



The Management of Chronic Illness in the Information Age

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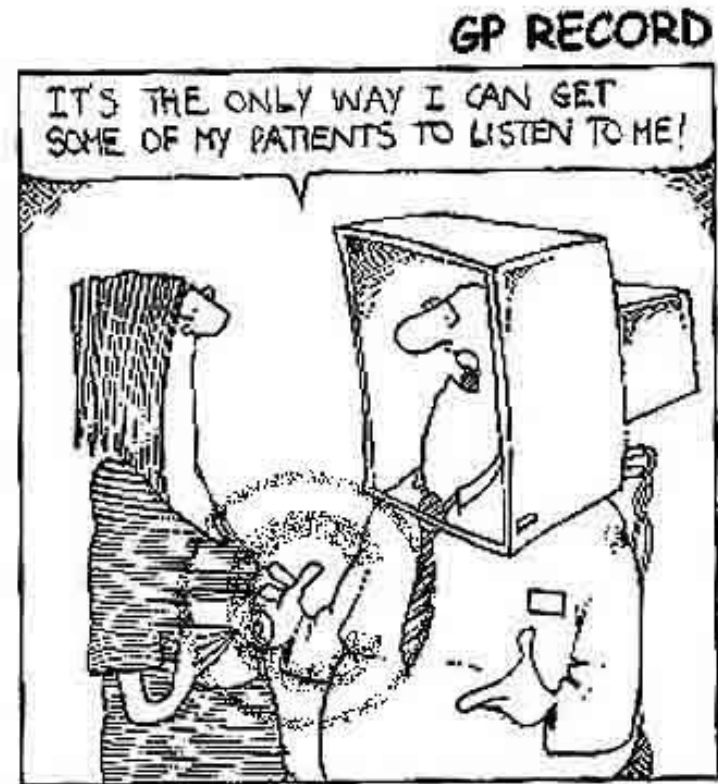
The Mundane Realities of the Everyday Use of the Internet for Health and their Consequences for Media Convergence

Sarah Nettleton, Roger Burrows and Lisa
O'Malley

Suggestion...

Concordance between the macro-structural foregrounding of health resources on the web and the ethnomethodological practices that lay people use to account for the trustworthiness of health information on the web.

- Internet major source of health information
- In USA 'more people go online for medical advice on any given day that actually visit health professionals' (Fox *et al* 2002)
- Likely that UK following a similar pattern



Parallel literatures

Consequences

Celebratory and
empowering

Concerned and
dangerous

Contingent and
embedded

Media theory

Critique of information

Convergence theory



Celebratory and empowering

The '*democratic imperative*' (Light, 2001) of the internet has the potential to:

- 'transform the relationship between the health professions and their clients' (Hardey, 1999)
- 'offer the prospect of a renegotiated relationship between medical knowledge and lay experience' (Loader, 2002)
- 'provide a forum for self representation by individuals who are excluded from the public sphere' (Gillett, 2003)

Concerned and dangerous

Primarily medical and media concerns:

- ‘much of the information available online is unregulated and unrated, meaning that the onus for determining accuracy and relevance often falls on the consumer, who may have no experience in making such judgements’ (Hirji 2004).
- ‘*Dial www.formisinformation*’: fake drugs; unfettered access to prescription medication; ‘a mass of undifferentiated information with no way for the lay person to judge its quality’ (Irving, 2004).
- *The health hazards of medical websites* (Times, 3 August 2004)

Contingent and embedded

- Haythorne and Wellman (2002) *The Internet and Everyday Life*
 - ‘First age’ - ‘cyber this’ and ‘cyber that’
 - ‘Second age’ - focus on more mundane realities of internet use within everyday life
 - Within SHI examine internet use within the context of routine management of health and illness; lay referral systems (e.g. Broom, Henwood, Zeibland)

Contingent and embedded

- Embodied and embedded
- Meshes with other approaches to seeking help and advice
- Prompted by specific health needs
- Complements and supplements information from formal health care (Pandey et al 2003)
- People don't want to become 'experts' but want to trust and depend on health professionals (Henwood, 2003; Lupton, 2002)

