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# SELF-REPORTED INFORMATION SOURCES AND PERCEIVED KNOWLEDGE IN INDIVIDUALS WITH LYMPHEDEMA

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## *ABSTRACT*

*Currently, a limited number of studies have been conducted that examine sources of information and knowledge level in individuals with lymphedema. This study aimed 1) to examine self-reported information sources and perceived lymphedema knowledge among individuals with lymphedema; and 2) to examine differences in self-reported information sources and perceived lymphedema knowledge among individuals with primary or secondary lymphedema; and with upper or lower extremity lymphedema. The National Lymphedema Network (NLN) conducted a survey to collect self-report data from March 2006 to January 2010. Overall, participants preferred a variety of sources of information. Participants reported low levels of knowledge about the types of lymphedema, treatment approaches and methods, and self-administrated therapies. In comparison to participants with secondary or upper extremity lymphedema, participants with primary or lower extremity lymphedema reported lower knowledge level regarding causes of lymphedema, risks for and complications of lymphedema, treatment approaches and methods for lymphedema, and self-administered therapies. Opportunities exist to expand lymphedema information sources. Healthcare professionals should focus on delivering high quality information about treatment and self-care management to individuals with lymphedema.*

**Keywords:** lymphedema, primary, secondary, upper and lower extremity, self-reported information sources, perceived knowledge, education, self-care

A large body of research has shown that individuals with chronic conditions or diseases consider accurate and understandable information to be of great importance in helping them cope with their chronic conditions (1,2). Studies have demonstrated that individuals who have access to information or who possess higher knowledge about their conditions are more likely to engage in self-care and report better symptom control and higher quality of life than individuals with less condition-related knowledge (2-4). Given that lymphedema is a chronic but manageable condition, individuals with either primary or secondary lymphedema need to be engaged in long-term lymphedema treatment and self-care management. Accurate lymphedema information and knowledge may increase patients' involvement in chronic disease management through self-care and effective disease management in turn may enhance their ability to lessen symptom burden or distress. In addition, patients' knowledge of disease management may facilitate effective communication with healthcare professionals as well as family members. Currently, a limited number of studies have been conducted that examine sources of information and knowledge level in individuals with lymphedema (2,5-8). Moreover, the majority of these studies have been only focused on secondary lymphedema that occurs following cancer treatment, specifically in breast cancer survivors (4,6-8).

Given the paucity of data pertaining to where individuals with primary or secondary lymphedema seek information and their knowledge levels related to lymphedema, the National Lymphedema Network (NLN) conducted a survey. The survey was available from March 2006 to January 2010 and sought to identify the self-reported information sources and condition-related knowledge levels among individuals with lymphedema. The findings reported here are part of a larger study conducted by the NLN focusing on the information related to lymphedema occurrence and how individuals with lymphedema access treatment, perceive treatment effectiveness, and access self-care information. The current article examines the self-reported experiences of individuals with lymphedema related to: 1) sources of information about lymphedema, including frequency of use, perceived accuracy, participants' understanding of information, participants' preferences for information sources, and time use in searching for lymphedema information; and 2) perceived knowledge levels about lymphedema. This report also examines whether or not there were differences in self-reported information sources and perceived knowledge levels among individuals with different types of lymphedema (i.e., primary or secondary) or different anatomical sites of lymphedema (e.g., upper or lower extremity).

## *METHODS*

### *Survey Development*

The data presented here were collected from a survey that was developed by the NLN Research Subcommittee using an iterative process that included: a) item generation; b) review and revision by clinical experts; and c) final review and approval by the NLN Research Subcommittee. Responding to this questionnaire was optional following completion of the parent survey. The questionnaire consisted of the following components: lymphedema information sources according to frequency of use, perceived accuracy of the information sources, participants' understanding level of the information sources, preferred information sources for receiving information about lymphedema, time spent searching for lymphedema information, time spent on other daily activities (i.e., reading the newspaper, magazines, listening to the radio, watching television, and using the internet), and participants' perceived knowledge level of lymphedema. The majority of items in the questionnaire were rated by respondents using a five-point Likert scales (1 = "little", 5 = "very much"), except for the use of information sources rated from 1 ("used most") to 9 ("used least").

