ELSEVIER

Social Science & Medicine 60 (2005) 1299–1309

SOCIAL SCIENCE & MEDICINE

www.elsevier.com/locate/socscimed

The 'expert patient': empowerment or medical dominance? The case of weight loss, pharmaceutical drugs and the Internet

N.J. Fox*, K.J. Ward, A.J. O'Rourke

University of Sheffield, ScHARR, Regent Court, 30 Regent St, Sheffield S1 4DA, UK

Available online 11 September 2004

Abstract

Do 'informed' or 'expert' patients challenge dominant traditions in biomedicine or simply adopt these as conventional ways of thinking about body shape and size, illness and health? This paper examines this question in relation to the use of the weight-loss drug Xenical by participants in an Internet forum for obese and overweight people. Ethnographic and interview data from the forum provides evidence that participants share information and support each other as they use Xenical, and in the process emerge as 'expert patients' in relation to their body shape and its treatment. However, it is argued that while an 'expert patient' can be perceived as desirable, enabling the democratisation of healthcare, it can also be constraining. The exchanges between the users in the forum perpetuate a biomedical model of overweight as a condition to be overcome. The discussion critically considers a number of options for the development of the expert patient, including the emergence of an 'informed consumer'.

Keywords: Consumer; Expert patient; Internet; Medical model; Xenical; Weight loss

Introduction: 'expert patients', information and technology

The notion of an 'expert' patient has emerged recently in UK health policy (Department of Health, 1999, 2001), and has been described as pivotal to government plans to 'modernise' the health service (Wilson, 2001, p. 134), linking patient expertise to ideas of 'empowerment', a 'better quality of life', 'self-esteem' and a 'user-led NHS' (Department of Health, 2001). Expert patients, according to this view, are those who can manage their own illnesses and conditions by developing knowledge relevant to maintaining health and countering illness (Shaw & Baker, 2004). By working in partnership with their health and social care providers, patients can be given greater control over their lives (Department of Health, 2001, p. 5), and training programmes for expert patients are now available in the UK (Shaw & Baker, 2004).

An Association of the British Pharmaceutical Industry (ABPI) review of expert patient policy (Illman, 2000) suggests such moves will transform the doctor–patient relationship from a 'professional led' interaction to a 'doctor–patient partnership', in which expert patients ensure that treatments are appropriate to their individual needs. This will allow professionals more time to make crucial clinical decisions rather than merely 'handing out instructions' (Jones, 2000, p. 3). Patients will employ effective modes of support such as patient groups and access 'gold standard' websites including the National Electronic Library for Health (NELH) and NHS Direct Online, to establish improved relationships with their doctor, increasing communication and

*Corresponding author.
E-mail address: n.j.fox@sheffield.ac.uk (N.J. Fox).

0277-9536/$ - see front matter © 2004 Elsevier Ltd. All rights reserved.
doi:10.1016/j.socscimed.2004.07.005

understanding between the two groups (Illman, 2000). Such propositions have been met with scepticism and some anxiety by health professionals, who fear more, rather than less, time will be needed to manage these patients (Shaw & Baker, 2004).

The concept of the expert patient has been problematised in Wilson's (2001) extensive review. While there is a logic to developing patient expertise in an age where one in three people has a chronic illness or disability, and medical interventions manage rather than cure these conditions, the notion of the expert patient ignores entrenched professional power and structural constraints to do with access to resources (Tang & Anderson, 1999) and conflates experience and education (Wilson, 2001, p. 135). Paradoxically, patient expertise both assumes compliance and a degree of taking control of the management of health (Thorne, Ternulf Nyhlin, & Paterson, 2000), and Wilson (2001, p. 139) suggests this reflects an extension of a Foucauldian 'gaze' that makes visible all aspects of a patient's life and self-care (see also Gastaldo, 1997, p. 124). Data from studies by Thorne et al. (2000) and Henwood, Wyatts, Hart, and Smith (2003) suggest that despite governmental enthusiasm for expert patients, this does not directly translate into professional behaviour: often professionals cling to power in their engagements with patients, controlling information and dismissing efforts by patients to theorise or explain their condition.[1] Professionals need to recognise the relationship between their power and knowledge before they can share their expertise with patients (Tang & Anderson, 1999, p. 92). Nor do all patients wish to take responsibility for their health, or possess the technical competence to become expert (Henwood et al., 2003, p. 605).

