

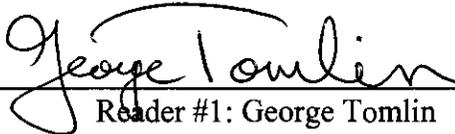
Adherence to exercise in phase two of complete decongestive therapy

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This research, submitted by Melissa Giles, has been approved and accepted
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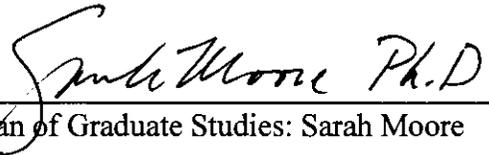
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Abstract

Recent research has shown that most individuals with secondary lymphedema can safely engage in aerobic, resistive, and flexibility type exercises during Complete Decongestive Therapy (CDT) phase 2; however, adherence to exercise remains low for this population. Since lymphedema is a chronic disorder, strict adherence to CDT phase 2, or self-management of symptoms, is necessary. In general, it appears difficult for individuals to adhere to all components of CDT phase 2, namely wearing of the compression garment, nail and skin care, manual lymphatic drainage, and exercise. The current study sought to explore factors influencing follow through with the exercise routine prescribed by the lymphedema therapist and the level of involvement in other physical activities. All individuals with secondary lymphedema, 12-15 months post-initial evaluation, from 2 local lymphedema clinics were invited to participate in this study. A survey was developed to gather descriptive information on the participants as well as examine the client and clinical factors associated with participants' adherence to a prescribed exercise routine. Eight individuals returned the survey, four with lymphedema in the bilateral lower extremities (LEs), one unilateral LE, two unilateral upper extremities (UEs), and one groin. The most common cause of lymphedema was cancer, however, infection, surgery, trauma, and disease were also causes present in this study. Adherence to exercise seemed to be associated with lymphedema location, original diagnosis, perception of exercise benefits for daily activity performance and self-confidence, level of satisfaction with the exercise routine, recall of a prescribed exercise routine, and involvement in a variety of physical activities. Individuals with UE lymphedema, secondary to breast cancer, reported two of the highest three adherence percentages and all three of the highest percentages were associated with participation in a wider variety of physical activities. Amongst the eight participants, a higher adherence

percentage was associated with the ability to recall the prescribed exercise routine, knowledge of exercise benefits for the lymphatic system, perceived effects of exercise on daily activities, increased self-confidence as a result of exercise, and the level of satisfaction with the routine. Further research should be implemented to compare the challenges of exercise between non-cancer versus cancer-related groups as well as to explore how occupational therapists working in this field can provide realistic and meaningful physical activity options for clients.

Living with secondary lymphedema requires a life-long commitment to managing its symptoms and taking the necessary precautions. This chronic disorder of the lymphatic system involves the filling of interstitial tissues with protein-rich lymph fluid, leading to an uncomfortably swollen body part, typically of the upper or lower extremity, rarely bilateral. If left unmanaged, this disorder can lead to severe functional and physiological deficits.

Deficits experienced as a result of an untreated edematous extremity include loss of limb flexibility, numbness, and pain. These symptoms are present in both primary and secondary forms of lymphedema. To avoid further exacerbation of symptoms, individuals can see an occupational therapist or physical therapist who is a Certified Lymphedema Therapist and undergo Complete Decongestive Therapy (CDT) phase 1. This process involves non-invasive methods to reduce the consequences of lymphedema (swelling and fibrosis of the affected body part). Once the reduction of lymphedema symptoms levels out, the client is taught how to self-manage and is discharged to CDT phase 2 (self-management). This second phase involves client follow through with previous CDT phase 1 procedures. Lymphedema therapists play a vital role not only in reducing symptoms, but also in educating and collaborating with clients during discharge planning to design an effective self-treatment plan.

Few individuals are consistently successful in the CDT phase 2, despite the fact that the physical effects of lymphedema greatly impair everyday activities (Bogan, Powell, & Dudgeon, 2007). Exercise is a key component of this phase and although recent studies support its positive effect on the physical and social repercussions of lymphedema, exercise is still feared by some to exacerbate lymphedema symptoms (McClure, McClure, Day, & Brufsky, 2010). Muscle contractions during exercise promote the flow of lymph fluid and an increase in body mobility, but further swelling is a possibility if the exercise routine is not slow, steady, and progressive

(National Lymphedema Network, 2009a). Thus, it is imperative that lymphedema therapists educate clients on the safest approach to exercise and collaborate with clients to ensure success in maintaining an exercise schedule. Studies have shown that maintaining an exercise schedule individually and in groups can be beneficial after receiving instruction by an individual knowledgeable in lymphedema and its symptoms. In individuals with breast cancer related lymphedema (BCRL), adherence to an exercise and relaxation program in the clinic and later the home leads to reduced fluid of the affected arm, weight loss, and improved mood and active shoulder range of motion (McClure et al., 2010). Similarly, participation in the The Lebed Method, a dance and movement program focusing on deep breathing and slow, non-resistive, repetitive exercises can increase shoulder range of motion and health-related quality of life (Sandel et al., 2005).

Exercise promotes a healthy lifestyle and improves lymphatic function when used on a regular basis (National Lymphedema Network, 2009a). Flexibility and resistive exercises can improve range of motion and prevent joint contractures, enabling individuals to better function physically and emotionally (McClure et al., 2010). Through experiencing these better outcomes with physical activity, participants are more likely to have a heightened self-efficacy and adhere to remedial exercise in CDT phase 2 (McClure et al., 2010). Adherence has been used to signify the “process by which patients’ behaviors match the recommendations they have agreed upon with their healthcare professional” (Palmer, 2006, p. 1). Research supports the positive effect of exercise on everyday life in those with lymphedema. Thus it is vital that prior to client discharge, occupational therapists consider the factors influencing exercise follow through in phase 2 CDT.

Background

Types and symptoms of lymphedema. Lymphedema has the power to adversely affect many aspects of everyday life. This chronic disorder is characterized by the inability of the lymphatic system to regularly transport lymph fluid in and out of lymph nodes in particular parts of the body (Pierson & Fairchild, 2008). The lymphatic system is overwhelmed by the high volume of protein-rich lymph fluid and it pools in the interstitial tissues. The filling of the tissues and obstruction of lymph flow are seen unilaterally or bilaterally as a swollen extremity, trunk, neck, or groin region of the body. Lymphedema may be diagnosed when the swollen area of the body contains at least 200 milliliters in excess volume or where there is at least a 2-centimeter difference in the circumference between the affected and unaffected limb (Ahmed, Thomas, Yee, & Schmitz, 2008).