### *Survey Administration*

Detailed information about the survey administration has been reported elsewhere (9). The survey was accessible to individuals in the United States and worldwide. The survey could be completed either on-line via the web site or with hard copies. Approximately 20% of the surveys were completed with hard copies. Completion of the survey served as the respondents' consent to participate in this survey study. The survey study was approved by the University of Missouri Health Sciences Institutional Review Board (IRB); secondary data analysis was approved by the IRB at Vanderbilt University.

### *Statistical Analysis*

Raw data were downloaded using a Microsoft Excel spreadsheet. Data were verified and cleaned via the Human-in-the-loop method (10) by screening for duplicate cases and invalid respondents, which were defined as surveys with missing data on key study variables. Data were analyzed using the statistical software package SPSS version 19.0. Descriptive statistics were used to describe the sample and the distributions of the study variables. Mean, median, as well as the 25th and 75th interquartile range (IQR) representing the middle 50% of values were used to describe ordinal variables (Likert responses). Sample size percentages were used to describe nominal responses. Mann-Whitney tests were used to test for differences between groups for the ordinal data and chi-square tests tested differences for nominal data. A maximum alpha of 0.05 was used for evaluating statistical significance.

## *RESULTS*

### *Sample Characteristics*

A total of 1,607 surveys were received. Of those, 41 surveys (2.6%) did not meet the inclusion criteria for this study (i.e., 41 surveys from respondents at risk for lymphedema). Of the remaining of 1,566, 24 surveys (1.5%) contained too much missing data to be included. Therefore, data from a final cohort of 1,542 (98.5% of total surveys received) respondents with lymphedema were available for analysis. *Table 1* shows the self-reported demographic characteristics of the study respondents.

**TABLE 1**
**Demographic Characteristics of Survey Respondents (n=1542)**

| Characteristic | Frequency (%) |
|---|---|
| **Gender*** | |
| Female | 1364 (89.5) |
| Male | 160 (10.5) |
| (total responses) | 1524 (100.0) |
| **Ethnicity** | |
| Caucasian | 1243 (80.6) |
| African-American | 103 (6.7) |
| Hispanic | 36 (2.3) |
| Other | 160 (10.4) |
| (total responses) | 1542 (100.0) |
| **Country** | |
| USA | 1422 (92.2) |
| Canada | 47 (3.0) |
| Other | 73 (4.7) |
| (total responses) | 1542 (100.0) |
| **Annual household income*** | |
| <$ 30,000 | 415 (30.0) |
| $30,000-$44,999 | 261 (18.9) |
| >$45,000 | 708 (51.2) |
| (total responses) | 1384 (100.0) |
| **Insurance coverage*** | |
| Yes | 897 (58.6) |
| No | 188 (12.3) |
| Don't know | 446 (29.1) |
| (total responses) | 1531 (100.0) |
| **Type of insurance*** | |
| Government | 145 (18.5) |
| Private | 522 (66.5) |
| Other | 118 (15.0) |
| (total responses) | 785 (100.0) |
| **Cancer-Related Surgery*** | |
| Yes | 788 (51.1) |
| No | 754 (48.9) |
| (total responses) | 1542 (100.0) |
| **Type/Site of Surgery*** | |
| Breast | 500 (65.8) |
| Gynecological | 132 (17.4) |
| Prostate | 2 (0.3) |
| Melanoma | 46 (6.1) |
| Other | 80 (10.5) |
| (total responses) | 760 (100.0) |
| **Treatment with CDT/MLD*** | |
| Yes | 717 (46.9) |
| No | 726 (47.5) |
| Don't know | 86 (5.6) |
| (total responses) | 1529 (100.0) |
| **Use of Alternative treatment*** | |
| Yes | 630 (43.6) |
| No | 814 (56.4) |
| (total responses) | 1444 (100.0) |

