physician, followed by an additional wait for an appointment with the CLT, may result in patients being treated weeks, months, or even years after symptoms appear.

There is a need to establish uniform instruction for risk reduction of BC SEs. Lymphedema and other SEs of BC treatments are a clinical condition; hence, input based on clinical experience is highly relevant for deciding on intervention [37]. As a first step towards the development of risk reduction guideline, we decided to learn about BC SEs' risk reduction from the opinion of a group of experienced CLTs. The aims of the study are to learn about CLTs: 1. Awareness of SEs after BC treatments; 2. Recommendations for SEs' risk reduction; 3. Opinions regarding protocol for patient guidance.The results were matched with recent literature to raise relevant topics for future guidelines.

METHODOLOGY

Design- This is amixed model qualitative study [38]. Data was collected by a phone call interview [39]. The interview was designed in a deductive approach using a predetermined framework for the analysis [40]. In this approach, the researcher tests pre-existing theories. Themes and concepts are decided before the analysis starts and are imposed on the material.

Participants- A convenience sample of 20 physical therapists,CLTs, working in private clinics, was recruited froma registry of physical therapy CLTs from five geographical re-

gions. Inclusion criteria were having done a post-graduate course in lymphedema treatment, and at least five years' experience working in the field. The first four therapists, from each region who answered a phone call and agreed to be interviewed, created the study population. All contacted subjects, except one, agreed to participate. Following recruitment, an explanatory letter and an online informed consent form were emailed to the participants with a request to return it signed. The study was approved by the ethics committee of Ariel University.

Interview The interview topics, were validated by three senior physical therapists (two are fully trained instructors of Lymphatic Therapy training courses, and one was in the process of training). Questions centered on risk reduction recommendations, target patient population, the timing for instruction and choice of medical personnel. Additional open questions facilitated free expression of opinions for issues not included among the pre-prepared questions.

Based on the lead researcher's experience, she typed the interview content during the interview. The questionnaire included potential answers, hidden from the interviewee that enabled the researcher to mark answers without needing to type them in full. She typed additional comments during the interview and immediately after it. Participants were also asked about their professional background and about the confidence they felt in their knowledge of risk reduction for SEs after BC treatments (Table 1). It was evaluated on an ordinal scale (low, moderate, high, very high). Each interview took between 45 to 60 minutes. For standardization, the same researcher conducted all interviews.

Data analysis- Data was sorted, using the pre-prepared framework, according to common denominators and frequencies of similar answers to each group of questions. Additional qualitative comments were chosen and sorted by topics and selected citations. During the first stage of analysis, the principal investigator and her colleague reviewed the data separately. Then, they discussed similarities and differences in their interpretations of the data.

RESULTS

Participants-Most of the participants were Casley Smith trained (11) and all were female. Their mean years of experience as physical therapists and as CLTs were 25.5 and 15.3, respectively. The majority expressed a high level of confidence in their knowledge and their recommendations for BC SEs risk reduction (Table 1).

Table 1: Characteristics of physical therapists certified in lymphedema treatments (CLT) (N = 20)

Characteristics	Approach	Results
Qualification as CLT	Casley Smith Földi Vodder	11 6 3
Professional experience as a physical therapist (years)	Mean ± *SD*	25.5 ± 5.3
Professional experience as CLT (years)	Mean ± *SD*	15.3 ± 5.2
Place of work as CLT	Private clinic Home care	19 1
Self-confidence in professional knowledge on risk reduction for lymphedema after breast cancer treatments	1. None at all 2. Low 3. Moderate 4. High 5. Very high	0 1 1 11 7
Self-confidence in professional competence in providing recommendations for lymphedema risk reduction after breast cancer treatments	1. None at all 2. Low 3. Moderate 4. High 5. Very high	0 0 3 10 7

Side effects- The most frequently mentioned SEs (>3 participants)were upper quadrant morbidities. Among themwere lymphedema ((limb (20), breast (14)), movement restriction ((shoulder (14),trunk (6), neck (4)),AWS (5), erysipelas (5), surgical scar tightness and pain (6), irradiation scars and burns (5)), sensory changes ((breast pain (8), arm/axillary pain (4), hypoesthesia mainly at the medial upper arm and axilla (4)). Other SEs added by a few participants (<3) were related to functional limitations, stress and anxiety, and hormonal therapy. The latter was not a reason for referral for CLT.