The pooling of lymph fluid can be a result of either primary or secondary causes. Primary lymphedema is a rare, congenital type and involves the abnormal development of the lymphatic system. This congenital form can be present in one limb or up to all four limbs. The age of onset may be birth, puberty, or adulthood and the specific cause is unknown (National Lymphedema Network, 2009b). However, it is understood that primary lymphedema is commonly present with vascular abnormalities, such as a hemangioma or lymphangioma (National Lymphedema Network, 2009b). Secondary lymphedema is acquired as a result of surgery, radiation, infection, or trauma. Surgeries that involve lymph node removal are likely to cause lymphedema and these types of surgeries are often done for those with breast, gynecologic, head and neck, prostate, testicular, bladder, or colon cancer (National Lymphedema Network, 2009b). In fact, in breast cancer patients, 6 to 30% of those undergoing cancer treatment will develop lymphedema (Tahan, Johnson, Mager, & Soran, 2010). Radiation therapy for various

cancers can also damage lymph nodes and vessels, causing the build up of scar tissue and hindrance of the lymph flow. For each individual at risk of developing secondary lymphedema, the time of onset will vary anywhere from immediately post-operative to years later (National Lymphedema Network, 2009b).

The symptoms of lymphedema vary in severity and include the following: tight feeling of the skin, decreased flexibility in the hand, wrist or ankle, difficulty fitting a specific area of the body into clothing, and difficulty donning and doffing rings, wristwatches, and bracelets (National Lymphedema Network, 2009b). In stage 1 of lymphedema development, the skin can hold an indentation from light pressure, called skin pitting, and in stage 2 the affected tissue bounces back in response to pressure. In stage 3 an individual has lymphostatic elephantitis, an irreversible swelling of the limb(s), which marks the beginning stages of tissue fibrosis. The constant accumulation of protein-rich fluid leaves the skin susceptible to infection, skin breakdown, and limb immobility and dysfunction. In the most severe cases, lymphangiosarcoma or lymphatic cancer can develop.

Cancer-related and non-cancer related secondary lymphedema. This array of symptoms can greatly affect individuals recovering from cancer treatment. According to Hayes, Reul-Hirche, and Turner (2009), BCRL is a constant reminder of the cancer and its debilitating nature, making it difficult to recover mentally and physically. Experiences of those with lymphedema of the groin and lower extremity secondary to gynecologic cancer have received less attention, but these conditions appear also to impair mobility and can lead to social isolation (Lockwood-Rayermann, 2007). Furthermore, painful lymphedema causes distress and fear of cancer recurrence greater than that in people without lymphedema (Cohen, Payne, & Tunkel, 2001). Although an increasing number of individuals are living beyond cancer treatment, there

remain detrimental physiological side effects and psychological morbidities (Fialka-Moser, Crevenna, Korpan, & Quittan, 2003).

Although cancer treatment is the most common cause of secondary lymphedema, non-cancer related lymphedema is prevalent and has not received as much research attention. Non-cancer related secondary lymphedema may be attributed to any one of the following: surgery, trauma, or infection (Bogan et al., 2007). This population is unique in that they typically experience a later diagnosis, more severe swelling, and edema in the bilateral lower extremities (Bogan et al., 2007). All the previously stated characteristics lead to difficulties in lymphedema management.

Lymphedema treatment. Although there is no cure for lymphedema, the National Lymphedema Network and the International Society of Lymphology affirm that CDT phases 1 and 2 are integral to ameliorating the symptoms (National Lymphedema Network, 2009b; Weiss & Spray, 2002). Upon physician referral to a lymphedema clinic, an individual can undergo this form of treatment with a Certified Lymphedema Therapist. CDT includes manual lymphatic drainage (MLD), compression bandaging, vasopneumatic compression, patient education about skin care and precautions, compression garment fitting, and remedial exercise (Pierson et al., 2008). The primary goals of this method are to decrease edema, increase lymph drainage from the congested areas, reduce subdermal fibrosis, improve skin condition, enhance the patient's functional status, and enable the patient to adhere to an independent self-care program (National Lymphedema Network, 2009b). The frequency and duration of treatment depends upon the clinic and severity of the lymphedema. CDT phase 1 can vary from 1- 3 times per week for 4 - 6 weeks or more, to once or twice per day for 2 - 4 weeks or more (Cohen et al., 2001). Following

reduction in fluid build-up, fitting for a compression garment, and client demonstration of knowledge in symptom maintenance, he or she is discharged to phase 2 of CDT.

The second phase of CDT involves the same principles and goals of phase 1 except that it is initiated at home by the patient himself or herself. Adherence to a life-long treatment plan is vital to reducing and controlling the symptoms of lymphedema. A lack of adherence to self-management can result in repeated infections, cellulitis, lymphangitis, and non-healing ulcers in addition to functional immobility such as restricted joint range of motion (Pierson et al., 2008). Despite the severe effects of not following through with the treatment plan, many find it difficult to manage the symptoms on their own (Bogan et al., 2007; Johnstone, Hawkins, & Hood, 2006). Individuals who participate in CDT phase 1 experience a reduction in the girth and volume of the affected body part, but return to baseline within 12 months after discharge without proper follow through during CDT phase 2 (Johnstone et al., 2006). Thus the benefits from CDT diminish when patients become responsible for their own care despite the reported satisfaction with CDT phase 1. The lack of adherence has been attributed to time demands, lack of social support, and depression (Bogan et al., 2007).

Lymphedema and daily occupations. A lack of follow through with CDT phase 2 can limit the likelihood of living an independent and active lifestyle. In a study that explored arm and hand swelling in response to breast cancer treatment, 69% of participants found the swelling to interfere with daily activities (Oliveri et al., 2008). In a 12-month follow up study of individuals recovering from breast cancer treatment with upper limb edema, lifting, carrying, and reaching were listed as impaired functions by the participants (Karki, Anttila, Tasmuth, & Rautakorpi, 2005). Functional impairments amongst those specifically with lymphedema appear to cause individuals to give up leisure and recreational activities and experience greater restrictions at

work (Holtgreffe, 2006; Karki et al., 2009; Miedema et al., 2008). This is unfortunate since research supports the idea that an active lifestyle enables an increase in functional capacity and quality of life (QoL) in patients with lymphedema (McClure et al., 2010; National Lymphedema Network, 2009a).

The importance and controversy of exercise. Exercise is an integral, but often forgotten or feared aspect of daily lymphedema management. According to the National Lymphedema Network, exercise is not only important to living a healthy lifestyle, but also in promoting, through muscle contractions, proper lymph flow and protein reabsorption (National Lymphedema Network, 2009a). Furthermore, the National Lymphedema Network affirms that a majority of those with lymphedema can safely engage in aerobic, resistive, and stretching exercises, thereby increasing range of motion and flexibility (National Lymphedema Network, 2009a). The National Lymphedema Network not only promotes exercise, but also the clinician's and client's careful monitoring of the exacerbation of symptoms. It is recommended that whatever exercise is initiated, compression garments should be worn, the affected body part should not be worked to fatigue, and the exercise should be low in intensity and gradually increased (National Lymphedema Network, 2009a).