One factor that has supported the creation of patient expertise has been the rapid growth in web-based health-related information, including the UK government's NHS Direct Online (Henwood et al., 2003). Numerous websites, interactive forums and email lists now offer information upon and discussion of healthcare; and consumers use websites to research their own conditions and healthcare and make decisions surrounding their treatment (Bessell, Silagy, Anderson, Hiller, & Sansom, 2002). Concerns remain over the reliability and validity of web-based information, and as part of the development of an 'expert patient culture', organisations such as the ABPI and the World Health Organisation (WHO) have developed print and web-based guidelines on how to interpret, assess and use web-based information. Furthermore, the ABPI provide a public link from their website to the Electronic Medicines Compendium (EMC), which provides a guide to available prescription medicines in the UK.

Lupton (2002) and Henwood et al. (2003, p. 597) suggest that the growth in health information availability has transformed the patient into a reflexive consumer, making active decisions concerning treatment procedures. The concurrent emergence of Internet-based pharmacies and other web-based outlets selling pharmaceutical drugs, including lifestyle drugs such as sildenafil (Viagra) and weight-loss drugs, has also contributed to health consumption. Numerous online outlets now supply pharmaceutical drugs direct to the public. Some, such as 'Pharmacy 2U' (a DoH-driven initiative that is part of the Electronic Transfer of Prescription pilot project) operate like conventional pharmacies, requiring a legitimate prescription before drugs are dispensed. Other (predominantly US-based) outlets will, however, supply prescription drugs on the basis of an online consultation questionnaire to be completed by a consumer before a drug is dispatched. On this basis, pharmaceutical drugs can be purchased online using a credit card, and dispatched to customers worldwide. At present, it is legal for UK individuals to import pharmaceutical drugs for their own use.

From a sociological perspective, the growth both of discourses on the expert patient and the technology to facilitate a consumerist approach to health, illness and its treatment, suggests an agenda for research into how these innovations construct patient-hood and notions of normality and pathology. Does this discourse encourage a new model of health and illness, or serve to reinforce a medical model of disease?

An interesting case study concerns the area of weight loss. Recently, some effective pharmaceutical treatments have been developed, notably the drug Xenical (orlistat). This weight-loss drug has become a significant treatment for overweight, reducing uptake of fat from the gut. It is now available globally through US Internet pharmacies, and people can freely purchase Xenical and other similar treatments online. This method of acquisition has been accompanied by a growing online consumer movement that explores issues concerning weight loss, obesity and body image, and apparently reflecting many attributes of the 'expert patient'.

As part of a larger ESRC-funded qualitative study of the pharmaceutical industry, consumption and the use of the Internet,[2] we report here on this phenomenon and, in particular, on the use made by consumers of weight-loss drugs of web-based discussion fora. We look at how users of Xenical share information to become expert in their condition and its management. In this

[1]Correspondence from the medical profession in the *British Medical Journal* suggests that doctors are strongly resistant to notions of expert patients, and that even the term is problematic from a disciplinary perspective.

[2]ESRC project L218252057, funded within the Innovative Health Technologies programme, and known as WISDOM-Pharmakon. Details may be found at http://www.pharmakon.org.uk.

paper, we report on users of an interactive Internet forum dedicated to the use of the weight-loss drug Xenical, here called 'X-Online'.[3] X-Online tends to foster a medicalised model of weight loss and the use of pharmaceutical drugs. Elsewhere (Ward, Fox, & O'Rourke, forthcoming) we describe the different philosophy and culture of weight-loss websites that resist medical models of obesity, body size and shape. Before reporting data from the study, we will now review briefly the biomedical and sociological perspectives on body size and food consumption.