Risk reduction recommendations- recommendations fell under three topics: general education, infection prevention, and arm lymphedema prevention. The most common general education topics returned to regular daily routine and PA (20); exercise for trunk and shoulder mobility (13); Increase patient awareness of changes in upper quadrant (6) and healthy lifestyle (5). The main recommendations for infection prevention were to avoid skin puncture (e.g., intravenous therapy, blood draw, sting), and exposure to extreme heat or cold (5). The main recommendations for lymphedema prevention were to provide information about lymphedema and to see a CLT immediately after appearance of symptoms (10); use arm compression during flights (10); avoid maintained limb circumferential pressure (e.g.: blood pressure measurement (20), constrictive clothing (6)); consult with a CLT (9). One participant said "We spend too much time on measurements, which creates stress for the patient. I prefer to count on (patient's) sense of swelling and tight clothing." Another one said, "Sometimes there is no change in circumferences, but there are other symptoms that arouse suspicion of arm swelling. Also, breast swelling may exist, but cannot be measured. Women with this SE need treatment as well." According to the participants, the main reasons for resisting the use of pressure garments were a discomfort (7), unaesthetic (7), wish to keep privacy (6), functional disturbance (5), and too hot (5).

Protocol to provide instruction- Most participants think that all women need instruction after BC surgery (10), while others believe that only women at high risk of developing SEs need (5). For example, one said "Maybe it is worthwhile to give instructions immediately after surgery only to women who are considered at high risk for developing SEs;" another noted that "It is sufficient to give a pamphlet after surgery and there is no need for a meeting at this time."

The optimal time for instruction provision ranged frompre-surgery (8), immediately after surgery, during hospi-

talization (5), and between one to two weeks post-surgery (8). The reason for delayed instruction was a belief that patients are not receptive to new information during the immediate post-surgical period. The time for the first session with a CLT was either before surgery (8) or one to four weeks after discharge (9). Currently the first session with a CLT is after symptoms appear (19).

One participant said, "General instructions should be given before surgery, without causing unnecessary worry. If this is not possible, then the first session with a CLT should be 1–3 weeks after discharge. During hospitalization, the patient is preoccupied with pre- and post-surgery issues and is not attentive to instructions. However, another one, who is probably not updated said: "I do not believe that it is possible to prevent SEs. Therefore, the first visit should be after the appearance of symptoms."

Half of the participants recommended PA for preventative purposes (10), although some defined it as continuing previous PA routine (5) and others as continuing with regular daily activity (3). They also recommended aerobic activities, such as walking with or without Nordic walking sticks (6), participation in various types of exercise classes (6), and also gradually increasing low resistance muscle strengthening exercises (3). For example, one interviewee said: "[I recommend] any activity that the patient likes and will continue to do. If she is in poor physical fitness, I refer her to physical therapy." Some participants indicated that the best time to give guidance for PA is a few weeks after discharge

DISCUSSION

This study presents the opinionsof 20 experienced CLTs about SEs after BC treatments regarding intervention required for SEs risk reduction. The group varied in the certification and location of their clinics. Most participants expressed confidence in their knowledge in the field. It was assumed that CLTs might provide valuable insights to add to the existing literature. However, there were some discrepancies between participants' opinions and recent scientific evidence, which need to be taken into account.

Awareness of SEs- Clinicians' knowledge of SEs is a prerequisite for providing instructions for risk reduction. Most participants were aware of upper quadrant morbidities and listed arm lymphedema first. Also, the majority mentioned breast swelling, movement limitations, and sensory deficiency, all of which may cause severe inconvenience and functional limitation, but are mentioned less in the literature. One author [37], for example, criticizedprevious studies for the use of arm circumferences as the sole measure for diagnosing lymphedema [13,30]. Improving and maintaining range of movement is mentioned as an important intervention, but rarely as anoutcome of intervention in studies on SE risk reduction [3,5]. Otherupper quadrants SEs, such as AWS, seroma, and infections were mentioned by few participants but are rarely described in the literature, and none have been identified in studies as a diagnostic measure of adverse SEs, despite high incidence [2,3,8,9,10].

Few participants mentioned general SEs such as stress, anxiety, and hormonal SEs [6], and none mentioned CRF, insomnia, or cognitive impairment, which are also common [5]. This may reflect CLTs' lack of awareness of these SEs and thus the absence of the necessary guiding questions during treatment sessions. The lack of CLT's awareness of general SEs is understandable as their training concentrates on the treatment of quadrant limb morbidity.

Recommendations for reducing the risk of SEs- The most common risk reduction methods, recommended by the participants in this study, are compatible with the literature. They includea return to daily routine and PA [7,22], exercises to improve and maintain trunk and shoulder range of motion [13,15,12], and infection prevention [13]. Also, most participants recommended education about lymphedema, immediate consultation with a CLT when symptoms appear, and follow-up of arm measurement. These recommendations are also compatible with the literature [15,16,24,25] and with "best practice" documents [32,33].However, there was disagreement regarding the use of pressure garments, PA, and the best time for patient instruction.