Note: 1) * Only valid cases; 2) CDT/MLD = complete decongestive therapy/manual lymph drainage

### *Distribution of Lymphedema*

The majority of the respondents (n=1025; 66.5%) reported having secondary lymphedema based upon the provided definition on the survey (i.e., lymphedema due to cancer surgery or radiation treatment or resulting from trauma, infection, and other operations). A total of 33.5% (n=517) reported having primary lymphedema defined on the survey as individuals born with lymphedema or onset during childhood/puberty/adult without an apparent reason. Among individuals with lymphedema, 68.7% (n=1059) of the respondents reported extremity lymphedema only, 25.6% (n=394) reported extremity(s) combined with other anatomic sites of lymphedema, 3.1% (n=48) of the respondents reported having only non-extremity lymphedema, and 2.6% (n=41) did not indicate site of lymphedema. Among individuals with extremity lymphedema (n=1059), there were 60.8% (n=644) with lower extremity lymphedema, 34.6% (n=366) with upper extremity lymphedema, and 4.6% (n=49) with both upper/lower extremity lymphedema. Based on the distribution of lymphedema, we were able to examine differences in self-reported information sources and perceived knowledge levels among respondents with: a) primary or secondary lymphedema; and b) upper or lower extremity lymphedema.

### *Self-Reported Sources of Lymphedema Information*

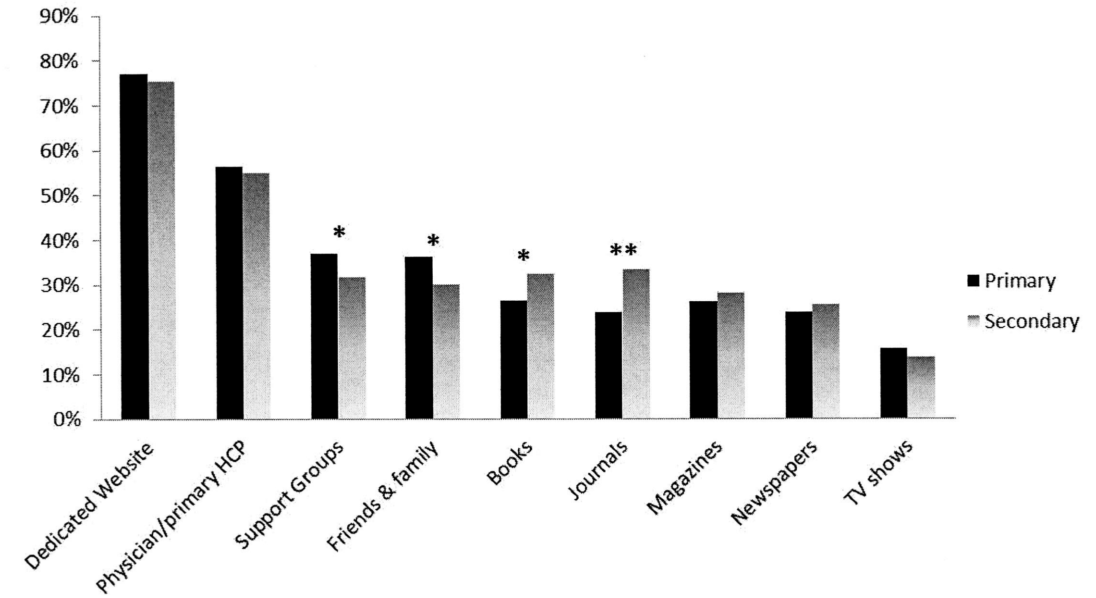
Dedicated websites (76.0%), physician/primary health care provider (55.5%), support groups on the internet (33.6%), and friends and family (32.1%) were reported as the top four most frequently cited sources of information about lymphedema. Dedicated websites and specialized books were perceived to be the most accurate sources of information about lymphedema. Dedicated websites, personalized email, articles in specialized professional journals, pamphlets with general information about lymphedema, and specialized books were listed as the top preferred sources of lymphedema information.

