

DIET AND BCRL: FACTS AND FALLACIES ON THE WEB

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Lymphoedema is a common sequela to breast cancer treatment. Until recently, patients were limited in how they obtained information, but now a range of medical-related websites provide numerous alternatives for managing the condition. With many patients consulting grey and popular literature, healthcare professionals need to be better aware of inaccurate or potentially dangerous information in the media and how to respond to questions about alternative therapies. This review summarises the current recommendations made on the web for lymphoedema patients following breast cancer, and critically analyses their real value in clinical practice.

Key words

Lymphoedema
Diet
Grey literature
Alternative therapies
Breast cancer

Lymphoedema is a devastating condition that affects millions of individuals and is often associated with filarial infections, especially in tropical areas of developing nations (Dawes et al, 2008). Breast cancer patients are at risk of lymphoedema following surgery or radiotherapy (Hull, 2000), and it is estimated that 6–30% of breast cancer survivors will develop lymphoedema (Petrek and Heelan, 1998).

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Until recently there were limited treatment options for people with lymphoedema because it was neither well recognised nor researched. However, the profile of this condition is gaining momentum and more alternatives are becoming available for patients. Some of these, although

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not well trialled, are associated with intensive publicity or promotion campaigns, for example, the alkalising diet (George, 2007; Hodges, 2009).

Since breast cancer-related lymphoedema (BCRL) has only recently been recognised as a condition requiring early detection and treatment (Nielsen et al, 2008), there is not a vast range of peer-reviewed evidence on therapies, such as diet and exercise. Despite this lack of evidence, literature on the worldwide web (www) is abundant with recommendations for lymphoedema management.

In a study of trends in the use of the

internet for the acquisition of health information, Schwartz et al (2006) found 48% of respondents had used the internet to find information on health issues or medical conditions, and 98% felt that the information was trustworthy. The great concern is that many uneducated patients with or at risk of lymphoedema may lack the discretion to critically appraise and separate facts from fallacies.

Objectives

This review provides practitioners with an up-to-date and concise report of diet and exercise lymphoedema therapies currently recommended on the worldwide web for breast cancer patients. Well-informed practitioners can give more credible advice to patients who approach them with information they have gathered from the internet, which, in the authors' opinion, may facilitate a more open and trusting relationship between doctor and patient, and optimise patient outcomes.

Methods

Search strategies

The search engine Google was used to find websites and the first 20 results from each search were investigated for claims about lymphoedema management strategies aimed at diet and exercise. E-books were purchased from sites and information contained in websites and discussion boards was included.

Search terms

General terms used for this search included: lymphoedema, lymphedema, lymphatic dysfunction, diet, exercise, cure, management, breast cancer.

Search results

This search strategy enabled themes to be identified and further investigated in the grey literature on the worldwide web. Nine separate topics were identified as management options for lymphoedema:

- » Achieve and maintain a healthy weight
- » Low carbohydrate diet
- » Low protein diet
- » Alkalisising diet
- » Low salt diet
- » Exercise
- » Drink distilled water
- » Abstain from alcohol and caffeine
- » Oil pulling.

Analysis

Each topic was investigated in the peer-reviewed literature for evidence that supported or refuted claims made. Information on discussion boards was not discussed separately as it was representative of what was contained in websites. Topics were further categorised into the following:

- » **Safe and effective:** Management strategies that are both safe to the patient and supported by peer-reviewed evidence
- » **No harm but no evidence:** Recommended strategies that are not supported by peer-reviewed evidence but that are of no harm to the patient
- » **No evidence and potentially dangerous:** Recommended strategies that are unfounded and can potentially cause physical, mental and financial harm to the patient.

Unfounded recommendations and their sources are shown in *Table 1*. Although some sites contained inaccurate information, this often accompanied accurate information, which may make elucidating right from wrong even more difficult for an uninformed patient. Sources with reliable and unbiased information are found in *Table 2*.

