

### Representation of cancer experiences on the web: A comparison of prostate and breast cancer websites

Source: Seale, C. (2005) 'New directions for critical internet health studies: Representing cancer experience on the web', *Sociology of Health & Illness*, 27(4): 515-40.

New information technologies have been heralded as having potentially democratizing effects, with lay people having increased access to information, advice and the ability to post about their experiences on the internet. However, argues Clive Seale, this ignores the ways in which new media might reproduce power relationships that are evident in more traditional print and broadcast media. Although the internet is in theory open to all, in practice there is a similar politics of production and use of internet technologies. The kinds of sites that become visible to users through search engines, for instance, are likely to be those that are enduring, and those from organizations with the resources to maximize their popularity, and this becomes reproduced as other sites link to them, in turn increasing their relative rankings on searches. Instead of representing a radical departure in terms of issues such as patient empowerment or the emergence of new forms of community, the internet (like other 'new' information technologies before it) may have rather more limited impact.

To test how far the internet was transforming media representations, and whether there was a 'convergence' of traditional and new media representation, Seale used a comparative case study of two UK-based websites, one for breast cancer, the other for prostate cancer. Both were top ranked in terms of popular search engines – the typical way in which users find information on the web. Each site consisted of content pages and spaces for users to post views. There is already a large literature on how gender is represented in print and broadcast mass media images of cancer, such as those of magazine stories and newspaper articles. This suggests that cancers that affect women are proportionally over-represented, and those that affect men (or that affect men and women

more equally) tend to be under-reported. There are also well reported differences in how the genders are portrayed in these outputs, with women typically shown in relation to a social network of friends and family, within which they experience cancer as a life-changing 'journey', whereas men more often shown in isolation, and with less emphasis on the transformation.

Looking at the content of websites in the light of this existing body of work enabled Seale to see if there was a convergence with traditional media. He found that the breast cancer site was larger, in terms of the number of pages, and contained very different types of images. The breast cancer site contained a large number of photographs of women with cancer, usually smiling and often in the presence of other people. In contrast, the prostate sites contained no pictures of men with prostate cancer, only photographs of staff or those connected with the charity. However, the prostate site contained more technical diagrams and medical images, with images of tools and toolboxes used to illustrate publications such as 'The prostate gland owner's user manual'. More of the content of the breast cancer site discussed emotional issues. There were also differences in terms of how often personal accounts were used on the sites, with several from women with breast cancer, but only one short quote using a male patient's own words on the prostate site. Analysis of keyword searches confirmed these differences in orientation to emotions, with 135 mentions of words such as 'anxious', 'fear' or 'grief' on the breast cancer pages compared with 9 on the prostate cancer one. These differences in content and framing are, argues Seale, similar to the differences reported in traditional mass media.

As well as looking at the content of the sites, Seale also documented the links to and from these sites, both on the internet, and between news media and the sites. Using a searchable database of all newspaper reports, he identified that the breast cancer site was more commonly mentioned in news reports than the prostate site. The number of internet 'inlinks' from other sites was high for both, suggesting that they were popular, and that 'old and new media tend to converge with broadly similar judgements of popularity and relevance' (Seale 2005: 524).

This study therefore used a mix of analysis methods to explore whether there was any evidence that websites offered new or different kinds of information for users. The content and images were analysed using interpretive content analysis, with quantitative counts of keywords used to add credibility to the analysis, and software used to download the structure and content of websites, including their hyperlinks. This enabled a study of both representations, and the ways in which those representations are produced and managed.

## Reflective questions

The use of both qualitative and simple quantitative data collection methods has enabled a more complex analysis of the intellectual puzzle posed (does the internet enable democratization of information?). Can you think of other areas of research where a similar mix might prove beneficial? Reflect on this perhaps somewhat surprising finding that internet-based cancer information is broadly similar to other media in terms of its content and style of representation; that is, it reproduces existing norms of gender relations. Why do you think this might be?

What additional question(s) might you like to ask in a study like this? If the researchers had chosen to ask questions about readership, rather than content and structure,

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might they have reached different conclusions about the democratizing effect of new media? How might this have been investigated?

## Feedback

This would be useful for many studies: for instance, on patients' experiences of a new health service, we would benefit from knowing both what they say about it and whether or not more or different people use it. It is not perhaps surprising that new media have not disrupted existing gender norms and roles, as websites such as these are designed by existing voluntary organizations, within existing funding structures.