These precautions and previous contradictory studies have left patients with lymphedema uneasy about engaging in exercise. Until 2008, the National Lymphedema Network had advised women with BCRL not to engage in strenuous activity, such as lifting heavy objects (Lee, Kilbreath, Sullivan, Refshauge, & Beith, 2010). Women have continued to protect their arm from strenuous activity out of fear of worsening lymphedema symptoms or contracting lymphedema (Lee, Kilbreath, Sullivan, Refshauge, & Beith, 2007). However, current research supports the use of the affected body part in gradually increased strenuous exercise and debunks the belief that it

exacerbates the symptoms (Hayes et al., 2009; Karki et al., 2009; Lee et al., 2007). According to Katz et al. (2010), individuals with cancer-related, lower extremity lymphedema can also engage in an exercise program without a worsening of symptoms, and may thereby experience significant improvements in functional status.

Therapeutic exercise programs. Specific exercise programs have been shown to improve symptoms of BCRL. McClure developed “The Circle of Healing” program where participants engaged in a 17 minute long, video-led exercise of low-to-moderate intensity that included muscle-shortening, gravity-resistive arm flexibility exercises, proximal to distal sequence of movements, deep diaphragmatic breathing, and imagery of nature with flowing water and background music (McClure et al., 2010). Participants attended 1-hour sessions, 2 times per week for 5 consecutive weeks followed by a 3-month continuation of the program in the home. Compared to the control group, the participants displayed good adherence to the program and improved arm flexibility, QoL, mood at 3 months, and weight loss (McClure et al., 2010). Although the study supports the use of an exercise program, the population was limited to those with BCRL and the results cannot be generalized to all cancer-related and non-cancer related cases.

Although few in number, studies on exercise programs for those with secondary lymphedema of the lower extremity support the positive effect of exercise in CDT phase 2. An exercise program used with individuals diagnosed with secondary lymphedema of the lower extremity involved the following: stretching, diaphragmatic breathing, and weight training (Katz et al., 2010). During the second, unsupervised phase of exercise at the local YMCA, adherence to the program varied (Katz et al., 2010). One of the reasons for this change in adherence was the inconvenient location of the YMCA. According to Katz et al. (2010), involvement in a clinic-

based, supervised exercise program did not lower edema volume, but did significantly improve balance, dorsiflexion of the affected ankle, and distance walked in 6 minutes. Although this study had a small sample ($N = 10$) and did not show a significant improvement in symptoms of lymphedema, it did facilitate discussion of the factors influencing adherence to exercise.

The previous studies support the use of exercise programs in treating secondary lymphedema. Despite the fact that physical symptoms did not consistently improve in response to routine exercise, they were also not exacerbated. Higher scores on QoL were noted and adherence to exercise appeared strong. There is a lack of research on individuals in CDT phase 2 with secondary lymphedema and the positive effects of their adherence to an exercise routine or program on daily activities. Furthermore, the question remains as to the predictive factors of client follow through with exercise in CDT phase 2. Therefore, the purpose of this study was to obtain descriptive information on exercise by individuals with secondary lymphedema, as well as to explore the possible associations between client and clinical discharge factors and adherence to a prescribed exercise routine in phase 2 of CDT.

Method

Research Design

For the purpose of this study, a descriptive method was utilized. This methodological design explored individuals' adherence to exercise in phase 2 of CDT without the researcher's manipulation of the conditions or context. A survey was chosen along with secure mailing procedures to maintain the respondents' anonymity. The use of a survey was thought to enable the researcher to potentially analyze the data of a large number of people, thus increasing generalizability of the results and lowering the risk of getting a small and homogenous sample. The survey was mailed to an accessible group or sample of the ideal population with secondary

lymphedema and the available data afforded the researcher the opportunity to analyze common factors in adherence. However, with any survey group, there is a risk of a high non-response rate, thus possibly skewing or limiting the power of the data. The answers of those who responded to the survey may not reflect the answers of all potential respondents, especially with a small response rate.

Participants

Two lymphedema clinics related to one Pacific Northwest hospital were contacted and informed about the inclusion criteria for the study. The sampling method for this study was defined as “purposive” because the participants were identified by the clinic according to the inclusion criteria. The inclusion criteria were the following: the client was older than 18 years of age, more than 12 to 15 months post-initial evaluation, in CDT phase 2, and had a diagnosis of secondary lymphedema. A lymphedema specialist from one facility relayed the inclusion criteria information to an individual working with the hospital’s database. This individual retrieved the contact information for 98 clients according to the time since the initial evaluation, to the CDT phase, and to age. The survey itself included questions regarding the cause of the clients’ lymphedema, which enabled the researcher to discard all surveys from those with primary lymphedema. The number of participants chosen was based upon the number of clients meeting the inclusion criteria of secondary lymphedema, as well as the expected response rate of 50%.

Instrumentation

The first step to carrying out the study was to compose the survey and obtain official approval of its format and content. To allow for richer data, this survey not only included close-ended questions, but also open-ended questions immediately following some closed and partially closed-ended questions. The inclusion of open-ended questions enabled the participant to explain

why he or she chose a particular answer. The partially closed-ended questions gave the respondent the option of creating his or her own response, written in the “other” section. When formulating questions for the survey, the researcher performed an in-depth literature review on lymphedema, exercise, and CDT phase 2. Furthermore, the researcher met with two lymphedema specialists to discuss the content of the survey. In this meeting the researcher and clinicians discussed the types of questions that would allow for thorough exploration of potential factors related to exercise adherence. This process of collaborating with the clinicians served to increase content validity of the survey. Within the survey there were questions on the demographics, type of lymphedema (primary or secondary), current status of the affected part of the body, past experience with lymphedema treatment, the amount of time spent on exercise per week, type of exercise most frequently used (aerobic conditioning, resistive, and stretching/flexibility types), perceived effect of exercise on the symptoms and function, and perceived barriers and motivators to exercise. A lymphedema specialist, as well as the research committee and one individual with secondary lymphedema, reviewed the survey and provided feedback on its readability, cultural sensitivity, and clarity prior to mailing.