Table 1

Sources with incorrect or misleading information

Source	Recommendations
Lymphedema and the Atkins Diet (www.atkins-diet-advisor.com/lymphedema-and-the-atkins-diet.html)	<ul style="list-style-type: none"> » Avoid alcohol and caffeine » Low carbohydrate high protein diet » Low salt diet » Achieve healthy weight
Diet for lymphoedema (www.lymph.com.au/)	<ul style="list-style-type: none"> » Achieve and maintain a healthy weight » Alkalisising diet » Low carbohydrate diet » Drink distilled water (Cost: \$27AUD for e-book)
Discover How to Heal Your Lymphatic System and Reduce Swelling caused by Lymphedema! (www.lymphedemaadvice.com/)	<ul style="list-style-type: none"> » Alkalisising diet (Cost: \$37AUD for e-book)
Lymphedema or Lipodema (www.lymphedemapeople.com/thesite/lymphedema_lipodema.htm)	<ul style="list-style-type: none"> » Low carbohydrate diet
Lymphedema Treatment (www.lymphedematreatment.org/)	<ul style="list-style-type: none"> » Reduce salt intake » Oil pulling » Exercise under medical supervision

Each topic will now be analysed separately.

Safe and effective

Achieve a healthy weight

Many sources (Lymph Notes, 2011; Lymphoedema Support Network [LSN], 2011; Medicine Net, 2011; National Cancer Institute, 2011) promote weight loss as a strategy to alleviate lymphoedema. Studies have shown a significant correlation between obesity and the occurrence of lymphoedema after breast cancer surgery (Clark et al, 2005; Helyer et al, 2009; Mak et al, 2009). Petrek et al (2001) and Soran et al (2006) demonstrated a relationship between both body mass index (BMI) and BMI change in the development of lymphoedema.

The exact mechanism has not

been elucidated, however, extra weight places greater strain on the lymphatic system's ability to move fluid, and endocrine functions of fat promote tissue inflammation (Bunce et al, 1994; Bray, 2004).

Achieving and maintaining a healthy weight can improve lymphoedema and patient-rated outcomes. McNeely et al (2010) and Shaw et al (2007) found that weight loss by low fat diet or overall caloric reduction resulted in reduced arm volume in lymphoedema patients after 24 weeks.

Weight loss is best achieved by following a healthy eating plan, rather than by using fad crash diets. Restricting certain food groups may mean that patients are missing out on important nutrients, while complicated diets with minimal kilojoule content

reduce patient adherence (Heymsfield et al, 2007). A healthy diet has plenty of fruit and vegetables and is low in saturated fat. Good resources include the Australian Guide to Healthy Eating (Children's Health Development Foundation, 1998) and NHS Choices (NHS, 2010), but there are many others from formal sites around the world such as the American Dietetic Association (2011).

Obesity has many health implications including increased cancer risk (Carroll, 1998). Carmichael (2006) found obesity to be implicated in the development and poor prognosis

of breast cancer, and this knowledge may further motivate patients to lose weight. It is often worthwhile to engage a registered dietician for patients requiring assistance in developing a healthy eating plan for weight loss and health promotion.

Exercise

There is growing evidence that exercise and physical activity are associated with a better quality of life and health outcomes (Pendo and Dahn, 2005). Sites on the worldwide web have recommended exercise for lymphoedema management (About.com, 2011; Lymph Notes, 2011;

Lymphoedema Support Network [LSN], 2011; Medicine Net, 2011; National Cancer Institute, 2011; The Lymphoedema Association of Australia, 2007).

There is increasing evidence (Bicego et al, 2006; Schmitz et al, 2009) to support the notion of exercise reducing lymphoedema in patients that have undergone breast cancer treatment. McKenzie and Kalda (2003) found that exercise significantly improved quality of life in lymphoedema patients in measures of physical functioning, general health and vitality.

As for lymphoedema prevention, Lacomba et al (2010) found that early physiotherapy involving movement and exercise, may be an effective prophylaxis for the development of secondary lymphoedema following breast surgery.

However, every patient is different, and their personal health will determine the level of exercise they can achieve. Engaging a physiotherapist may be of value for patients with mobility problems.

Avoid diuretics

Diuretics include medications as well as substances such as alcohol and caffeine. Sources on the worldwide web (Lymph Notes, 2011; Medicine Net, 2011) have discouraged the use of alcohol and caffeine in lymphoedema patients on the basis that they are diuretics. A review by Keeley (2008) recommends not using diuretics for the treatment of lymphoedema.

