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Patient compliance with a health care provider referral for an occupational therapy lymphedema consult

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Abstract

Purpose Limited information exists on breast cancer patients' compliance to attend outpatient appointments with an occupational therapy (OT) lymphedema specialist. The objectives of this study were (1) to examine patient compliance with a health care provider referral for an OT lymphedema consult and (2) to identify potential barriers to compliance.

Methods A retrospective chart review of female breast cancer patients at the UC San Diego Health System was conducted. Electronic medical records were queried for breast cancer patients, who received a health care provider referral for an OT lymphedema consult between June 1, 2010 and December 31, 2011. Descriptive statistics and Fisher's exact chi-square tests were used to examine how specific participant characteristics were associated with attending an OT appointment.

Results A total of 210 female patients received an OT referral from a health care provider related to their breast cancer diagnosis. Forty-three (20.5 %) patients did not attend an OT appointment. Non-attenders were more likely to have had fewer lymph nodes removed ($P < 0.01$) when compared to attenders. The two most common barriers to attendance were the presence of health problems and undergoing chemotherapy and/or radiation at the time of the OT referral.

Conclusions While most breast cancer patients attended recommended OT lymphedema consults, a substantial number of

women might benefit from further education about OT for lymphedema prevention following breast cancer treatment. Further research to understand barriers to attendance is recommended, particularly among women with only sentinel nodes removed.

Keywords Breast cancer survivors · Lymphedema · Patient compliance · Physician referral · Occupational therapy

Introduction

Of the estimated 2.7 million breast cancer survivors in the USA, a significant proportion will experience breast cancer-related lymphedema as a late effect of their breast cancer treatment [1–4]. Lymphedema occurs when the lymphatic system is damaged and unable to properly circulate the lymphatic fluid. This disruption of lymphatic flow results in variety of symptoms, such as arm swelling or tenderness. Depending on the severity of lymphedema symptoms, the management of lymphedema can be quite costly; one study using medical claims data found that the differences in 2-year health care costs between the lymphedema group and the non-lymphedema group ranged from \$14,877 to \$23,167 [5]. A prospective surveillance model (PSM), in which patients receive lymphedema education and arm measurements on a regular basis, has been shown to be a cost-saving and effective method of preventing lymphedema and/or detecting early stages of lymphedema in breast cancer survivors [6–8]. Additionally, the National Lymphedema Network recommends screening and early detection of breast cancer-related lymphedema [6].

Cancer rehabilitation offered as outpatient occupational therapy (OT) services is an integral part of a PSM [7, 9]. Occupational therapists (i.e., lymphedema specialists) are trained to provide patients lymphedema prevention education,

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including risk reduction strategies, as well as lymphedema treatment, if necessary. Prior studies have shown that patient education can prevent the development of lymphedema as well as improve health outcomes among those living with lymphedema [10–13]. Ridner [13] found that women without lymphedema were more likely to receive pretreatment lymphedema education compared to women with lymphedema. Fu and colleagues [11] found that patient education was an independent predictor of breast cancer-related lymphedema. These researchers also reported that participants who received lymphedema education reported fewer breast cancer-related lymphedema symptoms than those who did not receive lymphedema education [11]. Further, health care providers (e.g., surgeons, oncologists, and nurses) play a vital role in cancer rehabilitation through referring patients to see an OT lymphedema specialist. Tam and colleagues [14] found that 100 % of oncologists, 79 % of surgeons, and 36 % of primary care clinicians in their study reported having ever made a referral for breast cancer-related lymphedema.

While provider referrals and availability of OT lymphedema services are important components of cancer survivorship care, patient attendance at lymphedema services is also required in order to maximize opportunities for improved lymphedema-related outcomes. To date, no research studies have examined patient attendance at OT lymphedema consult appointments. One recent study examined patient attendance at a group educational session for breast cancer survivors referred to a survivorship clinic. Upon receiving the educational session invite, over one third of patients declined to attend the session for the following reasons: time conflicts, distance to the clinic, current medical problems, elderly, non-English speaking, and lack of interest [15].

Since little is known about breast cancer patients' compliance with attending an OT lymphedema consult after receiving a referral, the objectives of this study are (1) to determine patient compliance with a health care recommendation to attend an OT appointment and (2) to identify potential barriers/reasons for non-attendance, despite receiving a health care provider OT referral. This study will provide health care providers, lymphedema specialists, and public health professionals with needed patient compliance information regarding outpatient lymphedema prevention and treatment services.