Procedures

Prior to working with the centers, the research proposal was approved by the university and hospital’s Institutional Review Boards. Upon approval, the medical database worker for the two lymphedema clinics selected the contact information of all 98 clients satisfying the inclusion criteria. The contact information was then sent to the Rehabilitation Administrative Assistant at one of the hospital’s clinics. A cover letter explaining the study, a stamped return envelope addressed to the university’s occupational therapy department, and the surveys were placed in each of the 98 stamped envelopes and delivered to the clinic. The Rehabilitation Administrative

Assistant with the clients' contact information made address labels for each prospective participant and kept this document in a locked drawer. To obtain verbal consent to mail the survey, the Rehabilitation Administrative Assistant called all prospective participants and read from a telephone script drafted by the researcher. The Rehabilitation Administrative Assistant performed two rounds of phone calls and upon verbal consent, attached the address label to the provided envelope and mailed the survey from the clinic.

Data analysis

Upon receipt of surveys, data were entered into a spreadsheet of the Statistical Package for the Social Sciences (SPSS) computer program. The data included numbers from the Likert scales as well as data on age, sex, location and cause of the edema, the amount of time elapsed since the diagnosis, and physical activity preferences and perceived effects. Proper coding of open-ended and partially close-ended questions as well as missing data was completed for inclusion in statistical calculations. Each question was spot-checked by a classmate to ensure proper data entry. Descriptive statistics, namely frequencies, were used to examine the demographic data and to determine the individual and group responses to adherence to exercise, knowledge of and follow through with components of CDT phase 2, preferred types of physical activity, and perceived effects of lymphedema and exercise on daily life.

Results

Participants

As indicated by Figure 1, a total of 30 surveys were mailed to individuals who gave their verbal consent over the telephone. The hospital's database had provided the secretary with 98 names of those treated for lymphedema; however 15 were duplicate numbers, yielding a final total of 83. Fourteen of the 83 patients had wrong or disconnected phone numbers, decreasing

the number of prospective participants to 69. The Rehabilitation Administrative Assistant performed two rounds of calls and completed all phone calls within one month. Thirty-five prospective participants were reached during the first round of phone calls and six were reached the second round. Of these 41, a total of 30 agreed to be mailed a survey. Nine of the 30 mailed surveys were returned and one was not completed, yielding a 30% (9 /30) return rate and a 27% (8/30) usable response rate. Of the original pool of 41 individuals reached by phone, the response rate was 19.5% (8/41). A few of the respondents omitted or provided invalid answers and these data were removed from the analysis.

As seen in Table 1, 50% of respondents were between 51 and 60 years old, and approximately 88% (7/8) of the respondents were female. Of the respondent pool, 50% had bilateral lower extremity (LE) lymphedema, 25% had upper extremity (UE) lymphedema, 12% of the group (one respondent) had lymphedema in the groin region and the other 12% (one respondent) had lymphedema only in the left LE. Each LE case of lymphedema was the result of a different original diagnosis; however, the two cases of UE lymphedema resulted from breast cancer and the groin lymphedema from genital cancer. Time since diagnosis for the group ranged from 2 to 21 years. All participants had seen a lymphedema therapist within the past two years, and 75% indicated it was at least once for the re-fitting of a compression garment. Participant 2 was the only individual to indicate that he saw the lymphedema therapist for management of symptoms and this occurred three times in the past year.

Current Status in CDT 2

Since all participants were in CDT phase 2, each one was asked about the instruction he or she received on nail and skin care, compression garments, self-MLD, and exercise. None of the participants indicated instruction in nail and skin care; however, 87.5% indicated instruction

in wearing a compression garment. Approximately 50% received instruction in self-MLD and only 37.5% indicated instruction in exercise. Time spent attending to each activity was highly variable, and only 6 of 8 responded to the question. Participant 2 indicated two hours of exercise, Participant 3 indicated one hour of exercise, Participant 4 indicated 30 minutes nail and skin care, Participant 7 indicated five minutes MLD and 30 minutes of exercise, and Participant 8 indicated 10 minutes of MLD each day. As seen in Table 2, the most common symptoms for all individuals were tightness and heaviness of the affected limb, with 62.5% and 75% respectively indicating a mild severity. Half of all participants indicated a presence of pain in the affected area. The type and severity of current symptoms was not associated with levels of adherence to exercise according to the data of the current study.

Exercise Education and Recommendations

Participants were asked about their knowledge of safe exercise and the routine recommended to them by their lymphedema therapist. Six of the seven who responded to the question indicated that the lymphedema therapist had discussed the benefits of exercise and the most commonly recalled benefits are listed in Table 4. In regards to knowledge of the proper performance of exercise, the most frequent response at 50% was wearing a compression garment while exercising. Seven of eight provided information on the recommended exercise routine and two of the seven indicated not discussing exercises or being advised not to exercise. Of the remaining five, two indicated MLD as exercise and another two indicated walking. The average adherence of the six individuals who responded was 60.8%, with percentages ranging from 0 to 100%, as seen in Table 1.

Exercise Preferences and Satisfaction

Participants with the three highest adherence percentages were either satisfied or very satisfied with their exercise routine. As seen in Table 1, Participants 7 and 8, who had an original diagnosis of breast cancer, indicated a 95 and 90% adherence rate and Participant 3, with an unknown diagnosis and bilateral LE lymphedema, indicated 100% adherence. These same individuals indicated “yes” to the therapist’s explanation of exercise benefits and Participants 7 and 8 indicated an increase in self-confidence with exercise. In addition to the prescribed exercise routine, six of the eight indicated involvement in physical activities. One of the non-respondents to the physical activity question had lymphedema secondary to a C4-5 SCI and the other had Dercum’s Disease, a rare chronic disorder leading to edema in various parts of the body. Of those who responded, 50% engaged in a walking routine, 25% biked, 25% gardened, and one individual lifted weights. Two of the three participants who engaged in group activities also indicated a high adherence level, 100 and 90% respectively.

Effect of Lymphedema and Exercise on Function

Participants were asked to rate the degree to which lymphedema negatively and exercise positively affected activities. Participant 5 did not answer any of the questions and Participant 6 did not answer the questions on exercise and activities. Thus, the most frequent number of participants responding to the questions was $n = 7$. As seen in Table 4, lymphedema was reported by 71.4% to negatively affect rest and sleep to some degree (“a little”, “quite a bit”, or “a lot”) and recreational activities, meal preparation, and clean up likewise. Exercise was reported by 83.3% to positively affect rest and sleep, recreational activities, social participation, and clean up to some degree.

Of the participants with LE lymphedema, one indicated no positive effects from exercise, and the remaining three indicated some positive effect on work, rest and sleep, recreational activities, social participation, clean up, shopping, and walking. For all four participants, the same activities were negatively affected by lymphedema, except for work. The two participants with UE lymphedema agreed that exercise positively affected grooming, work, rest and sleep, recreational activities, social participation, and clean up. As for the negative effects of lymphedema, both participants indicated opposite answers of some degree and “not at all” for all activities. In other words, Participant 7 indicated rest and sleep and gardening as being the only areas negatively affected by lymphedema, whereas Participant 8 indicated grooming, work, recreational activities, meal preparation, and clean up. Participant 6 indicated that lymphedema had no negative effect on activities and that exercise gave her a “mental and physical boost.”