Diuretics reduce the amount of fluid present, however in doing so, they increase the concentration of protein in the lymphatic circulation which may exacerbate lymphoedema in the long term (Foldi et al, 2003; Lymphoedema Association of Australia 2011). This may confer other health benefits for the patient, as alcohol has been recognised as a risk factor for some cancers, including breast (Allen et al, 2009).

Table 2
Sources with good and correct information

Source	Conservative therapies recommended
Lymphoedema Support Network (www.lymphoedema.org/)	<ul style="list-style-type: none"> ▶▶ Exercise under medical supervision ▶▶ Achieve and maintain a healthy weight ▶▶ Eat a balanced diet
Lymphoedema Association of Australia (www.lymphoedema.org.au/)	<ul style="list-style-type: none"> ▶▶ Exercise under medical supervision ▶▶ A well balanced diet
Lymphedema (www.cancer.gov/cancertopics/pdq/supportivecare/lymphedema/Patient/page3)	<ul style="list-style-type: none"> ▶▶ Achieve and maintain a healthy weight ▶▶ Exercise under medical supervision
Breast Cancer: Side-effects of Treatment: Lymphedema (www.medicinenet.com/breast_cancer_and_lymphedema/article.htm)	<ul style="list-style-type: none"> ▶▶ Achieve and maintain a healthy weight ▶▶ Have a healthy and balanced diet ▶▶ Avoid alcohol ▶▶ Exercise regularly under medical supervision
Lymph Notes (www.lymphnotes.com/)	<ul style="list-style-type: none"> ▶▶ Exercise ▶▶ Achieve and maintain a healthy weight ▶▶ Avoid alcohol and caffeine ▶▶ Reduce salt intake
The basics of lymphedema after breast cancer (http://breastcancer.about.com/lw/Health-Medicine/Conditions-and-diseases/The-Basics-of-Lymphedema-After-Breast-Cancer.htm)	<ul style="list-style-type: none"> ▶▶ Maintain a healthy weight ▶▶ Exercise under medical supervision

No harm but no evidence**Low salt diet**

A low salt diet is recommended by some sources as a potential treatment option for lymphoedema (Atkins Diet Advisor, 2011; Lymphedema Treatment, 2011; Lymph Notes, 2011). Patients should not add salt during cooking or at the dinner table, and choose low salt alternatives at the supermarket.

Low salt diets can be effective in some clinical scenarios where fluid retention is a problem, because high levels of sodium exert an osmotic pressure (Foldi et al, 2003). However, it is oncotic pressure exerted by protein that mainly causes fluid accumulation in lymphoedema (Foldi et al, 2003). It follows that a reduction in sodium will not correct this.

There are other health benefits in reducing salt intake, particularly in the management of hypertension (He and MacGregor, 2004). However, patients should be aware that limiting salt intake is not a recognised or evidenced management strategy for the treatment of lymphoedema.

Oil pulling

Oil pulling is traditionally used as a remedy for gingivitis in Ayurvedic medicine. It requires the patient to take a tablespoon of oil, and swish it around the mouth for 15–20 minutes before eating. There are claims (Lymphedema Treatment, 2011) that oil pulling will cure lymphoedema as well as many other diseases on the basis that the process of the oil moving through the mouth causes the activation of enzymes that remove toxins from the blood.

There have been no studies to support this claim, and there is no sound physiology behind the theory. There is peer-reviewed evidence that oil pulling can improve oral health (Asokan et al, 2009), however, this is the full extent of its known properties.

No evidence and potentially dangerous**Low carbohydrate diets**

Diets that exclude carbohydrate and increase protein intake have been

recommended on the worldwide web to reduce cancer-related lymphoedema (George, 2007; Atkins Diet Advisor, 2011; Lymphedema People, 2010). This is for two reasons: firstly, to promote weight loss and, secondly, because carbohydrates are claimed to be 'toxic'. This diet is sometimes called the 'Atkins Diet', and promotes rapid weight loss as the absence of insulin stimulates fat catabolism.