Methods

Study population

The University of California (UC) San Diego Health System has a PSM for breast cancer-related lymphedema; patients who have breast cancer surgery and/or present with lymphedema symptoms during a clinic visit are referred for an OT lymphedema consult as a standard protocol. This study was a

retrospective chart review of female breast cancer patients, who received a health care provider referral for an OT lymphedema consult at the UC San Diego Health System. Patients were included in the study if they had a breast cancer diagnosis and received an OT referral for a lymphedema consult and if the lymphedema consult referral was related to their breast cancer diagnosis and/or treatment. Patients were excluded if the OT referral was not for a breast cancer-related lymphedema consult.

Procedures

At the UC San Diego Health System, records of all electronic order entries for OT referrals are available in the patients' electronic medical records (EMRs). The EMRs were queried for breast cancer patients (ICD-diagnosis code 174.9) who received a health care provider OT referral for a lymphedema consult between June 1, 2010 and December 31, 2011. From this query, a list of eligible breast cancer patients was created that included the following variables: the name of the health care provider who made the OT referral, the ordering date of the OT referral, the patient's year of birth, insurance type, height, and weight. Next, medical records from each patient were reviewed to identify and extract OT referral reason, demographics, breast cancer tumor and treatment characteristics, and other study-relevant patient characteristics. This study was approved by the UCSD Human Research Protections Program.

Dataset

Demographics

Demographic variables extracted include year of birth to determine current age in years, type of health insurance, height and weight to calculate body mass index (BMI), and relationship status. For this study, type of health insurance was categorized as HMO/PPO, Medicare, Medi-Cal (California's Medicaid plan), or self-pay. BMI was categorized as underweight/normal weight (BMI <24.9 kg/m²), overweight (BMI=25 to 29.9 kg/m²), and obese (BMI ≥30 kg/m²). Relationship status was dichotomized into married versus other (i.e., single, divorced, or widowed).

Medical characteristics

Medical variables documented include cancer stage categorized using the American Joint Committee on Cancer (6th edition) criteria [16], number of lymph nodes removed, type of breast cancer surgery (e.g., lumpectomy or mastectomy), year of breast cancer surgery, and administration of chemotherapy and/or radiation therapy. Cancer stage at diagnosis was categorized into stage 0, stage I (IA and IB), stage II

(IIA and IIB), stage III (IIIA, IIIB, and IIIC), and stage IV. For patients who had bilateral cancers, the highest cancer stage at diagnosis was included in the cancer stage variable. The present analysis dichotomized breast cancer surgery into lumpectomy/bilateral lumpectomies and mastectomy/bilateral mastectomies. For patients who had a less invasive surgery followed by a more invasive surgery, the most invasive surgery was used for the surgery variable. For example, if a lumpectomy was followed by a mastectomy, then mastectomy was recorded as the surgery type. Patients who received mastectomies at two different time points were coded as having bilateral mastectomies and the most recent surgery year was used in the analyses. The number of lymph nodes removed was recorded for each patient; in cases where lymph nodes were removed bilaterally, the average number of lymph nodes removed per patient was included in the analyses.

OT referral

The primary outcome of this study was attendance at an OT appointment for a lymphedema consult categorized as attenders versus non-attenders. For each patient, the ordering date of the OT referral was extracted; in some cases, there were multiple OT referrals during the study timeframe that were also documented. Additionally, the name of the health care provider and the reason listed on each referral was also extracted. Referral reason was dichotomized into current lymphedema symptoms versus routine post-operative care/lymphedema prevention. Since queried patients had a breast cancer diagnosis, the source of the OT referral was categorized as breast surgical team, breast oncology team, and other physician/nurse. The date of the OT appointment was also recorded to determine the amount of time elapsed between the referral and the appointment date. Since patients are recommended to make an OT appointment within 1 to 2 weeks of the referral date, the amount of time elapsed was dichotomized into less than or equal to 2 weeks or greater than 2 weeks. For patients with multiple referrals that went to an OT appointment, the time elapsed was calculated from the initial referral date to the date of the first OT appointment.

Barriers

For patients who did not go to an OT appointment, potential barriers, such as health problems, undergoing chemotherapy and/or radiation at the time of the referral, or primary language (English versus non-English), were extracted from the medical records by reviewing the content of clinical encounters with health care providers starting from the date of the OT referral.

