

# The internet, information seeking and identity

*Something's not quite right. You've been tossing and turning all night. It's your knee... you drag yourself to the bathroom and there in the mirror, a ghastly sight confronts you. Your knee is not only sore and painful, it has gone bright green! Before retreating to bed for a sleepless night of worry, you pass by your study and quickly log on to the internet. You Google 'green knees'... and sure enough, a host of sites spring to life – greenknees.co.uk, and the rest. All have message forums where people just like you are sharing advice and experiences. 'My kids couldn't help laughing,' says one, 'but people on here seem to understand my pain.' Another has some sage advice. 'The doctor will try to fob you off with paracetamol. But there is a drug that can clear up your knee in days. It's called greenkneeoxyl and by the way, you can get a great deal at greenkneeoxyl.com!' Another warns: 'The NHS repeatedly refuses to prescribe greenkneeoxyl – but it is the only proven cure for green knee disease.' You click on the link and print off the page. Perhaps that will support your case at the surgery tomorrow.*

**T**HE magic of the internet! Around the turn of the millennium, the newspapers were full of the ways that it was going to revolutionise our lives: our houses and even fridges would be fully wired up to the internet and we'd never go to the supermarket again. Psychologists did some pretty fanciful thinking around this time too. Books and papers panted enthusiastically about 'cyborgs' and MUDs and the 'identity



**DAVID GILES** on the implications of the quest for health information online.

laboratory' that the internet would become: in cyberspace you can be who you want to be, and so on (see Turkle, 1995, for an example).

As ever, the reality has turned out to be more interesting than the science fiction, at least for the psychologists. Who would have foreseen websites promoting suicide, ways to become 'a better anorexic', proposals to create a community populated solely by people with Asperger's syndrome, and endless advice from lay and medical sources alike on problems that you'd otherwise never know existed. The internet has been a godsend for anyone who feels misunderstood, ostracised, alienated, or lonely – whether as a result of 'neurochemical imbalance', self-absorption, green knees, or being the only person in town with a Mr Blobby fixation.

All of this may sound facetious, but there is something about the clique-ish nature of internet communities that reduces serious and enduring mental health conditions to the level of pop fandom or eccentric hobbies. Perhaps it is because the media of communication are essentially the same – discussion forums, chatrooms, message lists – or perhaps because they tend to be populated by the same kinds of people. But perhaps it is also because the internet, rather than becoming an 'identity laboratory', has instead become an identity sweetshop where you can peruse and choose at leisure a ready-made identity by becoming a member of the most attractive and/or exotic community. Just take the following as an example, from an autistic spectrum website:

*I have just heard about scannerism. I certainly fit. I have aspergers type symptoms without having AS. My brain drives me to constantly be searching for new interests for in depth research.*

*I have a huge number of disparate*

*interests, some of them relevant to my goals, some not. I figure this makes me a scanner.*

I figure this makes me – and you, reader – 'scanners' too...

## **The expert patient?**

Where does all this leave psychologists studying the internet? One very interesting question concerns the way in which internet users' access to all this information might shape their beliefs about mental, and physical, health. My own research has recently explored questions of identity relating to 'pro-ana' (ana = anorexia) websites (Brotsky & Giles, in press; Giles, 2006), where people with eating disorders exchange messages with others in environments that are free of health professionals, parents, friends, partners,

## **WEBLINKS**

'Diagnose yourself' (for a small fee of course)...:  
[www.mytherapy.com](http://www.mytherapy.com)

US online community aimed at teenagers:  
[www.yuku.com](http://www.yuku.com)

Commercial self-help site with lots of drug links. Includes depression and schizophrenia communities: [www.thehealthcentralnetwork.com](http://www.thehealthcentralnetwork.com)

'Building the autism culture':  
[www.aspiesforfreedom.com](http://www.aspiesforfreedom.com)

and anyone else who might be unsympathetic to their desires to maintain restrictive, and dangerous, eating practices. Most notoriously, the sites have featured the exchange of 'tips' for concealing one's eating disorder from family and friends.