With respect to the time spent searching for lymphedema information, 46.2% of the respondents spent less than 1 hour weekly (i.e., less than 10 minutes daily), while 36.9% of the respondents used 1-3 hours weekly (approximately 10 to 30 minutes daily) searching for information about lymphedema. In total, 83.1% of the respondents spent less than 3 hours weekly (i.e., less than 30 minutes daily) searching for lymphedema information. Other activities engaged in for more than an hour daily included: using the internet (84.1% of the respondents), watching television (82.4%), listening to the radio (44.4%), reading the newspaper (22.9%), and reading magazines (18.3%).

Compared to respondents with primary lymphedema, respondents with secondary lymphedema were more likely to use and understand information from specialized journals and books, and less likely to consult friends and family or internet-based support groups (all p<.05) (*Fig. 1*). They were also more likely to prefer information from specialized books or support groups (not online) (p<.05).

Compared to respondents with lower extremity lymphedema, respondents with upper extremity lymphedema were more likely to obtain lymphedema information from specialized journals and books, magazines, or newspapers (all p<.05); to understand information from dedicated websites, physician/primary healthcare provider, specialized journals and books, magazines and newspaper, friends and family, or television shows (all p<.05); to prefer information from specialized books (p<.05); and to trust information from specialized journals and books (p<.05) . Those respondents with lower extremity lymphedema preferred information from internet-based support groups (p<.05).

### *Perceived Lymphedema Knowledge Level*



* $p < .05$; ** $p < .001$

*Fig. 1. Self-Reported Sources of Information by Survey Respondents (N=1542)*

Overall, respondents perceived higher levels of knowledge about the etiology, signs and symptoms, risks, and associated complications of lymphedema (medians = 4) than knowledge of the various types of lymphedema, treatment approaches, and self-administrated lymphedema therapies (medians = 3).

Respondents with primary lymphedema perceived lower levels of knowledge about the etiology, risks, associated complications, treatment approaches, and self-administered therapies than those with secondary lymphedema (*Table 2*) (all $p< .05$).

Respondents with lower extremity lymphedema perceived lower levels of knowledge about the etiology, risks, associated complications, treatment approaches, and self-administered therapies for lymphedema than those with upper extremity lymphedema (*Table 2*) (all $p< .05$).

## *DISCUSSION*

Although lymphedema information sources have previously been reported in several studies (2-4,6-8), the primary focus of these studies has been on populations with breast cancer-related lymphedema. There are no contemporary studies in which information sources utilized by a broader group of individuals with primary and/or secondary lymphedema (other than breast cancer survivors) were reported, or that compared the information sources and perceived knowledge levels among various groups of patients. To our best knowledge, this study is the first to report the utilization of various information sources and the perceived knowledge levels among individuals in subsets of patients with primary or secondary lymphedema, and with upper or lower extremity lymphedema.

### TABLE 2
### Comparison of Scored Lymphedema Knowledge Level (Range 1 to 5) Among Individuals with Different Types of Lymphedema