Biomedicine, food and body weight: pathologising eating habits

Nettleton and Gustafsson (2002) suggest that in the West, a biomedical perception of the body dominates the construction of its meaning as a physical entity, such that the language and discourse of biomedicine has reached a 'taken-for-granted' status and retains a dominant position in presenting descriptions of the body. Given the esoteric nature of biomedical knowledge, its presentation and construction of the 'natural' or 'real' body has become accepted as the 'correct' understanding of the body. These authors suggest that the biomedical construction of the 'natural' body is based not only on the development of medical knowledge, but also by pathologising disease and locating illness in the anatomical body. In encounters with doctors, patients are forced to defer, allowing the medical profession to take over the command of the treatment and the decision-making process (Fox, 1999; Lupton, 1994). This 'competence gap' between lay and professional, Lupton argues, supports traditional and unequal power relations, and plays a large role in maintaining patient dependency.

Obesity has been associated with a wide range of health problems and conditions, including heart disease and diabetes (Abraham & Llewellyn-Jones, 1997; Després, Lemieux, & Prud'homme, 2001), and has been described as a global epidemic (Hitchcock-Noel & Pugh, 2002, p. 757). Abraham and Llewellyn-Jones (1997) suggest a number of causes of obesity, including genetic factors, low self-esteem and an under-estimation of the food eaten. Obesity and overweight can be diagnosed quantitatively by body mass index and waist measurement, and this may form the basis for population screening to identify those with mild or moderate overweight (Després, Lemieux, & Prud'homme, 2001, p. 719; Hitchcock-Noel & Pugh, 2002, p. 757). Treatment of obesity and overweight include restriction of calorific intake, exercise, surgery and pharmaceutical agents under medical supervision (Hitchcock-Noel & Pugh, 2002, pp. 758–9). Together, these propositions establish a biomedical 'explanatory model' (Kleinman, 1980) of obesity and overweight, in which both over- and under-eating are conditions ('eating disorders') to be managed within medical regimens (Luck et al., 2002). This model has also been influential within health journalism and popular media (Rothblum, 1999, p. 188; Thompson & Heinberg, 1999).

Despite professional and popular acceptance, the medical model of obesity and body weight is contested, predominantly by feminist writers. Social scientists such as Bordo (1993), Grogan (1999) and Gordon (2000) have examined the origins of the social meanings associated with excess flesh in the West. Gordon (2000) makes the link between the sacrifices associated with religion and those made to diet and limit food intake, and associates the powerful and all-consuming nature of diets with the continuing resonance of the protestant work ethic. The diet industry and weight-loss articles in magazines refer to 'attacking' fat and 'beating the bulge' (Bordo, 1993), while as Gordon (2000, p. 137) notes, Western media representations of thinness play on deep-seated societal fears of overweight. These analyses chime with propositions that in an era of reflexive consumption, people develop subjectivities that emerge from body identity practices and fears concerning perceived all-pervasive societal risk (Beck, 1992; Foucault, 1988; Fox, 1998; Giddens, 1991). Returning to the earlier discussion of patient expertise and reflexive consumption (Henwood et al., 2003), we may expect the self-management of body weight to be a prime arena for the development of patient 'expertise'.

Becoming expert: weight loss and the Internet

The Internet provides new opportunities both for publishing information about diseases and to enable patients and others to discuss conditions collaboratively. Turner, Grube, and Meyers (2001) found that among those recently diagnosed with cancer, online discussion groups were valued as they could provide support by other sufferers, particularly when other sources of support was poor. Patients and parents with rare conditions such as Asperger's syndrome can benefit from trans-geographic Internet groups that can provide social support and the 'discovery of community', although downsides include substitution of offline by online support and vulnerability to non-genuine participants (Mitchell, 2003, pp. 3–4). A study of women with lupus found they used the Internet for information exchange, to share experiences of living with the disease and to provide support to each other (Mendelson, 2003), while similar uses were made of online groups by carers

[3]The name has been chosen to protect the anonymity of respondents in the study.

of people with Alzheimer's disease (White & Dorman, 2000).