Discussion

For the purposes of understanding the client and clinical factors influencing adherence to exercise, the researcher collected data on the participants’ original diagnosis, experience with treatment, knowledge of exercise and lymphedema, satisfaction with current exercise routine, and follow through with the prescribed routine as well as their own preferred types of exercise. Furthermore, the perceived effect of exercise on activities and self-confidence was taken into account.

Variation of the Client Factors

Due to the small number of participants and large variation in the original diagnoses and affected body part, it was difficult to provide any statistically significant answers as to the factors associated with adherence to exercise. It is interesting to note that this varied sample

does not resemble the western world's prevalence of original diagnoses and lymphedema location. One would expect to see more UE lymphedema cases as well as lymphedema secondary to cancer treatment. According to Bogan et al. (2007), cancer treatment is the most common cause of secondary lymphedema in the western world and most research has been conducted on the more common, cancer-related and UE cases. As the qualitative study by Bogan et al. (2007) indicated, more non-cancer related cases result in LE lymphedema and these individuals typically experience the following: longer time until diagnosis and referral and a greater severity of edema.

In the current study, the most frequent cause of secondary lymphedema was cancer-related and the remaining four who gave their original diagnosis indicated different causes, such as the following: infection, surgery, Dercum's Disease, and trauma (spinal cord injury at C4-5). These four diagnoses all resulted in lymphedema of the LEs, which has also been explored less in research compared to that in the UEs (Bogan et al., 2007). Also explored less frequently is lymphedema secondary to gynecologic cancer and thus the inclusion of one participant is noteworthy and reflective of its low prevalence (Lockwood-Rayermann, 2007). Even though there was a small sample size ($N = 8$) for this study, the five cases of non-cancer related lymphedema of the lower extremities and one cancer-related lymphedema of the groin are of importance considering the paucity of research on both populations.

Client Factors and Adherence

Despite the small sample size, a suggestion of associated trends and themes can be drawn from the data. Although time since diagnosis does not necessarily indicate time since first experience with symptoms, this time may affect adherence to CDT phase 2. In this study, the two participants who had the diagnosis the longest gave no response to the adherence to exercise

question. However, all individuals diagnosed in the 2000s provided an adherence percentage, except for the individual with Dercum's Disease. Managing symptoms for longer periods of time could lead to lower levels of adherence to CDT phase 2 components in general; however, this remains hypothetical. Regardless of time since diagnosis, all individuals had seen the lymphedema therapist within the past 15 months and thus it would seem that adherence rates to prescribed components of CDT phase 2 would be high. However, other client factors might also be associated with adherence rates.

The original diagnosis and location of the lymphedema appear to be associated with levels of adherence. In this study, the two participants with a previous diagnosis of breast cancer and UE lymphedema indicated high adherence percentages. According to Bogan et al. (2007), it is more difficult for individuals with LE lymphedema to manage symptoms, and Katz et al. (2010) highlighted the fact that those with LE lymphedema have a decreased ability to compensate for the dysfunction of a limb; in other words, both limbs are necessary to walk, however one arm can be used in place of two for a variety of tasks. Thus, it is not surprising that two of the three highest adherence rates were UE cases. Depending upon the location of the lymphedema, an individual may self-restrict involvement in certain activities; for example, in this study, the participant with lymphedema of the groin indicated discomfort during initial treatment as well as when wearing a bathing suit for swimming. Swimming could have been a very appropriate option for her and her discomfort could be associated with her reported exercise adherence of 20%.

Within this sample of individuals with secondary lymphedema, differences appeared between cancer versus non-cancer related groups. As Bogan et al. (2007) stated, more meaningful data may come from looking at the differences between individuals' experiences

with non-cancer versus cancer-related lymphedema as opposed to primary versus secondary. In this study, those with an original diagnosis of breast cancer had the highest adherence to exercise as well as other components of CDT phase two, such as MLD. Furthermore, these same individuals participated in a wider variety of physical activities, such as gardening, weight lifting, and bicycling when compared to those with groin or lower extremity lymphedema. This occurrence could be due to the fact that there are now more studies and information on cancer-related lymphedema available to clients (Bogan et al., 2007). The remaining causes of secondary lymphedema, namely infection, trauma, and surgery, are considered to be rarer and all but Participant 3 had low or zero exercise adherence rates. Based upon the participants' comments, it appears that some were specifically advised not to exercise for reasons of recovery from surgeries or disease-specific reasons.

Knowledge of Exercise Routine and Adherence

Knowledge of a prescribed exercise routine seemed to be associated with higher adherence percentages. Participant 3 with 100% adherence and Participant 7 with 95% adherence both wrote about a specific exercise routine while Participant 8 with 90% wrote about MLD for exercise. As seen in Table 2, Participant 8 also could not recall the benefits of exercise. Participant 2 with 60% adherence included “keeping legs up” as a benefit of exercise and stated that it was part of his exercise routine. Responses to the questions on knowledge and benefits of exercise raised an interesting point. There seemed to be confusion amongst clients over whether or not MLD and elevating the legs were to be categorized as exercise. Regardless, the individuals with the two highest adherence percentages provided a more relevant and detailed explanation of their individual exercise routine and the associated benefits of exercise.

Physical Activity Choice and Adherence

Walking was chosen as the most frequent typical physical activity ($n = 4$) and three of the four who reported walking have bilateral LE lymphedema. Those with the highest rate of adherence to exercise seemed to engage in a wider variety of physical activities, such as gardening, bicycling, exercising at a local fitness center, and weight lifting. Those with BCRL reported the most variety of exercise type and this could be a result of more knowledge and availability of information on exercise and group exercise classes, such as bicycling and weight lifting. The participant with groin lymphedema stated that she had tried swimming, but was “too embarrassed” to be in a swimsuit, so stopped the routine. This is an unfortunate common barrier to exercise. According to Hayes et al. (2009), “lymphedema is a condition that is difficult to explain, but visible to all” (p. 487) and this could lead to social isolation and deterrence from exercising in public. This is unfortunate since studies on supervised exercise and exercise groups (Katz et al., 2010; McClure et al., 2010) have shown that supervised group exercises are correlated with higher rates of adherence to an exercise routine.