| **Lymphedema Knowledge** | **Primary lymphedema (n=517)** | **Secondary lymphedema (n=1025)** | | **Upper extremity lymphedema (n=366)** | **Lower extremity lymphedema (n=644)** | |
|---|---|---|---|---|---|---|
| | **Mean, Median (25th-75th IQR)** | **Mean, Median (25th-75th IQR)** | **p-value** | **Mean, Median (25th-75th IQR)** | **Mean, Median (25th-75th IQR)** | **p-value** |
| Causes of occurrence | 2.8, 3.0 (1-4) | 3.7, 4.0 (3-5) | <.001 | 3.7, 4.0 (3-5) | 3.1, 3.0 (2-4) | <.001 |
| Types of lymphedema | 3.1, 3.0 (2-4) | 3.2, 3.0 (2-5) | .149 | 3.1, 3.0 (2-4) | 3.1, 3.0 (2-4) | .681 |
| Signs and symptoms of lymphedema | 3.5, 4.0 (3-5) | 3.7, 4.0 (3-5) | .050 | 3.7, 4.0 (3-5) | 3.6, 4.0 (3-5) | .146 |
| Risks and complications of lymphedema | 3.2, 3.0 (2-4) | 3.5, 4.0 (2-5) | <.001 | 3.5, 4.0 (3-5) | 3.2, 3.0 (2-5) | .003 |
| Treatment approaches and methods | 2.9, 3.0 (2-4) | 3.2, 3.0 (2-4) | <.001 | 3.2, 3.0 (2-4) | 3.0, 3.0 (2-4) | .005 |
| Self-administered therapies | 2.6, 2.0 (1-4) | 2.9, 3.0 (2-4) | <.001 | 2.9, 3.0 (2-4) | 2.7, 3.0 (1-4) | .004 |

Note: 1) The 25th-75th interquartile range represents the middle 50% of the responses in the distribution of ordinal data; 2) Knowledge level: Little (1) to Very much (5); 3) Only valid cases.

### *Self-Reported Sources of Lymphedema Information*

Among study respondents, dedicated websites were the primary source of information for the vast majority (>76%) of participants. This finding is different from some studies conducted in breast cancer patients with lymphedema. For example, breast cancer patients with lymphedema most commonly identified surgeons and nurses as sources of lymphedema information at the time of pretreatment education (7); while physical therapists, books, and oncology staff were the most frequently cited sources of lymphedema prevention and management information in a telephone survey of recently-treated breast cancer patients (6). In a recent study, lymphedema information from the clinic (e.g., brochures, nursing staff) was the most cited source of information by breast cancer patients with lymphedema (4). Nevertheless, our findings are consistent with several reports from studies conducted on individuals with other chronic diseases as well as other patient populations with cancer. For example, one study (11) reported that more than half of respondents from a primary care internal medicine private practice used the internet for health information and the majority of respondents appeared confident that they were accessing reliable information. In another study by Walsh et al (12), although the internet was not the primary source of information, the authors identified that 30% of the respondents obtained information from the internet. The internet was particularly used by people with chronic conditions (13,14). In another review article, the author summarized that the internet provides a gateway to an abundance of information on cancer and emphasized the importance of the dedicated websites in providing cancer patients with needed and critical health information (15).

Our finding that physicians/primary healthcare providers was ranked as the second most commonly-used source of lymphedema information is consistent with previously published reports which examined information sources in individuals with secondary lymphedema (6,7). Two review articles have also noted that healthcare professionals are the most frequent information source among cancer patients (1,16). However, our study participants rated the quality of information from physician/primary healthcare provider at the moderate level. This finding is similar to the reports from two qualitative studies (17,18), in which breast cancer survivors revealed that they were marginalized by healthcare providers who are not well informed about lymphedema management and minimize its impact.

Internet-based support groups as well as friends and family were identified as the primary sources of lymphedema information for more than one-third of the respondents. These findings are similar to literature reports on individuals with cancer for seeking cancer information (12,19,20).

The findings from this survey revealed that individuals with lymphedema preferred a variety of types of information sources, which included dedicated websites, personalized emails, professional journals, pamphlets, and books. These findings provide a variety of opportunities for clinicians and professional lymphedema organizations to offer enhanced support for individuals with lymphedema. Furthermore, newspapers and television/radio talkshows were ranked as the least likely used information sources; and television and radio talkshows ranked as the least preferred information source by the study respondents. This may be related to the fact that currently very limited lymphedema information is available from television/radio talkshows and newspapers. Studies are needed to investigate the underlying reasons why individuals with lymphedema are less likely to prefer information from television and radio talkshows.