Recommendations for compression garments- One of the controversial interventions for reducing the risk of lymphedema is the use of compression garments [25,30,31, 42]. As in" best practice" publications, [32,33]most of the participants in this study recommended wearing a compressionsleeve during flights but ignored the use of a compression glove or bra. This contradiction can be explained in several ways. The recommendation to wear a sleeve is theory-grounded, citing the effect of atmospheric pressureon tissue pressure and fluid return [29]. Also, CLTs anecdotally reported that some of their patients claimed they developed arm lymphedema during or after flight. It is relatively easy to teach a patient to apply arm compression, and CLTs strongly believe that it is easier to prevent lymphedema than to deal with its long-term implications [32,33]. Therefore, to be on the safe side, they recommend wearing a sleeve during flights [37]. It is not clear why the same risk-avoidance rationale does not also apply to the use of a pressure bra. The interviewees in this study mentioned a long list of reasons limiting patients' compliance with compression garments.This indicated that, from the patients' point of view, wearing a compression garment is highly undesirable. The expense was also cited as a reason. This gives reason to suggest that the theory-based recommendation uses a compression sleeve needs to be brought to the discussion among CLTs along with encouragement to implement precision medicine principles and patient involvement in decision making when prescribing preventative arm compression.

Recommendations for physical activity- Most participants, said that PA is mandatory to reduce risk of SEs, which is compatible with the literature [15,22]. However, the interpretation of PA ranged from returning to regular daily activities, to resuming pre-surgery exercise regimes,-

to adopting a new aerobic and/or strength-building exercise program. These differences may lie in the belief, expressed by some of the participants, that PA habits cannot be changed and that asuitable exercise program should be customized to each patient. It is also possible that some of the participants were insufficiently updated on the most recent literature. Authors of another qualitative study on factors affecting decisions of BC survivors regarding PA concluded that one of the reasons for not exercising was lack of or inaccurate information about safe exercise [43].

Protocolto provide instruction- All except one of the participants think that all patients, after BC surgery need instruction, regardless of their risk for SEs. There is no consensus in the literature regarding this issue [18,33]. The rationale for the approach to instructing only women at high risk is to avoid unnecessary concern among women who are at low risk for SEs [18]. Most of the participants agreed that patients are not emotionally receptive to immediate post-surgical risk-reduction instruction but differed regarding the best time for instruction provision. Some supported pre-surgical instruction as recommended previously, [14]others preferred instruction 1–2 weeks after discharge; and some said that immediately after surgery is the best time. The last is a common protocol in most hospitals in Israel. In most Israeli hospitals physical therapists check for postoperative respiratory problems and also provide instructions for shoulder mobilizationas recommended by 'best practice' guidelines [32,33]. None of the participants mentioned the option of periodical surveillance conducted by a CLT, which was recommended recently by some researchers [3,18].Those who thought that the best time to give instruction is either before surgery or after discharge also thought that a CLT is the preferred medical staff for the purpose. Those who believed that patient has difficulty absorbing information immediately after surgery also said that brief instructions could be delivered, during this time, by any member of the medical staff (e.g.,a nurse, any physical therapist, or physician). All participants thought-that physical therapist CLTs are the optimal medical staff to guide for SE risk reduction. This conclusion contradicts the routine in hospitals in Israel today but supported by some researchers [44].We suggest that to provide evidence-based instruction and be sensitive to patients' ability to absorb the information, medical staff, involved in patients' instruction should undergo suitable training. Additionally there is a need to establish consensus on issues of recommendations, target population, time-table to provide instruction and the optimal health care staff for this purpose.

Study limitations- The main limitation of this study is its small convenience sample. However, this group raised important issues that should be heard. Also, the fact that all CLTs in Israel are physical therapists reduces the generalization of the results on other countries. Another limitation is in the research methodology. The use of an inductive approach is relatively easy and quick. However, it is usually used when the researcher is not seeking depth and new understanding, as is the case in the present study [40]. Participants were asked to provide answers based on their experience and professional beliefs.

CONCLUSION

The participants' awareness of upper quadrant SE risk reduction after BC surgeryis, for the most part, compatible with the available "best practice" recommendations. They are aware of the most commonly described SEs, but their suggested preventive interventions are not always evidence-based. Also, their awareness of upper quadrant SEs, other than lymphedema and general SEs is limited. Opinions differed on several aspects of protocol for instruction. The most controversial topic was on the best time to provide post-surgical risk-reduction instructions. These results emphasize whether to broaden CLTs' knowledge regarding SEs from BC treatments or train other staff and to establish a consensus and protocol for reducing the risk of SEs after BC surgery and treatment. Additional studies should also examine team co-operation with other health staff on these issues.The results may contribute to the need to establish uniform instruction for risk reduction of BC SEs.

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