Satisfaction, Self-confidence, and Adherence

As Fialka-Moser et al. (2003) wrote, “functional independence” results from regular exercise and affects many domains of QoL, such as self-confidence. The current study seemed to support this statement since those reporting higher self-confidence associated with exercise had the highest adherence percentages. Furthermore, individuals reporting satisfaction with their exercise routine had the highest rates of adherence at 100%, 95%, and 90%. However, the participant with Dercum’s Disease who reported not being allowed to exercise, was also satisfied with her routine. This could be because the decision to engage in exercise is out of her control and she fears exacerbation of symptoms.

Perceived Positive Effects of Exercise

The perception of positive effects of exercise seems to be associated with higher rates of exercise adherence. Two of the six participants who responded to the question regarding the positive effects of exercise stated that exercise affected all activities and these same individuals reported the two highest adherence percentages. Participants 2 and 8 with the two second highest adherence percentages also reported exercise affecting 7 of the 12 activities listed. Following the same trend, Participant 4 reported a 0% adherence rate and indicated that exercise had no effect on activities. Participant 6 reported that she got a “mental and physical boost” from exercise; however, she failed to indicate any specific activities affected. All in all, the current study seems to show that the highest adherence tends to be associated with the perceived benefits of exercise on daily life.

Implications for Occupational Therapy

Although the current study represents a small subset of individuals with secondary lymphedema, the trends in responses may be informative to occupational therapists working in the field of lymphedema treatment. Individuals in CDT phase 2 are required to manage symptoms on their own and it is imperative that they have a firm foundation of knowledge regarding the benefits of symptom management and staying active. Most respondents in this study indicated discussing the benefits of exercise with his or her lymphedema therapist and those able to reiterate the routine had the highest rates of adherence. A few of the respondents mentioned MLD and elevating the legs as exercise and this shows that what qualifies as exercise may need to be clarified by lymphedema therapists. Unfortunately, time is limited in the clinic and thus opportunities to discuss proper exercise may be minimal. Therefore, it may be beneficial to provide written information on safe and effective exercise groups for individuals

managing lymphedema. These resources could include exercise groups at local fitness centers or The Lebed Method. It would be most convenient if these individuals had access to these types of classes in the facility at which they receive lymphedema treatment and with others experiencing similar symptoms. Involvement in group exercise may allow for decreased moments of embarrassment and an opportunity to discuss the hardships associated with the diagnosis and management of symptoms.

The current study included a variety of original diagnoses and thus it appears that those with non-cancer related lymphedema seem to be less informed about the edema or how to stay physically active. The individual with Dercum's Disease may have benefited from a more individualized exercise routine and suggested ways in which to maintain an active lifestyle. Participant 5, with trauma-related lymphedema, may have benefited from assisted swimming routines or other exercises not involving limb movement or weight bearing activities. Occupational therapists have the challenge of treating clients with co-morbidities and restrictions due to primary diagnosis. Thus, reiterating the importance and precautions of physical activity to these clients and tailoring activities so that he or she can meet the demands is extremely vital. It is this information that can then be generalized to multiple settings throughout the client's life with this chronic disorder.

Limitations

The most apparent limiting factor is the small sample size of the study ($N = 8$), making generalization of findings problematic. Not only was it a small sample size, but also extremely varied. Even though 50% had bilateral lower extremity lymphedema, each was a result of a different diagnosis or not stated. Those with cancer-related lymphedema had different affected areas, namely the right upper extremity, left upper extremity, and groin region. The

variation and small sample size make it difficult to confidently state the client factors influencing adherence to exercise. It is plausible that had a different method of instrumentation been used, the response could have been higher. Of the 69 potential participants, 28 were never reached via phone. Had more time been allowed to reach these individuals or if a consent form had been mailed, then the participants might have had the opportunity to participate.

Narrowing the inclusion criteria of the participants from secondary lymphedema to cancer or non-cancer related secondary lymphedema might have provided more meaningful data. This survey does not account for those who may experience more physical barriers to exercise, such as SCI and painful diseases, such as Dercum's Disease; instead, it appears more geared towards those physically able to engage in activity and recovered from the original diagnosis, such as cancer. Some of these individuals might never have been given an exercise routine and thus, adherence to a routine is more difficult to assess. Furthermore, asking for a percentage may not be the most accurate method of gathering data on adherence. Fifty-percent adherence to one individual might mean something different to another. Thus, it might have been more valid of an answer if they were asked to state the prescribed routine and to which components they adhere.

Future Research

Despite the small sample size, this study does show that exercise and involvement in physical activity is positive, challenging, and often misunderstood. Most participants acknowledged the benefits of exercise and its effect on the lymphatic system; however, few reported strong adherence to a routine. Thus it appears that finding the time to exercise and the most appropriately demanding activities is a challenge. Furthermore, many stated prescribed routines involved aspects not related to exercise. To further explore each individual's knowledge of exercise, specific routine, and barriers to adherence, a qualitative method might be used. Since

each individual must adhere to specific restrictions due to co-morbidities and original diagnoses, a deeper analysis of their experiences with physical activity would be beneficial to occupational therapists practicing in this field. A qualitative study could also afford analysis of differences in responses between those with cancer and non-cancer related lymphedema. Based upon the variation of original diagnoses and restrictions, it appears that the inclusion criterion, secondary lymphedema, is too broad. If a quantitative survey method is to be used in the future, it is advised that a follow up telephone interview be added to the protocol. This study would have benefited from this additional component because many questions were omitted or answered incorrectly. The last proposed revision to future research instrumentation would be to survey occupational therapists regarding how often he or she is able to discuss exercise with the client and provide recommendations for factoring it into the client's daily routine.

Conclusions

Data from the current study revealed that adherence to exercise seems to be associated with lymphedema location, the original diagnosis, recall of a prescribed exercise routine, engagement in a variety of physical activities, perceived benefits of exercise, and satisfaction with the exercise routine, as follows. Those with bilateral LE lymphedema all had non-cancer related lymphedema and, in general, reported less overall adherence to exercise, compared to those with UE lymphedema. Original diagnosis of trauma or a rare disease appeared to be a barrier in maintaining a consistent exercise routine. These individuals reported not being allowed to exercise or that engagement exacerbated symptoms. Those who were able to engage in exercise and were involved in a variety of physical activities reported higher rates of adherence. Two of these individuals also reported engagement in group exercise classes supporting past research on improved adherence in supervised groups (Katz et al., 2010;

McClure et al., 2010). Lymphedema therapists may benefit from more information regarding the potential factors associated with adherence to exercise during CDT phase 2, especially for those with rare co-morbidities. It is this information that may help the therapist anticipate problem areas and provide the client with the tools for the most successful management program possible and improved health-related QoL.