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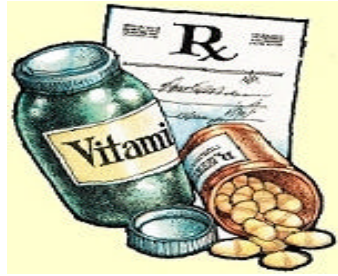
Critique of information

Convergence theory



Critique of information

...how can such highly rational production result in the incredible irrationality of information overloads, misinformation, disinformation and out-of-control information. At stake is a disinformed information society (Lash, 2002 p.2)



O'Neill (2002) Trust



Supposed sources proliferate, leaving many of us unsure where and whether there is adequate evidence for or against contested claims. In spite of ample sources we may be left uncertain about the supposed evidence that certain drugs are risky, or that fluoride in the water harms, or that standards for environmental pollutants are set too high (or too low or at the right level), that professional training of doctors or teachers are adequate or inadequate that waste disposal by incineration or landfill is safer (O'Neill, 2002)

Media Convergence?

But 'Google-isation'

...the distribution of Web sites and their audiences appears to follow what is called a power law: the top ten most popular sites are ten times larger than the next hundred more popular sites, which are themselves ten times more popular than the next thousand sites (Johnson, 2001: 119)



Media Convergence

Participants usually chose one of the first results displayed by the search engine and then rephrased their search rather than turning to the second page and exploring further results. In 281 (97.2%) of 289 user clicks on a link, the link ranked among the first 10 search results (Eysenbach and Kohler, 2002 *BMJ*)

Media Convergence

Audit of eczema, asthma and diabetes: top 20 sites mainly organisations e.g. charities, medical institutions, journals - content predominantly biomedical.

Politics of search engines

- So functioning of search engines not just a technical issue but political and sociological as well.
- Search engine algorithms are propriety.



Media Convergence

- But fact is that search engines lead people to ‘popular, large sites whose designers have enough technical savvy to succeed in the ranking game’ (Introna and Nissenbaum 2000).
- ‘Inevitably larger organisations achieve prominence so that structures of power that influence conventional mass media increasingly affect the internet experience of most users’ (Seale, forthcoming)

Media Convergence

- Search engines rank governmental, biomedical, commercial and charitable sites highest
- Convergence in content between the 'old' and 'new' media - undercutting earlier celebrations and concerns about the internet as a medium that promotes diversity of perspectives on health and illness.

Explanations of media convergence

- Structural
 - Technical Explanations?
 - Producer interests? Capitalist manipulation?
 - Changing demography of online population - as preferences and tastes become more mainstream?
- Agency
 - Mundane realities of everyday use...?

Mundane realities of everyday use

- Accounts of assessments for the trustworthiness of information
- Accomplishments of legitimacy
- Key is the necessity to accomplish the management of tension between the internet as a useful resource and – at the same time – as potentially dangerous.

Sources of Data

- ESRC Innovative Health Technology Programme: Project on the 'Management of Chronic Childhood Illness in the Information Age'.
- 3 Localities Top, Middle and Bottom quintile on child poverty measure. One large health centre from each locality.
- All parents with children with asthma, eczema and/or diabetes.
- 358 in survey; 69 parents and 16 children in qualitative interviews.
- Data here from the qualitative interviews.

Rhetorics of reliability

1. Real versus virtual organisations
2. Non- commercial versus commercial
3. UK versus 'others'
4. Professional/authoritative versus non-professional
5. Codified knowledge versus Experience
6. Replication of information versus occasional

Accounting for action

- On being sensible
- Context of use

Rhetorics of reliability

1. Real versus virtual organisations

- If you just put diabetes in, it would just come up with like a million and one sites and some of them may give you bad advice. So I wouldn't trust anything unless it was a recognised association like The British Diabetic Association or The American Diabetic Association or The World Health Organisation then at least you'd know you've got trustworthy information.
- You must be very wary of anything nowadays; where you get it from. But if you go somewhere like the National Asthma Society and places like that, [...] rather than, you know, some oddball place that you've never heard of

Rhetorics of reliability:

2. Non-commercial versus commercial

- Commercial I don't do commercial at all really more the medical. I don't go in for gizmos. I don't go in for anything like that. It's got to have a logical sound medical reason behind it
- The commercial ones are trying to sell you the product whereas the, the other ones are just giving you the information

Rhetorics of reliability:

3. UK versus 'other'

- I can see they're both doctors, one trained in Guys, one trained in Edinburgh, I know where they are, I'm more wary of foreign sites where I don't know these people's qualifications, I don't know where they're coming from. It makes sense to me -I would trust that, and you know where it's coming from. So yeah, a lot of this American stuff I think, I can't trust it cos I don't know it
- If it wasn't sort of backed up by anybody in this country then I probably wouldn't [trust it], I know they're doing the studies in Canada and what have you but .. I need it to be British

Rhetorics of reliability:

4. Professional versus non- professional

- Official sites by professional bodies [is] a way of knowing if a site is really safe and secure
- Official based, yeah, if it was backed up with a certain medical professional opinion. If it was an alternative therapy it wouldn't bother me as long as again it was professional. I only take any credence from something that I thought was professional that, you know, clinically based and so on ...

Rhetorics of reliability :

5. Coded versus Experiential Knowledge

- I would probably just sort of flick through, start at the top, the first few, and then maybe one that caught my eye. [...] If it was like just people's opinion on having asthma, I'd probably skip to the next one.
- I don't do chatrooms because again I wouldn't value anyone's opinion. Aren't I funny? No, I wouldn't do chatrooms at all. I wouldn't want advice from a chat room, cos it'd be like me giving it, it's only an opinion isn't it.

Rhetorics of reliability:

6. Replication of content

- I think finding out what was coming up most, cos the contradictory information I would think would only appear once or twice in a whole web of stuff. Whereas if there was the same pattern emerging and you could say well hang on a minute this is OK, this generally tends to be what happens

Accounting for action

On being sensible: contrast self with 'other people'

A: Sometimes too much knowledge can be dangerous.

Q: Why dangerous?

A: I just think it makes people think that they can treat themselves. Rather than going and getting proper medication or whatever from reputable sources. They think, 'Oh, well I've only got this, this'll do to cure this', or whatever.

Accounting for action

On being sensible: contrast structures

I've been careful to go on sites that I deemed legitimate. I mean there are thousands of sites out there that people have created themselves, but I don't go to any. But I'm always a bit cautious about the internet. I think you need to be critical in your use of it.

On being sensible: contrast structures?

I think most adults, they'll go to ones they know and trust but why they trust them, can be for a variety of reasons. But then other people just surf willy nilly and, and I mean some of the reports that you read can be amazing and you think, well who on earth has written that. But then people, they want that freedom. So yeah, it's made the world smaller, but it's not always necessarily good because one person who's had a tin pot idea over the other side of the world, could get a lot of people to think, cor yeah, that's a really great idea. But there's no evidence to back it up, so yeah, it's difficult. I am wary, I don't just believe everything I read there. But then some people do.

Accounting for action

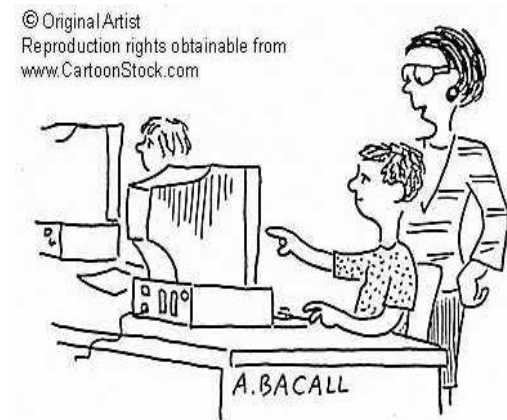
On being sensible: doctors are experts

- You couldn't actually diagnose yourself...you can read up when you've got something
- I mean as a lay person I haven't got enough broad knowledge to know when something isn't right
- I look at it as a melting pot ...its an interesting way to gather other people's opinions. But I would always trust my GP above the internet

Accounting for action

Context of use: rooted in everyday health practices

- Deciding whether to seek professional help
- Confidence to ask questions
- Clarification following consultations; e.g. about advice, medication, diagnosis etc
- Information about consultants, treatments, procedures etc
- Finding information for friends, relatives etc



"Those are interesting questions Timmy.
I suggest you ask your search engine."

Suggestion...

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Conclusion

- Rhetorical devices ideological etc. nationalism, professionalism, biomedical
- Concordance
 - agreement of opinions
 - a harmonious state of things in general and of their properties...
 - an index of all main words in a book along with their immediate contexts