



Original article

The Internet: What are our patients exposed to when considering breast reconstruction following mastectomy?



Amy Light ^{a, *}, Colin Munro ^a, William Breakey ^b, Adam Critchley ^c

^a South Tyneside District General Hospital, Harton Lane, South Shields NE34 0PL, UK

^b Plastic Surgery Department, Royal Victoria Infirmary, Queen Victoria Road, Newcastle NE1 4LP, UK

^c Breast Surgery Department, Royal Victoria Infirmary, Queen Victoria Road, Newcastle NE1 4LP, UK

ARTICLE INFO

Article history:

Received 26 March 2014

Received in revised form

18 June 2014

Accepted 12 August 2014

Available online 2 September 2014

Keywords:

Breast reconstruction

Decision making

Information provision

Internet

ABSTRACT

Background: The exponential increase in internet use has transformed the healthcare provider–patient relationship. There is a need to guide patients. This study analyses the information available, clinicians approach and patients' experiences.

Methods: An internet search, “breast reconstruction after mastectomy” was performed on Google and Bing search engines. The first 100 sites on each search were analysed. Target audience, provider and readability were assessed. Modified Health on the Net criterion was used to assess quality. Additionally clinicians and patients were surveyed about their experiences.

Results: Private companies dominated, accounting for 67% of sites, the majority advertised private healthcare groups. Of “information pages”, 16% were government sites and 9% were from professional bodies but 28% were private. Blogs had high rates of surreptitious advertising. Patients wanted guidance on which sites to use. Endorsed sites were commonly recommended and used despite only accounting for 13 of the 100 sites.

Conclusion: The internet is a powerful tool for disseminating information. There is a wide variety of information presented on breast reconstruction following mastectomy from a range of providers with different interests. Patients should not only be provided with a list of internet resources but also counselled on the types of information they may encounter.

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Introduction

The exponential increase in access and use of the Internet has led to a dramatic transformation in the relationship between care providers and their patients. Increasingly, patients are seeking information for themselves [1,2]. It is not infrequent that patients present information to clinicians that they themselves have discovered on the internet. A recent study estimated that approximately 40% of patients will consult the internet before undergoing surgery [3]. Of these, over one in four are confused or scared by the information they find [4]. The use of this source and access to

patients is increasingly utilised for commercial gains and receiving accurate information via the internet is increasingly problematic [5]. Clearly, there is a need to guide patients through this useful but potentially misleading source of information.

In the United Kingdom, the Association of Breast Surgeons (ABS) and the British Association of Plastic, Reconstructive and Aesthetic Surgeons (BAPRAS) have published clear guidelines for immediate breast reconstruction following mastectomy [6]. Within this it is clearly stated that “Patients should have easy access to current, reliable, balanced information relating to suitable surgical options”. They provide a list of recommended online resources. In the USA, the National Cancer Institute provides an online page of information on breast reconstruction in the context of mastectomy [7]. In Australia, the Breast Cancer Network Australia provides a list of resources which link to patient stories [8]. There are no direct links in USA or Australia to recommended resources that offer greater detail on the procedures available to patients.

* Corresponding author. Permanent address: 59 Elsdon Road, Gosforth, Newcastle NE3 1HY, UK.

E-mail addresses: mrsamylight@gmail.com (A. Light), C.j.munro.05@aberdeen.ac.uk (C. Munro), willianbreakey@gmail.com (W. Breakey), Adam.Critchley@doctors.org.uk (A. Critchley).

Yet, a survey of 106 patients undergoing breast reconstruction revealed that 68% of the patients used the internet for information related to breast reconstruction. The categories searched were procedure (39%), risks or outcome (35%), surgeon (13%), pictures (11%), and hospital (4%). It was perceived to be helpful, easy to understand and trustworthy in 72%, 69% and 63% of patients respectively. In over half, the information sourced on the Internet influenced their choice of surgery [9]. A survey into patients' choice for microsurgical versus non-micro surgical breast reconstruction found the Internet to be a significant influencing factor on patient choice [10].

There are no studies specifically into what information is available on the Internet to patients undergoing breast reconstruction following mastectomy for breast cancer. There are also no studies that assess how patients choose Internet sites when researching an operation.