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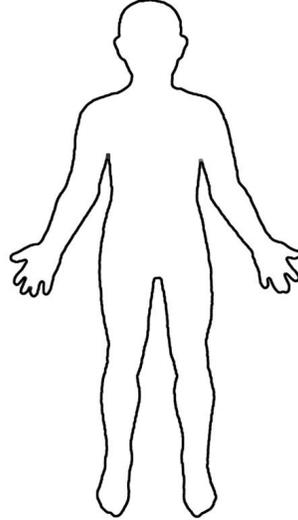
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Appendix

1. Please use the figure below and shade in the area(s) of the body which were treated for lymphedema:



2. Please check the type of lymphedema you have.

Primary (born with lymphedema OR onset during childhood/puberty/adult without an apparent reason)

Secondary (due to cancer surgery or radiation treatment OR resulting from trauma, infection, other surgeries, accident)

**If you checked that you only have primary lymphedema, stop here and please return the survey to the provided address. It is important that you still return this survey so that every survey can be accounted for.*

3. Please check any of the following diagnoses and procedures that you experienced prior to developing lymphedema.

Breast Cancer treated with one or more of the following procedures: axillary node dissection, mastectomy, lumpectomy, radiation, chemotherapy

Head and/or Neck Cancer treated with one or more of the following procedures: surgical resection, head or neck node dissection radiation, chemotherapy

Genital Cancer or other cancer of the lower extremity treated with one or more of the following procedures: surgical resection, inguinal lymph node dissection, radiation, chemotherapy

Surgery not related to cancer treatment

Infection

Trauma

Other, please specify: _____

4. When was your lymphedema first diagnosed? (e.g. Jan. 2011)

_____Month _____Year

5. When were you last seen by your lymphedema therapist? _____Month _____Year

6. Please write the number(s) of times in the past year that you saw your lymphedema therapist for one or both of the following:

Re-fitting for a compression garment

Management of symptoms

Other: _____

7. Which of the following were you instructed by your lymphedema therapist to do for your lymphedema home self-care program?

Attend to nail and skin care

Wear a compression garment(s)

Self-manual lymph drainage

Exercise (perform active, repetitive, non-resistive, motion of the involved body part) while wearing a compression garment or short stretch compression bandage.

8. State the approximate amount of time per day you spend doing each activity.

Attend to nail and skin care: _____ hours _____ minutes

Manual lymph drainage: _____ hours _____ minutes

Exercise while wearing a compression garment or short stretch compression bandage:
 _____ hours _____ minutes

9. To what extent are you currently experiencing the following symptoms in the affected body part(s)? Please circle the appropriate level of severity.

Increased swelling: None-----Mild-----Moderate-----Severe

Pain: None-----Mild-----Moderate-----Severe

Tightness: None-----Mild-----Moderate-----Severe

Heaviness: None-----Mild-----Moderate-----Severe

Numbness: None-----Mild-----Moderate-----Severe

Poor range of movement: None-----Mild-----Moderate-----Severe

Please answer the following questions regarding your exercise routine and involvement in daily activities.

10. How many times per day were you advised by your lymphedema therapist to do active, repetitive, non-resistive motion of the involved body part(s)? _____

11. Please state the exercise routine recommended to you by your lymphedema therapist. _____

12. How much do you think you are following instructions provided by your lymphedema therapist regarding your exercise? Please indicate by writing a percentage from 0% to 100%.
 _____%

13. Did your lymphedema therapist explain to you the benefits of exercise for the lymphatic system?
 ___ Yes ___ No

14. If you answered yes to #13, please write in the space below what your therapist told you. _____

15. Did your lymphedema therapist inform you how to properly perform exercises? Please check all statements that apply.

- Perform low-intensity exercises with the affected body part(s).
- Increase the exercise intensity gradually
- Wear your compression garment when exercising
- Avoid aggressive stretching
- Stop exercising when you have pain, increased swelling or discomfort.
- Other: _____

16. Please place a check mark next to the type(s) of physical activities that you typically engage in. Indicate the time you spend on that activity and whether or not it is done individually or in a group setting. If in a group setting, please indicate the type of group from the available options under “group type.”

Physical Activity	Time (per week)	Individual	Group	Group type: -Family/Friends -Gym group -Community Center -Other: _____
<input type="checkbox"/> Swimming				
<input type="checkbox"/> Walking				
<input type="checkbox"/> Running				
<input type="checkbox"/> Weight lifting				
<input type="checkbox"/> Dancing				
<input type="checkbox"/> Other _____				
<input type="checkbox"/> Other _____				
<input type="checkbox"/> None				

17. How satisfied are you with your current exercise routine? Please circle one of the following.

Very dissatisfied-----Dissatisfied-----Neutral-----Satisfied-----Very satisfied

18. What would you like to see change in your current exercise routine? _____

19. How much does your **lymphedema negatively** affect your ability to do the following activities in your daily life? Please place a check in the appropriate box.

	Not at all	A little	Quite a bit	A lot
Dressing				
Bathing/Showering				
Grooming				
Work				
Rest and Sleep				
Recreational Activities				
Social Participation				
Meal Preparation				
Clean Up				
Shopping				
Walking				
Running				
Other:				

20. How much does involvement in an **exercise routine positively** affect your ability to do the following activities in your daily life?

	Not at all	A little	Quite a bit	A lot
Dressing				
Bathing/Showering				
Grooming				
Work				
Rest and Sleep				
Recreational Activities				
Social Participation				
Meal Preparation				
Clean Up				
Shopping				
Walking				
Running				
Other:				

21. Because of exercise, how has your self-confidence changed? Please circle the appropriate type of change.

Decreased a lot-----Decreased some-----No change-----Increased some-----Increased a lot

Please answer the following demographic questions.

22. Please check your age category. _____ 18-20 _____ 21-30 _____ 31-40 _____ 41-50
_____ 51-60 _____ 61-70 _____ 71-80 _____ 81 + years

23. Please indicate your sex. _____ Male _____ Female

Please include any additional information in the space below that may be relevant to this study.

Table 1

Description of Respondents (N = 8)

Respondent No.	Age Range	Sex	Affected Body Part	Year of Lymphedema Dx	Original Dx	Date of Last Clinic Visit	Adherence (%)
1	61-70	F	(B) LE	1990	NR	Sept 2010	NR
2	51-60	M	(B) LE	2005	Infection	3 days ago	60
3	31-40	F	(B) LE	NR	Surgery	2010	100
4	51-60	F	(B) LE	2009	Surgery & Dercum's Disease	June 2010	0
5	51-60	F	LLE	1996	Trauma & C4-5 SCI	Aug 2010	NR
6	51-60	F	Groin	2009	Genital CA	Dec 2009	20
7	61-70	F	LUE	2008	Breast CA	Feb 2011	95
8	71-80	F	RUE	2003	Breast CA & Infection	2010	90

Note. Dx, diagnosis; NR, no response given; (B), bilateral; LE, lower extremity; LLE, left lower extremity; LUE, left upper extremity; RUE, right upper extremity; 3 days ago, 3 days prior to receipt of survey.

