

QUALITY OF LIFE IN BREAST CANCER SURVIVORS: AN ASSESSMENT OF INTERNATIONAL BREAST CANCER DRAGON BOAT RACERS

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ABSTRACT

Resistance exercise is deemed safe for women recovering from conventional breast cancer therapies but few clinicians are aware that dragon boat racing, as a form of resistive exercise, is available to the breast cancer community. The objectives of this study were to 1) increase clinician awareness of dragon boat racing (DBR) in breast cancer survivors as a community-based physical activity, and 2) evaluate quality of life (QOL) in breast cancer survivors with or without lymphedema who participate in DBR. This prospective, observational study surveyed 1,069 international breast cancer dragon boat racers from eight countries to compare function, activity, and participation in women with and without self-reported lymphedema using the Lymph-ICF questionnaire. Seventy-one percent of women (n=758) completed the questionnaires. Results revealed significantly higher Lymph-ICF scores in the lymphedema participants, signifying reduced QOL, when compared to the non-lymphedema participants ($p<0.05$), except for "go on vacation" for which no statistical difference was reported ($p=0.20$). International breast cancer survivors with lymphedema

participating in DBR at an international competition had reduced function, limited activity, and restricted participation compared to participants without lymphedema. Clinicians should consider utilizing DBR as a community-based activity to support exercise and physical activity after a breast cancer diagnosis.

Keywords: breast cancer, dragon boat racing, DBR, lymphedema, exercise, quality of life, Lymph-ICF

Lymphedema is a post-surgical complication of breast cancer subsequent to lymph node removal. Lymphedema presents as chronic swelling in the arm and/or trunk on the surgical side. This may lead to significant physical, psychological and social problems which impact quality of life (QOL) (1). Previously, health care providers recommended breast cancer survivors avoid upper extremity repetitive resistance exercise, including basic activities of daily life like gardening and cooking, out of concern strenuous exercise would induce inflammation and exacerbate lymphedema (2). In 1998, McKenzie published the first seminal study to debunk this myth

demonstrating that breast cancer survivors could safely participate in strenuous exercise without causing or worsening lymphedema symptoms (3). This study generated an increase in popularity for breast cancer survivors to participate in dragon boat racing (DBR) and perpetuated a critical turning point for clinicians and researchers to allow breast cancer survivors to participate in resistance exercise. Health care providers have changed practice guidelines and no longer recommend avoidance of exercise in their patients with breast cancer. Researchers have since launched numerous studies analyzing the effects of exercise in breast cancer survivors (4-10).

In the past 20 years, DBR has become a rapidly growing community-based activity gaining international popularity among breast cancer survivors. The International Dragon Boat Federation (IDBF), the governing body for worldwide dragon boat races, recognizes a separate division specifically made for survivors of breast cancer to provide competitions specific to breast cancer survivors. The International Breast Cancer Paddlers' Commission (IBCPC) Participatory Dragon Boat Festival is the largest of these competitions, which provided the unique opportunity to gather data from a large cohort of international breast cancer survivors participating in DBR.

The purpose of this community based participatory research project was to 1) increase clinician awareness of DBR in breast cancer survivors as community-based resource for exercise and physical activity, and 2) compare impairments in function, activity limitations, and participation restrictions in international breast cancer survivors with and without lymphedema who participate in competitive DBR. A priori, we hypothesized dragon boat racers without lymphedema will have significantly better Lymph-ICF scores compared to those with lymphedema.

MATERIALS AND METHODS

The project was a community based participatory research study consisting of a partnership between the University of

Minnesota/Masonic Cancer Center and a local breast cancer dragon boat team from St. Paul, MN. In partnership, the study was designed to be a prospective, observational design comparing the function, activity, and participation of breast cancer dragon boat racers with self-reported lymphedema to those without lymphedema who participated in the IBCPC festival in Sarasota, FL. This study was reviewed by the University of Minnesota Internal Review Board Human Subjects Committee and determined the study was exempt from full review under federal guidelines 45 CFR Part 46.101(b), category 2. Therefore, consent was waived, and women chose to participate in the study if they willingly completed and returned the surveys to the distributing team. Inclusion criteria included women with a history of breast cancer that dragon boat race and attended the IBCPC festival in Sarasota, FL. Women unable to read English were excluded from the study. The St. Paul DBR team selected the questionnaire for the IBCPC Festival during a routine meeting. The primary investigator (PI) provided a choice of established QOL and function questionnaires to the DBR team. The team members then chose the Lymph-ICF based off of content, ease of use, and time to administer the questionnaire. The PI requested and was granted permission from the author of the Lymph-ICF to use the questionnaire for distribution at the festival.