Statistical methods

Descriptive statistics were used to characterize the data extracted from the medical records, including barriers to attending an OT appointment. Bivariate analyses were conducted to assess if patient demographics, breast cancer tumor and treatment characteristics, and OT referral source and reason were associated with attendance at an OT appointment. Fisher's exact chi-square tests were used to analyze the categorical variables. Significance for all analyses was set at $P < 0.05$. All analyses were conducted using IBM® SPSS® Statistics version 20.0 (Armonk, NY).

Results

A total of 274 breast cancer patients received a lymphedema consult OT referral from a health care provider between June 2010 and December 2011. Sixty-four patients received a referral for a non-breast cancer-related health problem and were excluded from the study, making the final study cohort of 210 patients. As shown in Table 1, the mean age of study participants was 57.2 years (SD=11.7). The majority of patients was married (61.7 %), had private health insurance (66.5 %), and was overweight/obese (62.9 %). In terms of medical characteristics, 69.8 % of patients had stage 0, I, or II breast cancers. Approximately 96 % of patients underwent a lumpectomy or mastectomy, and 69.8 % had chemotherapy and/or radiation. Additionally, patients referred to OT had an average of 13.9 lymph nodes removed. Breast oncology physicians and nurses referred 49 % of patients, and members of the breast surgical team referred 41 % of patients. Approximately 51 % of patients were referred to OT for presenting with current lymphedema symptoms, such as arm swelling or tightness; the other 49 % were referred for lymphedema prevention (i.e., education or sleeve measurements) or routine post-operative care. Additionally, 127 (61.6 %) of the OT referrals occurred within 2 years of the patient's breast cancer surgery date; of these referrals, 70.9 % were made for lymphedema prevention/routine post-operative care. In contrast, of the OT referrals that occurred 3 years post-surgery, 86.1 % were made for lymphedema symptoms.

Of those who received a lymphedema consult OT referral, 43 (20.5 %) patients did not attend an OT appointment over the 18-month time period and were classified as non-attenders. Of the 167 attenders, 83 (49.7 %) attended an OT appointment within at least 2 weeks of the referral ordering date. Twenty-six patients (12.4 %) received more than one OT referral during the study time period; of these, 88.9 % were compliant with at least one referral to attend an OT appointment. The results of the chi-square tests found that non-attenders were more likely to have fewer lymph nodes removed ($P < 0.01$) when compared to attenders (Table 1).

Table 1 Participant characteristics by occupational therapy (OT) appointment attendance in a cohort of breast cancer survivors