The growing attention paid by the media to obesity and weight loss has been reflected in a plethora of websites and discussion groups on the Internet (Thompson & Heinberg, 1999, p. 347). These range from sites sponsored by weight-loss organisations and commercial bodies, through sites and public fora supporting users of weight-loss pharmaceuticals, to radical fora promoting extreme weight loss through drugs and supplements (Ward et al., forthcoming). We undertook research on websites devoted to weight loss and the use of drugs such as Xenical, and in this paper report findings from research on a public discussion forum established in 2001, referred to here as 'X-Online'. At the time of study, this forum had 495 users: predominantly females between 30 and 40 years from the UK, US and Australia, with a daily traffic of 20–30 messages. Participants addressed a variety of topics concerning the effectiveness of the drug, its side effects, their progress and their encounters with the medical profession. The forum was typified by high levels of support, encouragement and advice for others concerning diet and for those new to using Xenical.

Methodology, setting and participants

The methodology of the study was 'virtual participant observation': an emerging approach that has adapted 'face-to-face' ethnographic methods (Mann & Stewart, 2000), and can be used to explore how communication technology is experienced in use (Hine, 2000). Despite the lack of direct engagement with participants as in traditional ethnography, Thomsen, Straubaar, and Bolyard (1998) suggest that multi-method triangulation, involving textual analysis, prolonged participant observation and qualitative interviews can provide valid and reliable data.

> …effective participant observation requires time and persistent observation. We argue that the ethnographer/researcher must find a way to penetrate the online community, effectively gain entry and membership, and then remain as an active participant for sufficient time to understand, and become a part of, the world of his subjects. Only then, can he (sic) effectively analyze and interpret the discourse or text that he "sees" in his cyber fieldwork (Thomsen et al., 1998).

This approach has been adopted productively in previous research (Ward, 1999), and was followed here. Applying ethical principles for online research that forbid covert 'lurking', KW subscribed to X-Online with the permission of the organisers, announced her 'presence', and made clear that she was researching the topic of the Internet and pharmaceutical drugs for weight loss. A period of acculturation to the norms of the values of the group was followed by active participation in the forum and questioning forum participants about their feelings towards weight loss, pharmaceuticals, the medical profession and weight-loss-related Internet use. Some participants responded to the questions via the forum, while others chose to email their responses direct to KW, which led to 12 in-depth online interviews. Table 1 provides details of respondents interviewed during the research: all names used are pseudonyms. Data reported here include verbatim transcripts of forum messages and interview extracts.

The organisers of X-Online advocated a controlled approach to weight loss, using Xenical alongside 'sensible, balanced diets' and exercise. In a disclaimer, they denied being medical experts, advising participants to refer to their doctors if unsure about aspects of Xenical use. For the majority of participants in X-Online, the objective was to lose considerable weight and

Table 1
Biographical details of interviewees

Pseudonym	Age	Occupation (self-ascribed)	Place of residence	Marital status
Julie	32	Professional	Australia	Married
Sarah	20	Student	New Zealand	Single
Gemma	34	Self-employed	US	Co-habiting
Jenny	33	Housewife/mother	US	Married
Jane	32	Nanny	UK	Single
Emily	35	Clerical	UK	Co-habiting
Clare	20	Care worker	UK	Married
Jessica	34	'Mom'	US	Divorced
Marie	27	Teacher	Bahrain	Single
Lesley	42	'Stay at home mom'	US	Married
Kelly	31	Florist	UK	Married
Organiser	35	Mum of two	UK	Single

achieve a target weight, often announced by participants in early postings.

> I am getting weighed again on Monday. I started at 140 kgs, now I am 135 kgs. I aim to get at least 35 kgs off and keep it off (Jenny).

Interactions on the forum indicated that most participants were clinically obese and used weight-loss drugs to treat an undesirable overweight condition. For example, Sarah indicated during interview that she took Xenical because she had 'always been overweight' and suffered from a related depression. For these users, Xenical had become part of a lifestyle: a means to help achieve weight loss when linked to diet and exercise regimens.

Participants' motivations for weight loss

As a participant observer, the researcher became immersed in a community in which being overweight had complex meanings. Participants applied biomedical constructions of the body as 'treatable', aiming to restore 'good health', but also revealed their feelings and social meanings surrounding weight gain. Users of the forum were thoughtful and reflexive about the causes of overweight and the difficulties inherent in living in Western society where there is a strong cultural bias towards slimness. They offered personal insights and stories relating their feelings towards weight gain, how it had shaped interactions and experiences in the social world, and consequent motivations to lose weight.