Lymphedema Functioning, Disability and Health Questionnaire (Lymph-ICF)

The Lymph-ICF is a valid and reliable tool for assessing impairments in function, activity limitations and participation restrictions in patients with arm lymphedema (11). The Lymph-ICF is a 29 item visual analog scale (VAS). Participants mark on the scale from 0 - 100, their average score experienced during the previous two weeks in five different domains. These domains include: (1) physical function, (2) mental function, (3) household activities, (4) mobility activities and (5) life and social activities. The total score on the Lymph-ICF is calculated by

summing the scores on all the questions and dividing by the total number of answered questions. Scores can also be determined for each of the 5 domains by summing the scores from the questions in the domain divided by the total number of answered questions in the associated domain.

Dragon Boat Racing in Breast Cancer Survivors

DBR is a competitive team activity requiring intense repetitive exercise. It is a rapidly growing sport with international popularity that is increasing among breast cancer survivors following McKenzie's seminal study (3). McKenzie put a group of breast cancer survivors from Canada through intense repetitive and resistive training to compete in dragon boat racing (DBR). No new cases of lymphedema occurred and none of the existing cases became worse in this group of dragon boat racers demonstrating breast cancer survivors could safely participate in strenuous exercise such as DBR (3).

The IBCPC Participatory Dragon Boat Festival was held in Sarasota, Florida in 2014. The IBCPC hosted 2500 registrants from 102 teams representing at least 9 countries. Most teams consisted of at least 20 paddlers, 1 drummer, and 1 steersperson. The paddling technique integrates repetitive full body, synchronous movements requiring consistent strength and cardiovascular training of all team members. Races usually vary from 250 to 2000 meters with 500 meters being a standard distance for more competitive festivals. A 500 meter race typically takes 2-3 minutes depending on the crew. Races of 200-500 meters are most common at festivals and are considered sprints, ranging from about 1 - 3 minutes to complete. Breast cancer survivor teams welcome racers of all stages of disease, including advanced disease, to participate.

Self-Report of Lymphedema

Lymphedema was identified by self-report based on the written question, "Have you ever been diagnosed with lymphedema or

experienced swelling in the arm, hand, shoulder, or upper body since diagnosed with cancer?" Individuals were separated into two groups, (1) lymphedema and (2) non lymphedema based on their self-reported response.

Questionnaire Acquisition

Lymph-ICF scores and individual characteristics, such as self-report of lymphedema, cancer history, and country of residence, were gathered utilizing a paper format questionnaire. Members of the St. Paul DBR team (Dragon Divas of St. Paul) who took part in the IBCPC Participatory Dragon Boat Festival held in Sarasota, FL distributed and retrieved the paper questionnaires at the festival. Prior to delivering the questionnaires to the University of Minnesota, the DBR team discarded blank questionnaires without any markings. Members of the St. Paul team were excluded from participating in the study to avoid potential bias.

Once the questionnaires were delivered to the research lab, the PI managed and stored the data and representatives from the St. Paul DBR team and DPT students from the PI's lab assisted with measuring and data entry. The Lymph-ICF VAS scales were double measured and double entered, and the participant history responses were double entered. Responses that were difficult to read or interpret were flagged and reviewed by the PI, at minimum, and most often also reviewed by a second person from the research team for final interpretation. Data entry for the Lymph-ICF scores were entered separately from the patient history responses then linked together after data entry was complete.

Data Reduction and Statistical Analysis

The research team strived to maximize representation of the DBR breast cancer survivors by minimizing data reduction since one of the primary goals of the study was to increase awareness of DBR in breast cancer survivors. Therefore, the number of individuals used for each statistical analysis was different dependent on the available data.

Participant characteristics: The criteria to analyze participant characteristics required a response to the self-report lymphedema question and a minimum of 1 item answered on the Lymph-ICF questionnaire. This allowed the research team to maximize the use of the full data set for analyses which was an important condition for the dragon boat race breast cancer community.

Group difference (lymphedema vs. no lymphedema) in Lymph-ICF scores (individual questions, each domain, and total score): Lymph-ICF questions were analyzed individually for all questions answered (even if only one question was answered) if the participant also responded to the self-report lymphedema question. Since the number of missing items allowed on the Lymph ICF domains and total scores is unknown, missing data was not allowed for the Lymph-ICF total score and each of the domain analyses. To be included in the Lymph-ICF total score group analysis, all 29 Lymph-ICF questions had to be answered. Group analysis for each domain required all questions to be answered within that domain (physical function=7 questions, mental function=4 questions, household activities=4 questions, mobility activities=8 questions, life and social activities=6 questions).