These sites have spawned a network of communities broadly linked under a 'pro-ana' stance. Once you dissect the communities themselves you find a very ad-hoc set of positions on the topic, much interchange of terms like 'disease', 'syndrome' and 'lifestyle', and contradictory statements about causality, that can range from 'it's genetic' to 'it's the media' in practically the same sentence. But much of the time, the discussion forums cover much more mundane material – how to deal with the more problematic aspects of school, such as homework, teachers and boys.

Anorexia or otherwise, the pro-ana phenomenon has clearly struck a chord with disaffected teenagers of many types, spawning commercial activity – you can buy red or purple wristbands to display pro-ana sympathies, and some pro-ana merchandising has even strayed offline. Ruby Gloom, a neo-Goth teenie cartoon character with bright red hair and huge doleful eyes, began life as a pro-ana icon, and now crops up on a range of pencil cases, backpacks and T-shirts, and has her own show on Canadian television.

The pro-ana phenomenon has also captured the imagination of many academics, within the eating disorders field and elsewhere (see Lyons *et al.*, 2006; Mulveen & Hepworth, 2006; Norris *et al.*, 2006). It is a fascinating topic because it raises all sorts of difficult questions for clinicians, medical experts, educationalists and feminists alike about resistance to treatment, anti-recovery positions, the notion of anorexia as 'hunger strike' (Orbach, 1993), and so on. Are the sites, as characterised in the mainstream media, a lethal threat to vulnerable young people? Should they be forcibly suppressed? Or will they simply resurface in a different guise, as has already happened?

A lot of the questions echo earlier concerns about other media – for instance, the 'effects' of violent film, television, or video games on the behaviour of young people. And there is the danger that many mistakes are repeated – the use of artificial and inappropriate measures, wild claims about causality from correlational data, spurious post-hoc theorising based on chance findings (see Freedman, 2002, for a thorough trashing of the media violence literature).

Above all, one of the lessons to be learned from earlier research on media is the limitation of the functionalist approach to media (see McQuail, 1994) – where each new medium is seen as an updated and improved version of the old one. According to the functionalist approach, newspapers should have long been wiped out by radio and TV, and the internet should by now be making things like, well, supermarkets redundant.

But of course these things haven't happened. And the key to why they haven't happened may lie in the work of the celebrated 1960s media theorist Marshall McLuhan (McLuhan, 1964). He believed that each new medium opened up unique possibilities for human behaviour, rather than simply satisfying fundamental, and universal, Maslow-like

'needs'. McLuhan classed technological inventions such as the electric light and the car as media, arguing that their original function quickly becomes irrelevant once human inventiveness gets to work. One can hardly imagine that late-night clubbing was high on Thomas Edison's list of priorities for inventing the electric light; or that early car manufacturers dreamed of people filling up their boots with two weeks' worth of groceries at out-of-town shopping malls.

Likewise, the US army (who developed a system that would survive a nuclear war and then handed it on to academics) are unlikely to have wondered how it would revolutionise the way we think – and correspond – about anorexia. This isn't technological determinism: it's about the adaptability and creativeness of the human mind. We may not always like the things it creates – but our ability to predict (and, dare I say it, control) them may be more limited than psychologists once believed.

With media phenomena it always pays to think about the ways things got done before that medium came along. Try imagining the following statements being made by anyone, in any context, prior to the arrival of the internet:

*i think im going to cut again, its getting harder and harder for me to resist...my ex is moving to texas on sunday...he has become my best friend now...god, im losing him all over again...*

*i dont get art and thought all aspies were the same but i was wrong, a lot of aspies get art, a lot of them are good at it.*

The first statement is posted on a website devoted to self-harming behaviour. Pre-internet, such a confession would have had to be restricted to professional consultation, in which case it could have serious clinical implications, or perhaps an intimate revelation to a close confidant. Either way, it would have been problematic. But the anonymity of a website allows it to be made in a non-problematic way, and to invite a host of responses, most of them supportive and sympathetic, from fellow website users – who have joined the discussion forum on the grounds that they, too, self-harm.