Thus, participants such as Gemma and Sarah had given considerable thought to the origin of their weight gain and early memories of being overweight as children. Gemma had vivid memories of being bullied by other children and her recognition she had a 'weight problem'. Being overweight was a family issue, and she saw the condition as inseparable from the context of family relations and environment. Weight gain had become part of her family's culture and history.

> My mother died in my early teens, but I remember her going to Weight Watchers… My father used to be a long-distance runner, but broke his leg in a nasty fall, and had to stop running. He has been overweight ever since. My younger brother lost a lot of weight in his early 20 s and has kept it off for about eight years so far.

Sarah felt she was a victim of discrimination by a slim society where she was an 'intruder'. The discussion forum provided support for her quest to fit into this world.

> I want to be able to go into a shop and not worry about if I can fit any of their clothes. I want to swim. I want to achieve a goal… There are so many disadvantages to being overweight, people find you un-attractive, clothing, sickness, limiting in experiences, uncomfortable-ness). Talking with people who understand is so refreshing; who know what it is like; who have had strangers yell at them about the way they look.

The online community also provided anonymity: Gemma had told only a limited number of people about her use of Xenical and perceived a stigma attached to taking the drug, which she connected to her negative stereotypes of overweight people as slothful, bad mannered and greedy: She saw use of Xenical as 'a sign of personal weakness that I couldn't do this on my own'.

Towards expertise: information exchange

Various studies of Internet discussion groups have identified the exchange of information as a key element (Mendelson, 2003; White & Dorman, 2000). In the X-Online forum, the users exchanged a high volume of information, including exercise tips, diets and progress reports. Discussion in one thread[4] was dedicated to side effects of taking Xenical, and focused on experiences during the first few weeks of taking the drug, and how to manage their diet to avoid the unpleasant side effect of diarrhoea (or 'oranges' in X-Online jargon). Questions about the appropriate way in which to take Xenical were also frequent in the forum. Clare wanted to know the most appropriate time to take the drug to achieve effective results. This question received responses that passed on medical advice or referred to personal experience.

> I was told with my meal or 1 or 2 hrs after.
>
> You need to take your pill either 1 hour b4 eating or with or no later than 1 h after eating. I find its best to take it with your meal and that way you know for sure that you have taken it.

New users regularly joined the forum and asked simple questions about what to expect. Jessica asked about foods that might trigger unpleasant side effects.

> I'm getting my Xenical tomorrow (hopefully) but am scared to death of the side effects… Can anyone tell me things to really avoid…like if I have wine with dinner, will I be really sorry? Does it really make you lose control of your functions if you should over-indulge on fats? What's the 'escape-to-the-bathroom' time if this happens? How is this really different from a serious laxative? Does Xenical have any impact on sugar/carbs that are fat-free? If you do not eat fat, it is still working? I was wondering about this, am I

[4]A 'thread' is a series of related communications on a particular topic.

> understanding right that if you haven't eaten much fat that the X works on the fat stored in your body??? Or am I just wishing???

These questions received responses from more experienced users.

> I haven't had that problem and I don't believe too many have but I guess they tell you that as a possible worse case scenario because it does happen to some people when they exceed the fat grams to the extreme. I know someone that it did happen to and it was at a McDonald's Fast Food Outlet. She was with friends and had already eaten her grams of fat for the day but decided to get a Big Mac, Fries, apple pie. She didn't make it out of her chair. Xenical helps steer you towards a healthy lifestyle and if you decide to go astray it gives you a reminder.

> I don't think it works on the fat stored. only on the fat you digest. so if you aren't eating a lot of fat i believe it is still taking 30% of the fat you did digest. i guess it is best to ask the xenical people, but, i believe that is how it works

Some participants were taking anti-depressants while also using Xenical, and one articulated concerns about the interaction between drugs:

> The Xenical seems to have stopped working since my doctor increased my dosage of Effexor. I have deliberately eaten a high fat content meal for 3 days running and suffered no ill effects… Has anyone else experienced this? I phoned the Xenical hotline and they said that if you're using Xenical properly you shouldn't be getting any oily 'waste' at all !!!… Be glad of any help.