It is paramount that, as clinicians caring for patients who are considering breast reconstruction in difficult circumstances, we are insightful of what information they may be retrieving. Furthermore, we should use this insight to enable us to provide guidance and improve the quality and accuracy of information patients are receiving.

This study evaluates the type and accuracy of information, providers of information and target audience of internet sites that are retrieved when undertaking the most common searches by patients. Additionally, we analyse how clinicians are involving and guiding patients in their gathering of information and how much guidance patients feel they receive or would like to receive on where to look for information. We aim to provide the information necessary to aid clinicians in guiding patients to accurate sources of information when deciding on breast reconstruction following mastectomy.

Methods

Internet searches

An Internet search was performed on the two top Internet search engines (Google and Bing). Medical reference search engines were not assessed as this study was focused on assessing the information accessible on the Internet to the general public. The principal search term “breast reconstruction after mastectomy” was chosen using the commercial programme ‘wordtracker’ (Wordtracker, London, UK, www.wordtracker.com). The first 100 websites analysed in each search engine. No sites were excluded and duplicate results were counted. Cookies and other preference settings were not disabled on the browser.

Information was retrieved on type, readability and accuracy of information, level of evidence, commercial interest and advertisement, provider of information and target audience of Internet sites.

Type of information was categorised as textbook, patient video, procedural video, procedural description, scientific publication, information for scientific meetings, commercial advertising, news headlines or magazines articles, blogs, or other. This was further classified as objective, subjective or mixed.

For information targeted at general public, readability was assessed as easy, moderate, or difficult.

Providers of information were categorised as NHS or government bodies, institutions or individual hospitals, profit making companies, individual surgeons working in the private sector, non-profit making companies, magazines and blogs. Target audience was categorised as patients, healthcare professionals, other professionals (e.g. lawyers) and healthcare industry.

A modified HON (Health on the Net) criterion using 14 questions was used to assess the quality of sites [11]. This included

accountability and appropriateness of who was providing information, how well evidenced information was, information of any funding and advertising and whether this was clear and unambiguous.

To check for concordance an additional search term “breast reconstruction cancer”, identified using ‘wordtracker’, was used and compared against the principal search term. The first 50 pages were assessed and compared against the principal search results. Chi squared analysis was used to check for any statistically significant differences in types of Internet sites returned on each search term.

Patient survey

Patients were recruited within the Tyne and Wear and Northumbria NHS Trusts, UK from June 1st–14th 2014. All patients attending clinic who were considering a breast reconstruction in the context on oncological mastectomy were invited to participate. In addition, patients were identified through a breast reconstruction focus group. All participants were counselled and provided written consent to participate in a 10-point questionnaire (see [Appendix A](#)). All data was anonymous and local approval was granted.

Data collected included patient demographics, usual Internet usage and access, the role of the Internet in their decision and how they selected Internet sites. We also asked patients how much guidance they had received and whether this would have been something they would have liked.

Clinicians survey

All Consultants, Senior Registrars and Breast Care Nurses within Tyne and Wear and Northumbria NHS UK Trusts were invited to participate in a questionnaire assessing their views on Internet usage and how they guide patients (see [Appendix B](#)). A list of recommended sites were included and selected if these were something that healthcare professionals recommended to patients.

Results

Internet search

Using the search term “breast reconstruction after mastectomy” resulted in over 2,710,000 results on Google and 295,000 on Bing. Of all the sites, 82% were targeted towards patients. The intention of the site was clear in three-quarter of cases. Of those sites targeted towards patients, the majority were easy to read, with just 7% being classified as difficult.

Commercial and private companies dominated, accounting for 67% of total sites (see [Fig. 1](#)). There was a significant commercial influence with the type of information being commercial rather than factual in just under half of cases. The majority of these sites were from private healthcare groups advertising their services or products. Most of these sites explained the surgery in detail but did not discuss risks of surgery or complications.

Of all pages that were portrayed as information sites on the topic, 16% were government sites and 9% were from professional bodies but just under a third were provided by private companies. Blogs were very common, accounting for 13% of all sites. Blog sites very commonly featured advertising. The nature of the advertising was surreptitious in nature in 15 of the 24 blog sites that featured advertising. Newspapers and magazines also commonly featured surreptitious advertising.

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