Statistical analysis was performed by the PI using NCSS 11 Statistical Software (NCSS 2016, LLC. Kaysville, Utah, USA, ncss.com/software/ncss.) A two sample student t-test compared group differences in Lymph-ICF scores for each question, domain, and total scores and years since surgery in women who self-reported lymphedema to women who self-reported not having lymphedema. If data were not normally distributed or homogeneity of variance was violated, the Mann-Whitney U non-parametric test was used.

Analysis of variance (mixed model) assessed between group (lymphedema/non-lymphedema) and differences in Lymph ICF-scores and their interactions. The Mauchly test statistic checked for homogeneity of variance. If violated, the p-value was corrected using the Geisser-Greenhouse correction. United States, Australia, and Canada were the only countries with adequate data to run

this analysis. Descriptive statistics were used to describe the other countries that did not have adequate data (i.e. 3 or less in a group).

Sample size: Although this was a convenience sample size, a priori an estimated sample size of 98 (24 lymphedema:74 no lymphedema) was calculated to provide 95% power to determine a 12 point difference in Lymph-ICF scores with a standard deviation of 14 using a p-level of 0.05.

RESULTS

Approximately 2,000 written questionnaires were brought to the IBCPC Festival in Sarasota, FL for distribution. Before returning, members from the St. Paul team discarded questionnaires that were blank to minimize the burden of traveling with blank questionnaires. A total of 1,069 questionnaires were returned to the University of Minnesota. Seventy-one percent of the returned questionnaires were sufficiently completed; therefore, final analysis included 758 questionnaires.

Returned surveys represented eight different countries with the majority of surveys representing the United States (39.37%), Australia (38.31%), and Canada (11.10%). Other countries included United Kingdom (3.30%), Italy (1.72%), Ireland (0.92%), South Africa (0.79%), and New Zealand (0.79%). The name of the country was not reported in 3.7% of the questionnaires returned. Participant characteristics are presented in *Table 1*. Lymphedema group differences were found in cancer recurrence, chemotherapy, stage of disease, and type of axillary lymph node surgery ($p < 0.05$). Of the surveys included in this final analysis of DBR diagnosed with breast cancer, this corresponds to 61.3% and 38.7% reporting no lymphedema and lymphedema symptoms, respectively. This is consistent with previous reports of the incidence of breast cancer associated lymphedema being anywhere from 5-50% (11-12). Data collected by the Lymph-ICF questionnaire demonstrated significant differences in total score ($p < 0.001$) and in each of the five

Table 1: Participant Characteristics of Breast Cancer Survivors with and without Lymphedema

	Lymphedema			p-value
	Yes (%)	No (%)	Total (%)	
	n=293	n=464	n=757	
Breast with cancer				0.54
Right	124 (42)	212 (46)	336 (45)	
Left	139 (48)	208 (45)	347(46)	
Bilateral	30 (10)	40 (9)	70 (9)	
Breast with surgery				0.89
Right	108 (37)	177 (38)	285 (38)	
Left	113 (39)	180 (39)	293 (39)	
Bilateral	71 (24)	106 (23)	177 (23)	
Breast surgery				0.08
Lumpectomy	119 (41)	225 (48)	344 (45)	
Mastectomy	171 (58)	233 (50)	404 (53)	
Not applicable	3 (1)	3 (1)	6 (1)	
Recurrence	42 (14)	31 (7)	73 (10)	0.005*
No	249 (85)	429 (92)	678 (90)	
Radiation	208 (71)	317 (68)	525 (69)	0.61
No	82 (28)	138 (30)	220 (29)	
Reconstruction	63 (22)	111 (24)	174 (23)	0.47
No	181 (62)	277 (60)	458 961)	
Bilateral	46 (16)	61 (13)	107 (14)	
Axillary surgery				<0.001*
Sentinel node biopsy	59 (20)	169 (36)	228 (30)	
ALND	220 (75)	248 (53)	468 (62)	
Not applicable	11 (4)	46 (10)	57 (8)	
Stage				<0.001*
0 or DCIS	4 (1)	15 (3)	19 (2)	
I	60 (20)	187 (40)	247 (33)	
II	101 (34)	122 (26)	223 (30)	
III	86 (29)	76 (16)	162 (22)	
IV	13 (4)	14 (3)	27 (4)	
Unknown	28 (10)	38 (8)	66 (9)	
Hormone therapy	204 (70)	303 (65)	507 (67)	0.22
No	88 (30)	159 (34)	247 (33)	
Chemotherapy	222 (76)	268 (58)	490 (65)	<0.001*
No	71 (24)	195 (42)	266 (35)	
Time since surgery (years) Median (95% CI)	10 (6,14)	9 (5,14)	9 (5,14)	0.17