This diet has many potential adverse health effects (Sumithran and Proietto, 2008). Exclusion of carbohydrates results in reduced consumption of some nutrients, vitamins and minerals which may lead to deficiencies and protein catabolism in the body. This diet is also high in fat which may increase the workload of the lymphatics (Foldi et al, 2003), as well as conferring other health consequences of a high fat diet such as poor cardiovascular health. There have been case reports documenting severe ketoacidosis following exclusion of carbohydrates from the diet (Chen et al, 2006; Shah and Isley, 2006). Finally, low carbohydrate diets can be dehydrating, which may actually worsen lymphoedema (Foldi et al, 2003).

Patients are correct to assume that achieving a healthy weight will help to improve lymphoedema. However, a diet devoid of carbohydrates is unhealthy and poses some risks, possibly even worsening lymphoedema.

Low protein diet

The low protein diet is recommended on the basis that protein-rich fluids are transported in lymph, thus it follows that a diet low in protein will reduce the workload of the lymphatics. No evidence supports this, and low protein diets can be potentially dangerous. Proteinaceous foods are high in amino acids that are essential for the body. If protein is not acquired in the diet, the body begins to catabolise its own protein stores, resulting in muscle wastage and malnourishment (Mahan and Escott-Stump, 2007).

Alkaline diet

The profile of the alkaline diet has

gained momentum in the media over the past decade as a cure and preventative strategy for most illnesses and diseases, including lymphoedema. Some websites and e-books (George, 2007; Hodges, 2009) claim that the average western diet contains more 'acidic foods' which promote acidic conditions within the body, and that an acidic body is more likely to develop cancer and other diseases. The alkaline diet entails a strict regimen of prescribed 'alkaline' foods with an emphasis on limiting 'acidic' food intake. There is also strong promotion of expensive 'water alkalisers', which produce drinking water that is more alkaline.

Despite what some well-presented websites and authors claim, no peer-reviewed evidence could be found to support the alkaline diet as a treatment for lymphoedema.

The pH of the body is strictly maintained between 7.3–7.4 and any slight deviation from this stimulates homeostatic mechanisms that attempt to maintain the pH within a normal range (Boron and Boulpaep, 2009). A pH that deviates from this narrow range is not compatible with healthy life, which is why the human body's mechanisms to control and maintain pH are so effective.

The alkaline diet may also be detrimental to the patient. Expensive products need to be bought, while the intake of essential nutrients is limited.

Deionised water

The idea of purification or detoxification appeals to many people, and, recently, the drinking of deionised water has become a popular but controversial activity. It has been claimed that the benefits of this include alleviating lymphoedema (George, 2007).

No peer-reviewed literature could be found to support the ingestion of distilled water to alleviate lymphoedema. According to the World Health Organization (2008), drinking distilled water may have adverse health

Table 3

Summary of treatment strategies in the grey literature and their use in clinical practice

	Safe and effective	No harm, but no evidence	Potentially dangerous
Achieve healthy weight	√		
Low carbohydrate high protein diet			√
Low protein diet			√
Alkaline diet			√
Low salt diet		√	
Exercise	√		
Drinking distilled water			√
Avoid diuretics	√		
Oil pulling		√	

outcomes, including low intake of essential elements and microelements and a direct effect on metabolism and mineral homeostasis. No evidence could be found as to whether deionised water has a role in health, and it appears that nothing can be gained by using it to treat lymphoedema.

Discussion

This search of grey literature on the worldwide web has revealed some alarming insights into the information available for breast cancer survivors with lymphoedema. This is of concern as, while the profile of lymphoedema is increasing, there is often inadequate peer-reviewed evidence available about the dietary treatments for practitioners and patients. *Table 3* summarises the treatments currently recommended on the internet and their validity in clinical practice.

Achieving and maintaining a healthy weight, exercising and avoiding diuretics have been identified in this review as safe and effective strategies

Patients should not be discouraged from taking the initiative about their own health. It is, however, crucial that they are aware of the significance of being extremely critical of any information that they may gain from the internet, and that they discuss any potential treatment strategies with their doctor before starting a new intervention.

for managing lymphoedema. They can all be done inexpensively under the supervision of a healthcare professional.

Oil pulling and a low salt diet were identified as strategies in the grey literature that did not confer any benefit to lymphoedema, but neither

would they cause any direct harm to the patient. However, it may be considered unethical to advocate these strategies because, although they cause no harm, patients who have explored other alternatives may invest a lot of money, time and emotion into them.