Table 2
Frequency of Current Symptoms Experienced (N = 8)

Types of Sx	None (%)	Mild (%)	Moderate (%)	Severe (%)
Increased Swelling	37.5	37.5	25	0
Pain	50	25	25	0
Tightness	12.5	62.5*	25	0
Heaviness	12.5	75*	12.5	0
Numbness	50	37.5	0	12.5
Poor Range of Movement	50	50	0	0

Note. * = Highest percentages (>50%)

Table 3

Recalled Benefits of Exercise

Respondent No.	Stated Benefits of Exercise
2	“Walking assisted the body to keep the infection and swelling under control, keeping legs up released swelling.”
3	“I need to exercise at least 30 minutes a day to keep the circulation flowing to help keep the swelling down.”
4	“Keeping things moving is better for heart, circulation. Move and do what I can.”
6	“That body movement stimulates the lymph system.”
7	“There is no pumping system for the lymph glands so must stimulate for removal of excess fluid...”
8	“Can’t remember”

Table 4
Lymphedema Negative Effects on Activities

Activities	To some degree (%)
Other: gardening (<i>n</i> = 1)	100
Rest & Sleep (<i>n</i> = 7)	71.4
Recreational Activities (<i>n</i> = 7)	71.4
Clean Up (<i>n</i> = 7)	71.4
Meal Preparation (<i>n</i> = 7)	71.4
Social Participation (<i>n</i> = 6)	66.6
Shopping (<i>n</i> = 7)	57.1
Walking (<i>n</i> = 7)	57.1
Work (<i>n</i> = 6)	50
Running (<i>n</i> = 5)	40
Dressing (<i>n</i> = 6)	33.3
Bathing/Showering (<i>n</i> = 6)	33.3
Grooming (<i>n</i> = 7)	28.6

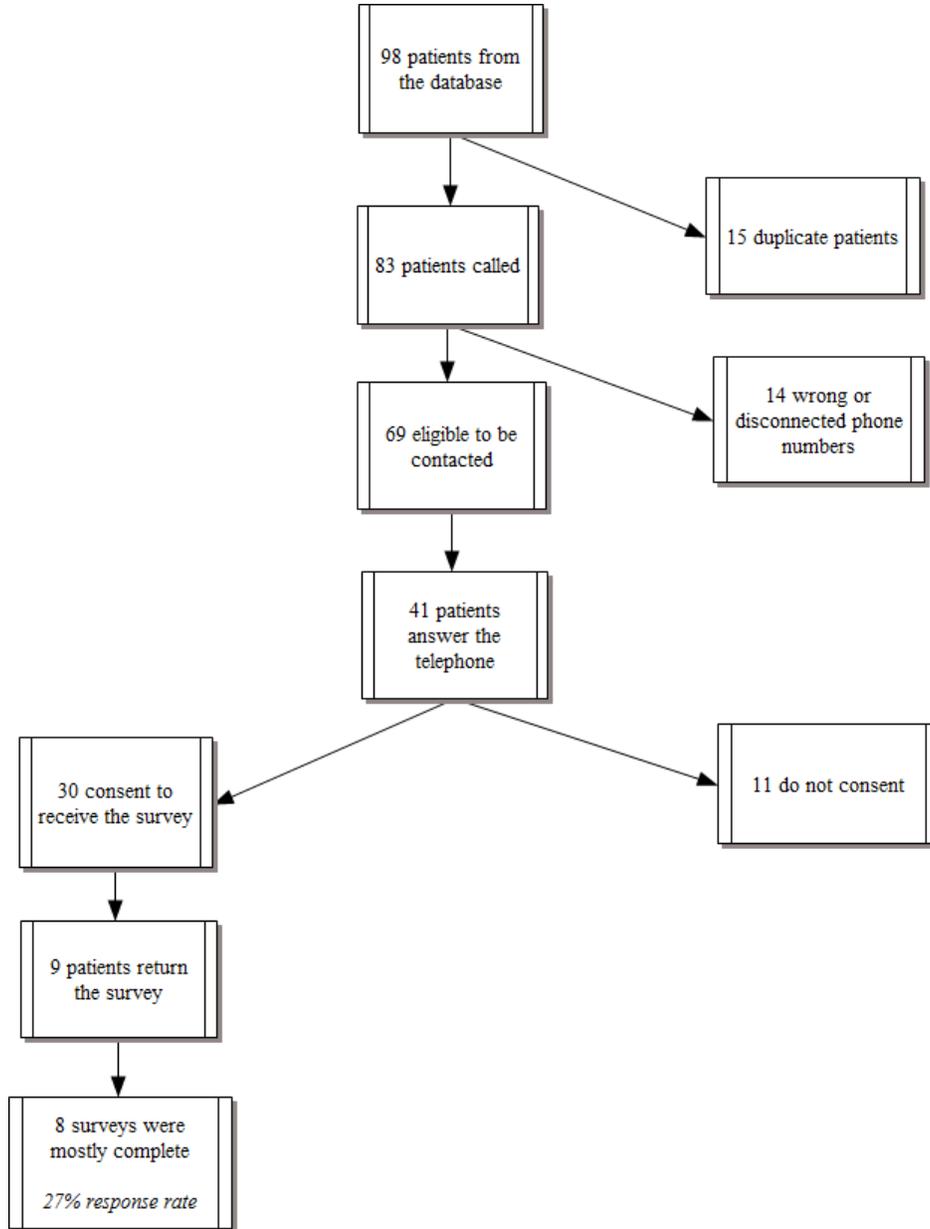
Note. To some degree: A little, quite a bit, a lot. All others reported, “Not at all.”

Table 5
Positive Effect of Exercise on Activities

Activities	To some degree (%)
Other: gardening (<i>n</i> = 1)	100
Rest & Sleep (<i>n</i> = 6)	83.3
Recreational Activities (<i>n</i> = 6)	83.3
Social Participation (<i>n</i> = 6)	83.3
Clean Up (<i>n</i> = 6)	83.3
Grooming (<i>n</i> = 6)	66.7
Walking (<i>n</i> = 6)	66.7
Work (<i>n</i> = 5)	60
Dressing (<i>n</i> = 5)	60
Shopping (<i>n</i> = 5)	60
Meal Preparation (<i>n</i> = 6)	50
Bathing/Showering (<i>n</i> = 5)	40
Running (<i>n</i> = 4)	25

Note. To some degree: A little, quite a bit, a lot. All others reported, “Not at all.”

Figure 1 Flow of Participants



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