DCIS= ductal carcinoma in situ, ALND=Axillary lymph node dissection, CI=confidence interval
*significant at <0.05

TABLE 2: Lymph-ICF Scores of Breast Cancer Survivors with and without lymphedema

Lymph-ICF Domains	With Lymphedema		Without lymphedema		z-value	p value
	n	Median (IQR)	n	Median (IQR)		
Physical function score	239	12 (5,36)	390	4 (1,11)	10.39	<0.001*
1. Heavy	282	16 (4,43)	421	2 (1,6)	11.90	<0.001*
2. Stiff	278	9 (2,33)	423	3 (1,7)	7.75	<0.001*
3. Swollen	279	17 (6,52)	421	2 (1,5)	14.51	<0.001*
4. Lost strength	266	8 (2,43)	419	3 (1,10)	5.99	<0.001*
5. Tingle	273	7 (1,30)	423	3 (1,9)	5.53	<0.001*
6. Hurt	278	8 (1,34)	418	2 (1,7)	6.41	<0.001*
7. Tensed skin	272	4 (1,26)	406	2 (0,5)	5.08	<0.001*
Mental function score	280	4 (1,14)	424	2 (0,7)	3.77	<0.001*
8. Feel sad	282	3 (1,11)	419	2 (0,5)	3.76	<0.001*
9. Feel discouraged	285	4 (0,12)	420	2 (0,5)	4.93	<0.001*
10. Lack of self-confidence	285	2 (0,10)	422	2 (0,5)	2.58	0.01*
11. Feel stressed	286	3 (1,16)	420	2 (0,8)	2.59	0.01*
Household activities score	233	5 (1,17)	383	2 (0,6)	5.46	<0.001*
12. Clean	282	5 (1,19)	421	3 (1,7)	4.98	<0.001*
13. Cook	284	3 (0,11)	421	2 (0,5)	2.96	0.003*
14. Iron	258	3 (1,11)	406	2 (0,5)	3.44	0.001*
15. Garden	267	5 (1,26)	407	2 (0,7)	4.56	<0.001*
Mobility activities score	220	9 (2,23)	363	2 (0,9)	7.97	<0.001*
16. Tasks with arm elevated	279	8 (2,32)	407	3 (0,10)	6.16	<0.001*
17. Lift heavy objects	286	12 (2,42)	412	2 (0,12)	7.62	<0.001*
18. Sleep on affected side	284	17 (2,49)	407	2 (0,11)	8.28	<0.001*
19. Work on computer	277	4 (1,17)	405	2 (0,5)	6.00	<0.001*
20. Sunbathe	230	3 (0,28)	353	1 (0,6)	4.61	<0.001*
21. Drive a car	281	2 (0,6)	403	1 (0,3)	2.92	0.003*
22. Walk	284	2 (0,5)	406	1 (0,3)	2.30	0.02*
23. Cycle	247	2 (0,7)	382	1 (0,4)	2.34	0.02*
Life and social activities	228	3 (1,13)	374	1 (0,4)	6.18	<0.001*
24. Go on vacation	283	2 (0,5)	414	1 (0,4)	1.29	0.20
25. Perform Hobbies	286	2 (0,6)	413	1 (0,4)	3.77	<0.001*
26. Practice Sport	286	2 (0,9)	415	1 (0,4)	3.77	<0.001*
27. Wearing clothes of choice	287	4 (1,33)	415	2 (0,5)	6.06	<0.001*
28. Do a job	263	2 (0,8)	382	1 (0,4)	4.46	<0.001*
29. Do social activities	285	2 (0,6)	417	1 (0,4)	2.33	0.02*
Lymph-ICF total score	209	9 (4,23)	353	3 (1, 8)	8.46	<0.001*

n=number of participants in the category, *IQR*=Interquartile range

*significant at <0.05

domains ($p < 0.001$) when comparing the lymphedema group to the non-lymphedema group. Each individual question scored statistically higher ($p < 0.05$) in the lymphedema group compared to the non-lymphedema group, except for "go on vacation" which was not statistically different between groups ($F = 1.29$, $p = 0.20$). *Table 2* provides a summary of the data including the number of participants represented in each of the analyses.