The second statement is just as interesting because, although it appears on a website for people with a condition on the autistic spectrum, it is so firmly about

group identity ('aspie' = individual with Asperger's syndrome). Much of the communication on pro-ana websites is of this nature too. 'Are you an X?' 'No, I'm a Y. But I used to be an X.' And it's easy to see how the concept of 'lifestyle' becomes irrevocably bound up with diagnosis and condition. From another Asperger's site:

*As I walked away eating my muffin, part of me wondered if I should explain that my neurological condition sometimes makes me oblivious to certain kinds of humour.*

This kind of deterministic thinking is rampant on the internet – clinical diagnosis as a blueprint for, and causal explanation of, any given piece of behaviour. Discussion forums teem with wild claims about things that specific groups of people can and can't do, and homespun remedies

for various problems. 'Are bipolars better in bed?' asks one message thread. 'Could alcohol cure dyslexia?' asks someone who found it easier to read bedtime stories to their children after a session in the pub.

One of the biggest concerns about the 'effects' of all this material is that it threatens the position of the expert. If we return briefly to my opening 'green knees' vignette, we can see how the notion of the 'expert patient' as championed by many current health systems including the NHS (Department of Health, 2001) potentially undermines the advice of professionals, leading service users to amass all kinds of diagnostic information, including commercial propaganda, before they even set foot in their GP's surgery.

Such fears have been played down by some researchers in the field, who argue that the reliable information available far outweighs the quackery, and that most internet users trust 'official' sites, such as those provided by the NHS or the WHO when hunting for health information online (Nettleton *et al.*, 2005). However, there is a difference between searching for tips on how to get rid of green knees and finding out how to hide your eating disorder from your parents. Or to discover the best way to get your child diagnosed as dyslexic, thereby saving you a small fortune in private school fees. This isn't health information seeking in the conventional sense, but it has a huge potential impact on professional practice.

### Ethical issues

I have happily browsed through all these discussion forums as a 'lurker', though some researchers (e.g. Fox *et al.*, 2005) regard even this practice as unethical. I have always defended it on the grounds that anything on the internet that is not password-protected is public domain material, equivalent to readers' letters in a newspaper, regardless of what the contributors believe about the accessibility of the material.

Nevertheless, there are times when such research does feel voyeuristic: some discussion forums list the numbers of 'views' of a particular message thread alongside the number of 'responses' that have been posted. The difference is usually enormous. It's difficult to avoid the sensation that reading these often painfully intimate discussions has overtones of gawping at the 'lunatics' in 17th-century Bethlem.

Similar objections have been raised about reality TV, and talk shows such as *Jerry Springer*. However, in a provocative study of talk TV (Gamson, 1998), the American sociologist Joshua Gamson argued that while such shows seem voyeuristic to the aloof, uninvolved academic, the audience – particularly those affected by the issues – have a different perspective. The high visibility of marginalised groups, such as transgender people, on such shows sets in motion a 'normalisation' process that could be seen as quite liberating, and leads to higher acceptance and tolerance of these groups in the audience as a whole.

For many people, the global village effect of the internet has served to reassure them that they are not alone. As one OCD site user puts it,

*i can't stop reading [these posts], because each one is so different, and i can find elements of my own quirkiness in almost each of them. on one hand, it solidifies my fears that i have ocd, but on the other hand it helps me realize that many people have it, and live with it without anything bad happening to them.*

Is this a good thing? Is it better to have a world populated with 'obsessives' and 'compulsives', and a multitude of other groups with their own websites, philosophies, and sets of normalised, accepted, and treated behaviours; or one with a lot of plain old 'quirky' people who don't quite fit in? This is, I suspect, a question that will keep psychologists busy for decades to come.

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### DISCUSS AND DEBATE

Is this craze for diagnosis/group identity linked to prevailing ideas about the biological origins of mental 'illness'?

Whose commercial interests might be at stake?

What role could clinical psychologists play in a self-help society?

*Have your say on these or other issues this article raises. E-mail 'Letters' on [psychologist@bps.org.uk](mailto:psychologist@bps.org.uk) or contribute via [www.psychforum.org.uk](http://www.psychforum.org.uk).*

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