The strategies that are identified as potentially causing harm are concerning. Information can be presented in a manner that appears convincing to a lay person. On two incidences there were e-books for sale which contained possibly harmful information, and it would be natural for a lay person to assume that a resource being purchased contains only accurate information.

Potentially harmful aspects of some of the treatments include expenses incurred from purchasing e-books, company products or other supplements that a site might recommend. Some treatments may be dangerous and potentially life-threatening, such as the Atkins Diet.

Patients should not be discouraged from taking the initiative about their own health. It is, however, crucial that they are aware of the significance of being extremely critical of any information that they may gain from the internet, and that they discuss any potential treatment strategies with their doctor before starting a new intervention. This is important not only for any possible dangers that the treatment may have, but also because some patients may have medical conditions such as hypertension or diabetes that contraindicate some interventions. In addition, websites containing inaccurate information often have a great deal of accurate information, making it even more difficult for patients to critically analyse the information.

It is natural that inquisitive patients will use this resource to learn more about their condition and treatment options. Doctors do not have time to do grey literature searches of their own. This review is intended to be a useful resource for medical

practitioners faced with the dilemma of answering questions about lymphoedema treatment that were precipitated by patients searching the worldwide web.

The results revealed that patients are being presented with extensive recommendations from the sources investigated. Much of this information is concerning, and could cause financial, physical and emotional harm to patients.

Implications for clinical practice

To make an informed decision, healthcare professionals should attempt to educate their patients or encourage them to attend educational sessions. They should urge patients to seek medical advice before undertaking any conservative treatments for their disease. Patients may have different health needs which require discussion before starting any treatment. Patient comorbidities should also be considered.

Conservative measures instigated by the patient empower them to take charge of their own health care, and should be encouraged provided that they are safe and the patient is fully informed of the potential consequences, both positive and negative.

Clinical practice points

- ▶ Achieving a healthy weight is beneficial in lymphoedema management, but only if this is done with a sensible, healthy eating plan, and not necessarily involving expensive (or fad) diets. It would seem crucial to engage a dietician for some patients
- ▶ Exercise is beneficial, however, patients should see their doctor before starting an exercise regimen and, ideally, engage a physiotherapist or exercise physiologist to offer advice and support
- ▶ The patient should be familiar with current management strategies in the grey literature and their strengths and weaknesses, as outlined in this review

- ▶ We all have a responsibility to better educate our patients so that when they search the worldwide web they are well-informed and able to make good decisions about what strategies they may choose in their self-management of lymphoedema.

Patients should not be discouraged from taking an interest in their own health, but should visit an informed healthcare professional before proceeding with any conservative treatment.

Conclusion

With such overwhelming information available on the worldwide web for breast cancer patients with lymphoedema, it is impossible for clinicians to stay up to date with what patients are reading in their own time. It is only natural that patients will access the internet to search for relief or treatment information. Often, poorly researched/evidenced treatments are presented with high levels of marketing aplomb and pressure.

This review has outlined the information currently presented in the grey literature on the worldwide web and has critiqued its validity. It is clear that achieving a healthy weight with a balanced diet, exercising under medical supervision and abstaining from alcohol and caffeine are the only conservative strategies identified in the grey literature that are supported by peer-reviewed literature. Some management strategies recommended in the grey literature are potentially harmful to the patient financially, physically and emotionally. Patients, however, should not be discouraged from taking an interest in their own health, but should visit an informed healthcare professional before proceeding with any conservative treatment. JL

Acknowledgements

To the Cancer Council of South Australia who provided a Summer Research Scholarship for this project to be undertaken.

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Key points

- ▶▶ Many uneducated patients with or at risk of lymphoedema may lack the discretion to critically appraise information on the internet regarding treatment options.
- ▶▶ Achieving a healthy weight, exercise and avoiding diuretics are supported by peer-reviewed literature as measures for preventing or reducing lymphoedema.
- ▶▶ Some strategies promoted on the internet for lymphoedema treatment are potentially harmful to patients physically, emotionally and financially.
- ▶▶ Patients should not be discouraged from taking an active interest in their own health and lymphoedema treatment options, however, an open relationship is required with their doctor to ensure all treatment strategies are discussed.

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