DISCUSSION

This study on DBR in breast cancer survivors contributes to the growing evidence supporting an active lifestyle after a breast cancer diagnosis in all stages of disease. DBR has increased in popularity worldwide among breast cancer survivors, since 1998 when McKenzie demonstrated that participating in resistive exercise, such as DBR, did not induce or worsen lymphedema in breast cancer survivors (3). The IBCPC Participatory Dragon Boat Festival is the largest BCS competition worldwide allowing breast cancer survivors, with and without lymphedema, to participate in this competitive strenuous physical activity. International breast cancer survivors with lymphedema participating in DBR at this international competition had reduced function, limited activity, and restricted participation compared to participants without lymphedema. Although this multinational lymphedema group reported reduced QOL compared to participants without lymphedema, they still could participate in an aerobic and resistive intensive competitive exercise program.

This study included a large multicultural cohort investigating the impact of lymphedema on breast cancer survivors from DBR, which brought strength to this study. Community based breast cancer dragon boat racers were an integral part of the research team providing valuable input on the questionnaire, recruitment strategies, and data acquisition. Double measuring and entry of data, independent of each other, and not allowing the DBR research team to participate in the study reduced potential error and bias. Of particular note was that

there was no significant difference in the groups on the question related to "how well you are able to go on vacations." This lack of difference between the groups is likely specific to the DBR competitors since participants were "on a vacation" and traveling for the event. Limitations to this study include missing data as a result of incomplete questionnaires, no objective measure to substantiate a lymphedema diagnosis, potential survey bias, and distributing surveys only written in the English language.

Previous DBR studies have not investigated lymphedema in such a large sample size from a multicultural setting. Prior studies using Lymph-ICF among breast cancer survivors with and without lymphedema had similar findings but were smaller, non-international studies (13,14). Devoogt demonstrated significantly higher Lymph-ICF scores in a general group of women with breast cancer related lymphedema compared to women without lymphedema, which provided evidence on the construct validity of the Lymph-ICF in Belgium (13). Though our study was not a validity study, the results provide early evidence to support validity of the Lymph-ICF questionnaire. Using the Lymph-ICF scores to study international breast cancer survivors who participated in DBR demonstrated differences between breast cancer survivors with and without lymphedema. There is the question of the cultural attitudes and nationality affecting the patient's perception of lymphedema and their experience with this diagnosis. This study only touched on some of this variability. Yet, patient QOL is a concern that should be addressed by all health-care providers, regardless of location and cultural background. Though not directly comparable, it is notable the Lymph-ICF scores were lower in the DBR group compared to the general population of breast cancer survivors (13), indicating potential positive effect on QOL in women participating in DBR. Ray demonstrated the positive effect of DBR when QOL scores significantly improved from baseline in a group of breast cancer survivors participating in DBR (14). Regardless of the potential positive effects of participating in physical activity such as DBR, this study showed the negative impact

lymphedema has on function, activity, and participation.

Medical providers need to increase their awareness of utilizing community-based programs, such as DBR, that promote participation in exercise and physical activity, which could further enhance a patient's recovery. DBR is a community activity that is available worldwide and can potentially improve QOL (5,10,14-20). Living a physically active lifestyle is essential for breast cancer survivors in all stages of disease, including advanced disease that is likely to reduce the risk of breast cancer recurrence and improve survival (21). Breast cancer survivors with and without lymphedema can participate in this activity without inducing or worsening lymphedema (3-5). Unfortunately, lymphedema negatively impacts QOL regardless of participation in physical activity such as DBR, although the impact could be less. Further research needs to be conducted to show that DBR, along with other types of exercise, may have a positive effect on QOL in breast cancer survivors in all stages of disease. Investigation should include the effect of duration, type of exercise, and intensity of participation. These variables were not included in this study. Interventions and strategies to prevent or reduce the risk of lymphedema require ongoing investigation. This study on DBR in breast cancer survivors contributes to the growing evidence supporting an active lifestyle in all stages of disease, including advanced disease, after a breast cancer diagnosis. A quarter of the participants in this study had Stage 3 or 4 disease.

International breast cancer survivors with lymphedema participating in DBR had reduced function, limited activity, and restricted participation compared to participants without lymphedema attending in the IBCPC Participatory Dragon Boat Festival. Although QOL was reduced in breast cancer survivors with lymphedema, the impact could be less in breast cancer survivors with lymphedema that participate in DBR. Breast cancer survivors can participate in an

aerobic and resistive intensive competitive exercise program safely. Medical providers can better educate their patients accordingly on how to exercise safely and participate in an active lifestyle. There needs to be multiple exercise options for patients with breast cancer, including advanced disease, to enhance their mental status, physical ability and emotional QOL.

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CONFLICT OF INTEREST AND DISCLOSURE

The authors declare no competing financial interests exist.

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