Characteristic	Overall (N=210) N (%)	Women who attended OT appt (N=167) N (%)	Women who did not attend OT appt (N=43) N (%)	P value ^a
Demographics				
Age				0.61
Mean [SD (range)], years	57.2 [11.7 (25–92)]	57.1 [11.3 (25–92)]	57.5 [13.3 (33–91)]	
25 to 44	29 (13.8)	21 (12.6)	8 (18.6)	
45 to 64	126 (60.0)	102 (61.1)	24 (55.8)	
≥65	55 (26.2)	44 (26.3)	11 (25.6)	
Relationship status				0.22
Married	129 (61.7)	106 (63.9)	23 (53.5)	
Other	80 (38.3)	60 (36.1)	20 (46.5)	
Health insurance type				0.60
HMO/PPO	131 (66.5)	107 (66.9)	24 (64.9)	
Medicare	45 (22.8)	36 (22.5)	9 (24.3)	
Medi-Cal	19 (9.7)	16 (10.0)	3 (8.1)	
Self-pay	2 (1.0)	1 (0.6)	1 (2.7)	
OT referral source				0.24
Breast surgical team	86 (41.0)	68 (40.7)	18 (41.9)	
Breast oncology team	103 (49.0)	85 (50.9)	18 (41.9)	
Other physician/nurse	21 (10.0)	14 (8.4)	7 (16.2)	
OT referral reason				0.74
Current lymphedema symptoms	108 (51.4)	87 (52.1)	21 (48.8)	
Routine post-op/lymphedema prevention	102 (48.6)	80 (47.9)	22 (51.2)	
Body mass index				0.43
<25 kg/m ² (normal/underweight)	78 (37.1)	65 (38.9)	13 (30.2)	
25–29.9 kg/m ² (overweight)	69 (32.9)	55 (32.9)	14 (32.6)	
≥30 kg/m ² (obese)	63 (30.0)	47 (28.2)	16 (37.2)	
Medical characteristics				
Stage (AJCC 6th edition)				0.18
0	10 (5.0)	6 (3.7)	4 (9.5)	
I (IA, IB)	54 (26.7)	43 (26.9)	11 (26.2)	
II (IIA, IIB)	77 (38.1)	64 (40.0)	13 (31.0)	
III (IIIA, IIIB, IIIC)	55 (27.2)	44 (27.5)	11 (26.2)	
IV	6 (3.0)	3 (1.9)	3 (7.1)	
No. nodes removed				<0.01
Mean [SD (range)]	13.9 [9.8 (0–44)]	14.5 [9.7 (0–44)]	11.2 [9.9 (0–32)]	
0 nodes	5 (2.5)	1 (0.6)	4 (10.5)	
1 to 10 nodes	76 (38.2)	59 (36.7)	17 (44.7)	
11 to 20 nodes	69 (34.7)	61 (37.9)	8 (21.1)	
≥21 nodes	49 (24.6)	40 (24.8)	9 (23.7)	
Breast cancer surgery				0.86
Lumpectomy/bilateral lumpectomies	86 (42.6)	68 (42.2)	18 (43.9)	
Mastectomy/bilateral mastectomies	116 (57.4)	93 (57.8)	23 (56.1)	
Time since breast cancer surgery, years				0.23
≤1	68 (33.0)	56 (33.7)	12 (30.0)	
2	59 (28.6)	51 (30.7)	8 (20.0)	
≥3	79 (38.4)	59 (35.6)	20 (50.0)	
Chemotherapy	143 (69.8)	117 (70.5)	26 (66.7)	0.70
Radiation	143 (69.8)	116 (69.9)	27 (69.1)	1.00

Note: Due to missing data, some variables do not add up to 210

^a Categorical variables were tested with Fisher's exact χ^2 test

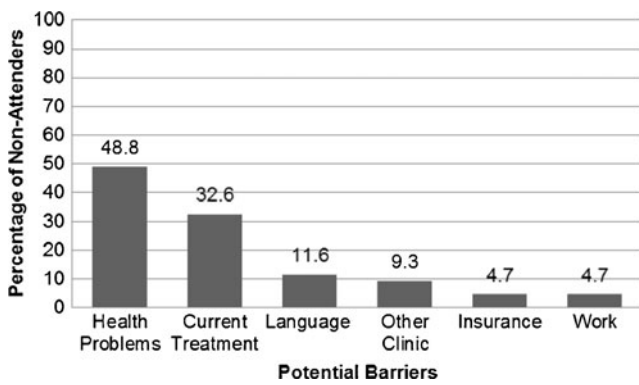


Fig. 1 Potential barriers for not attending an occupational therapy appointment after a health care provider referral ($N=43$)

Attendees had an average of 14 lymph nodes removed, whereas non-attendees had an average of 11 lymph nodes removed. Additionally, when examining the number of lymph nodes by referral reason, there was a significant difference in the number of lymph nodes removed for women referred for lymphedema symptoms ($M=15.7$, $SD=9.8$) compared to women who were referred for lymphedema prevention/routine post-operative care ($M=12.1$, $SD=9.6$), [$t(197)=2.64$, $P=0.01$].

Figure 1 illustrates the potential barriers/reasons for non-compliance documented from the medical records. Approximately 49 % of non-attendees had other health problems around the time of the OT referral; some examples of health problems experienced by the non-attendees were seizures, pneumonia, depression, grief, pulmonary embolism, and cancer metastasis. Of the 43 non-attendees, 32.6 % were undergoing chemotherapy and/or radiation at the time of the OT referral. Other barriers identified were language (English versus non-English speaking), most likely seen at another clinic, health insurance, and work demands. Additionally, 11.6 % of the non-attendees made an OT appointment, yet either canceled or were a no-show at the appointment.