In addition, the study found that 45.6% of the respondents used less than 1 hour weekly (less than 10 minutes daily) and 36% used less than 1-3 hours weekly (less than 30 minutes daily) searching for lymphedema information. Currently, no studies are available to report the optimal amount of time daily searching for lymphedema information. As healthcare professionals, we may not have the goal to increase the amount of time searching for lymphedema information, but to help individuals with lymphedema to search information more efficiently and effectively. Interestingly, we found that the majority (79.9%) of the respondents spent more than at least 1 hour watching television daily, nearly half (43.1%) of the respondents spent more than at least 1 hour listening to the radio daily; and more than one fifth (22.3%) of the respondents spent more than at least 1 hour reading the newspaper daily. Thus, healthcare professionals and lymphedema investigators should consider how to effectively utilize these media sources to provide individuals with lymphedema and their family members with needed information. These media sources (e.g., television, radio, and newspaper) may become important additional resources to increase public awareness of lymphedema and deliver proper and critical information related to lymphedema management and self-care to individuals with or at risk of lymphedema.

In the study, we also examined the differences in self-reported information sources by types and sites of lymphedema. We found that the respondents with primary lymphedema were more likely to use information from family and friends, and support groups on the internet; however, respondents with secondary lymphedema were more likely to use journals and books as information sources. Although no corresponding studies are available for review, these findings may be explained by the fact that individuals with primary lymphedema may be more likely to have family members with lymphedema and also more likely to have early-onset lymphedema, which may trigger them to seek more support from community levels, e.g., family, friends, and support groups on the internet. Alternatively, the paucity of research associated with primary lymphedema may reduce the number of information source alternatives when compared to those with secondary lymphedema. Secondary lymphedema is an acquired and more substantially studied condition; thus, individuals with secondary lymphedema may be more likely to rely on journals and books that include more updated lymphedema treatment information. Similarly, respondents with upper extremity lymphedema were more likely to use information from specialized journals and books, magazines, and newspapers, compared to respondents with lower extremity lymphedema. This may be explained by the fact that the majority of the respondents with upper extremity lymphedema (97.5%) were secondary to an acquired condition; while more than half of the respondents with lower extremity lymphedema (54.7%) were from an inherited or sporadic primary condition. Paucity of research related to lower extremity lymphedema compared to upper extremity lymphedema may also play a role in these findings.

### *Perceived Knowledge Levels Related to Lymphedema*

Overall, respondents perceived higher levels of knowledge about the etiology, signs and symptoms, risks, and associated complications of lymphedema than knowledge of the types of lymphedema, treatment approaches, and self-administered therapies. This finding regarding the needs of treatment approaches and self-care management is consistent with reports from several studies (8,21,22). Given that lymphedema is a chronic condition, individuals' long-term self-care and monitoring is critical, and effective management strategies of lymphedema are required. Accurate, evidence-based information must be widely available for lymphedema patients. Findings from this study and others (3,6,7,21) have underscored the urgent need for developing and implementing strategies for individuals with lymphedema to access the latest information, especially related to self-care management and treatment options. Such strategies could make significant difference in symptom management, functional improvement, infection prevention and control, and quality of life improvement in individuals with lymphedema.

In the study, we also examined the differences in perceived lymphedema knowledge level by types and sites of lymphedema. We found that respondents with primary or lower extremity lymphedema perceived lower levels of knowledge in the causes, risks and complications, treatment approaches and methods, and self-administered therapies for lymphedema than respondents with secondary or upper extremity lymphedema. Currently, no studies are available to examine the differences of knowledge levels across different types or anatomical sites of lymphedema. These differences may be extrapolated based on the status of the current available body of knowledge related to lymphedema. That is, as healthcare professionals have become more aware of the problem of secondary lymphe-dema related to cancer treatment (especially in the breast cancer population), more research studies have been focused on individuals with secondary or upper extremity lymphedema. In addition, little attention has been given to issues and needs among individuals with primary or lymphedema in other anatomical sites (e.g., lower extremity lymphedema). Therefore, our findings indicate that more studies are needed to investigate contributing factors related to the differences of knowledge levels among individuals with different types and sites of lymphedema; intervention studies may be required to address these discrepancies.