You might want to ask additionally: who uses the site? Is that different from the targeted audience? That is, does the anonymity of both searching and reading web pages allow a wider audience (for instance, men reading 'women's pages' and vice versa?) Does the fact that it is free and easily available mean that whilst potentially still only appealing to the same segmented target audience (in terms of perhaps social class and gender), more of those targeted groups are able to access it? Looking at readership could be done by content analysis of other social media such as Facebook, Twitter, web fora, for instance.

## Narratives in health policy documents

Source: Prior, L., Hughes, D. and Peckham, S. (2012) 'The discursive turn in policy analysis and the validation of policy stories', *Journal of Social Policy*, 41(2): 271-89.

The study of policy documents as 'discourses' aims to uncover the cultural and political frames that make certain courses of policy action possible, and others unthinkable. Theoretical approaches to discourse analysis vary, from those focusing more on the ways in which the language and rhetoric of the documents themselves do this work, to those more concerned with the broader social context of the production of documents. Lindsay Prior and colleagues were interested particularly in the narratives of health policy documents: how 'they framed problems, facts and solutions affecting the provision of health care' (2012: 272), and in how an analysis of narratives in such documents could be validated. Narratives, they argue, belong to collectives (such as governments) as well as individuals, and documents are a key source of data for analysing these.

Their case study is a comparison of official health policy documents from the four countries of the United Kingdom (England, Wales, Northern Ireland and Scotland) published between 2000 and 2009 by the respective governments, assemblies and executives of these nations. To understand the documents as narratives, Prior and colleagues focused on the three major features of: (1) plot; (2) actants (these are the 'characters' in a traditional story, or here the agents, including human individual and collective subjects, and more abstract agents such as 'partnership'); and (3) chronology. The first step was to identify the particular actants in each narrative, and then to look at how they were linked together in a story. One challenge for qualitative discourse analysis is validity, or defending against the charge of subjective selection of the key themes. To strengthen the reliability and validity of their analysis, Prior and colleagues used text mining software to identify a list of concepts in the documents. Concepts are single words (e.g. 'choice') or words occurring together such as 'determinants of health'. This software uses algorithms to first identify word and concept frequencies within the texts, and then to look at the associations between these concepts, by mapping when they occur closely related with other ones, and how often this happens. Visual maps were then produced showing the clusters of concepts, and how strong the relationships between them are. This ensured that the initial selection of actants in the documents could be replicated, and ensured that the researchers were not simply identifying concepts that fitted with their own preconceived assumptions about health policy narratives.

The next step was to build up the plot from these elements. The concept maps for each country suggested some common actants (such as 'change', 'improvement' and 'performance', which occurred in all four sets) and some which were less uniformly distributed across the four, such as 'choice' and 'mental health'. To put together a summary narrative for each country, the researchers used the documents from across the years included, which utilized the main concept clusters identified in each set. In the Scottish and Welsh documents there were strong narratives of nationhood which framed the story of the future planned development of health services, with an emphasis on 'the Scottish people' or 'the people of Wales', and stories of progress from a background of under-development. In Northern Ireland, with a more contested history of nationhood,

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there was less focus on this, and more on the need to make services more 'efficient' for the health of the public (rather than the nation). The Northern Ireland documents also contained a rather broader concept of health, with concepts of 'equity', 'well-being' and 'disability' appearing. However, there was a large degree of overlap in both actants and plot across the four countries, with all emphasizing a need for 'change' and re-organization, and focusing on such issues as partnerships and monitoring. All four narratives were located in the context of a general acceptance of the worth of a nationalized health care system free at the point of delivery.

Using the visual concept maps also enabled an analysis over time, to explore how stable concepts in the four sets of documents were across the years. This suggested that the main concepts were relatively similar across the period. This analysis of four sets of policy documents over time therefore suggested that the narratives from each country framed health services differently, in terms of the national symbols and rhetoric that were important politically, but that they did not utilize vastly differing concepts. This analysis provides some empirical data to contribute to debates around how far health care policies are diverging or converging, and illustrates one way to strengthen the validity of qualitative analysis with quantitative techniques.

### Reflective questions

How far do you think this approach does establish validity? How might you ensure that your sample (selection of documents) is representative of all national policy narrative over these years?

### Feedback

The identification of concepts is reliant on a computer algorithm, so in so far as you trust the software package to identify all the 'concepts', where they may be couched in other forms of language (i.e. words not immediately associated with the concept), negative sentence constructions, or other more colloquial forms of expression. To look at all policy discourse over the period, you might want to take a representative sample including sources such as 'grey literature'.