Discussion

A prospective surveillance model is a crucial strategy in the prevention and treatment of lymphedema among breast cancer survivors. One key component of a PSM is the availability of cancer rehabilitation programs, such as occupational therapy lymphedema services. The primary purpose of this study was to examine patient attendance at OT lymphedema appointments after a provider referral within our medical center. Of those referred to an OT lymphedema consult, approximately 21 % failed to attend the appointment. The number of lymph nodes removed was the only participant characteristic shown to have a statistically significant difference between attendees and non-attendees. Numerous research studies have concluded that lymph node removal is a key risk factor for developing

breast cancer-related lymphedema [3, 17–22]. Since non-attendees had fewer lymph nodes removed, one may posit that a reason for their lack of compliance was that they did not feel they were at risk for lymphedema or in need of an OT lymphedema consult. However, when examining compliance based on the OT referral reason (i.e., current lymphedema symptoms versus routine care/lymphedema prevention), there was no significant difference found between groups.

A secondary objective was to identify potential barriers to patient compliance with attendance at an OT lymphedema consult appointment. A significant proportion of non-attendees (48.8 %) were experiencing other health-related problems, such as pneumonia, cancer metastases, or seizures, around the time of the OT referral. Additionally, 32 % of non-attendees were currently undergoing either chemotherapy and/or radiation therapy. We also identified language, work, and health insurance as other potential reasons for not attending an OT consult. Two patients mentioned at clinic visits that they had not made an OT appointment due to scheduling conflicts with work. Other studies examining non-attendance at medical appointments/programs have also found health problems [15, 23], language [15], and work [15, 23, 24] as barriers to attendance. For example, Wheelock and colleagues [15] reported that 14 patients declined an invite to an educational session due to a medical condition or their elderly status. In contrast to our study, previous studies also reported forgetfulness [23–25], transportation [24], and lack of interest [15] as barriers to attendance. Our lack of finding these additional barriers is most likely due to differences in study design; the other studies contacted each non-attender to determine reasons for non-attendance. In contrast, we did not contact non-attendees. Instead, we used information documented in the patient's medical chart to determine barriers to attendance.

A key strength of our study is the methodology of a retrospective chart review, which allowed for an examination of patient compliance with a health care provider referral for an outpatient OT lymphedema consult appointment within our medical center. Nevertheless, this study is not without its limitations. First, data collected for this study relied solely on information found in the patients' electronic medical charts and, hence, was subject to incomplete documentation for some of the study variables. For example, the medical charts of four patients indicated that they had gone to a clinic other than our medical center to receive lymphedema services. Demographic characteristics, such as race and ethnicity, education, and employment status, were not well documented in the medical charts and were not included in this study. Another limitation is that potential barriers identified cannot be verified with the patient and may not accurately describe the reasons for non-attendance. Also, we do not know if health care providers gave their patients any instructions regarding the OT lymphedema consult referral. Additionally, only one medical center was examined in this study and as a result, the

findings may not be representative of all medical centers with outpatient OT lymphedema clinics.

Conclusions

While most breast cancer patients were compliant and attended an OT lymphedema consult, some women did not attend, despite having a provider referral and OT lymphedema services readily available. Since previous studies have shown that lymphedema education can prevent lymphedema as well as improve lymphedema symptoms [10–13], it is important for any breast cancer patient who undergoes or has undergone treatment (e.g., surgery and radiation therapy) to receive lymphedema education. When referring patients to an OT lymphedema consult, health care providers may need to emphasize the benefits of lymphedema education and early detection of lymphedema symptoms. However, it is the patient's responsibility to attend the lymphedema consult, and future research efforts should focus on identifying the personal and contextual barriers to attending outpatient OT lymphedema appointments among breast cancer patients/survivors.

Additionally, health behavior or system-level interventions geared towards providers and patients could be developed to increase patient compliance with attending outpatient appointments. For example, multiple provider referrals may encourage patient compliance; 89 % of the 26 patients who received multiple referrals in our study population attended an OT lymphedema consult. A recent review article found that telephone, mail, and text/short message service reminders improved patient attendance at outpatient clinic appointments [26]. Approximately 12 % of the non-attenders in our study population made an OT lymphedema consult appointment yet failed to keep it, despite receiving an automated telephone reminder 2 days prior to their scheduled appointment. Another potential research direction would be to examine the most effective appointment reminder method (e.g., telephone, email, and text) for increasing patient attendance among breast cancer survivors.

In conclusion, patient attendance at outpatient OT lymphedema appointments is an important aspect of survivorship care. Future research is needed to better understand the individual, interpersonal, institutional, and policy factors that impact patient attendance.

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