### *Strengths and Limitations*

There are several strengths to this study. A large number of respondents were involved in this survey, which allowed the examination of self-reported information sources as well as perceived knowledge levels among individuals with lymphedema. Second, we provided easy access to the survey; that is, the participants could complete the survey either online via the website or with hard copies. Third, there were 33.5% of the respondents with primary lymphedema and 66.5% with secondary lymphedema in the sample. This percentage representation of respondents with primary versus secondary lymphedema almost mirrored the projected percentage of individuals with primary or secondary lymphedema in the United States (23-25). That is, it is estimated that there are approximately 1 million individuals potentially with germline or somatic gene-associated primary lymphedema, and 2 to 3 million individuals experience secondary lymphedema in the United Stated (23-25). Fourth, this is the first study we are aware of to examine self-reported information sources and perceived knowledge levels among individuals with primary lymphedema. We also identified the differences in self-reported information sources and perceived knowledge levels of lymphedema among individuals with primary or secondary lymphedema and with upper or lower extremity lymphedema. These findings shed light on the importance of providing tailored information and education opportunities to individuals with different types or anatomical sites of lymphedema.

Despite its many strengths, the current study's approach also has several limitations. First, the data collected in the study were constrained from a convenience sample rather than a defined denominator of broad potential participants. Second, the study cohort included only a small percentage of minority participants and male respondents, and therefore, it may or may not be representative of the general population of lymphedema patients, and study results may not be generalizable to minority populations or males with lymphedema. Third, although the definition of primary and secondary lymphedema was provided in the survey, respondents had to self-identify as primary or secondary lymphedema, and some cases may have been mistakenly defined by either the respondent or their healthcare provider. Fourth, the results of the study should be considered with respect to selection bias as the reported results are based only on the information sources reported by survey respondents. Also, recall bias exists because this is not an observed study. The study only obtained perceived knowledge levels of lymphedema, rather than using any objective measurement of lymphedema knowledge. The survey extended over nearly four years, during which both general internet usage and available lymphedema educational resources may have changed, which may impact the study findings. In addition, searching for lymphedema information may vary individually depending on such factors as newly diagnosed or long-term, treated or untreated, and availability of resources.

In summary, our findings indicate that the availability of patient information and the preferences of patients in using education sources need further research. These are questions that need to be researched in a clinical setting, where the full range of patient experience could be represented, including those unfamiliar with internet usage, and those seeking information because of known risk (cancer treatment, trauma, familial history).

## *CONCLUSION*

Participants preferred a variety of sources for seeking lymphedema information. Regardless of etiology and anatomic site of lymphedema, individuals with lymphedema desire to increase their knowledge about etiology, risk factors, treatment options, and self-care strategies. Moreover, individuals with primary or lower extremity lymphedema perceived having lower levels of lymphedema knowledge than individuals with secondary or upper extremity lymphedema.

Although more studies are needed to investigate the differences in lymphedema knowledge levels across individuals with different types or anatomical sites of lymphedema, tailored or individualized information should be considered when conducting lymphedema education, especially based on types of lymphedema and/or anatomical sites of lymphedema. Clearly, healthcare professionals need to provide high quality of information to individuals with or at risk of lymphedema. Addressing the need for research in individuals with primary and/or non-upper extremity lymphedema is significantly important based on the study findings.

Opportunities exist to expand lymphedema information sources, improve quality of existing information sources, and increase individuals' knowledge levels related to lymphedema. Although our data show that media (e.g., television, radio talkshows) are not currently preferred sources, the study participants spent a great deal of time using these media. Thus, healthcare providers and lymphedema investigators should consider using these media to extend lymphedema information sources and deliver high quality of lymphedema information to individuals with lymphedema.

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