In response, another participant suggested:

> Oh don't worry you're not the only one! The side effects of the effexor will wear off in a couple of weeks to about a month and you will 'return to regularity' I have been on effexor for almost three years. I have noticed that the xenical works slower…but it does eventually work… I recently opted to go off of effexor because I didn't ''think it was working''. Going off of it made a believer out of me! Just a few days and I could tell a difference in myself. I even gradually reduced the dosage under my doctor's supervision. So I am back on the effexor-…and yes I had a couple of weeks that were pretty bloating. My advise is to hang on and take them both regularly.

Another response was contradictory, and sounded a note of caution.

> I really think u should go to the doc tho, it doesn't sound normal what u are going thru! take care and let us know what happens ok?

These interactions within the forum not only sought technical advice on using Xenical, but also continually made connections into the wider experience of being overweight, and demonstrated a high degree of awareness of cultural associations with fatness. Participants in X-Online articulated nuanced observations upon their own condition, were critical of the medical profession at times, yet accepted a biomedical notion that overweight must be treated, with Xenical as a method of weight reduction.

Reflecting on experience: becoming expert

Information exchange was a first step in becoming 'expert patients', enabling participants to apply relevant knowledge to their condition. Sharing and reflecting on the experience of treating body size with Xenical was a pre-requisite for participants to manage their condition pro-actively, and this was a crucial element of X-Online's culture. During interview, users such as Gemma described how they had used the Internet to research their condition prior to seeking medication.

> My reaction to the suggestion to go on Xenical was to do all the research I could first. I was totally prepared for all the side-effects that I might experience… The research I did was on the Internet mainly… I actually found the X-Online group during that research as I was looking for feedback from people who had taken it. I probably looked into it for three weeks or so before actually going to my own doctor for a prescription.

While 'shopping around' for best value Xenical was a recurring theme, many participants obtained it from their family doctors, and reinforced this 'formal' relationship by the use of the forum as an information resource. Lesley managed her condition within a medical model, checking advice from her doctor against other users' experiences.

> I phoned the GP today and asked him if I could have X… One thing concerns me though, he gave me a warning that 90% of the people taking it, are incontinent. From what I have seen in this group, you are all managing okay, surely if you go over the fat grams you are supposed to have each day, then you'll suffer with the ''Os'' *(oranges)*, but if you stay within the limits, wont you be fine??

Responses from the forum were used to fill in 'knowledge gaps'. Mandy supplied this response for Lesley:

> Incontinent??? Even the Xenical websites don't mention it… Read the instructions in the box and if register with the Xenical help-line in your country. We all get 'oil' attacks if we eat too much fat, the only other thing you will get are severe cramps and the urge to pass more gas, but that's only with eating a high fat content diet.

Other participants felt their doctors were not providing sufficient information and used the forum to obtain supplementary information and exchange experience and questions to gain further insight into their condition and treatment. Kelly revealed that her doctor provided little information about Xenical, which led her to carry out personal research and use the forum as a space to ask questions:

> My doctor just prescribed me the Xenical… She didn't go into detail about much of anything. I looked on the computer and found out a little about the medicine. I was wondering if someone could explain to me what I'm supposed to eat…what not to eat…how am I going to feel and things of this nature…

While users of X-Online were becoming expert on their condition, data suggest that this expertise was paradoxical, echoing Wilson's (2001) theoretical analysis. Engagement with the forum supported participants' self-management of their weight and in this sense, becoming an 'expert patient' appeared as a radical, democratising process, giving the patient control over their options. However, by using Xenical to 'treat' weight gain and 'normalise' the body, the users were—intentionally or unintentionally—accepting and perpetuating a conservative and constraining biomedical perspective that a 'faulty body' could be 'treated'.

Adopting the medical model

Some participants in X-Online were critical of the medical establishment and its normative perspective on the overweight body.

> The medical profession is made up of people and many of them have their own prejudiced views as to people who are overweight. Unless you have been over weight you can't understand it. They may know more of the scientific reasons for a person's body shape but quite often I reckon they think people are just plain lazy (Sarah).

Despite this, they were often dependent on doctors to supply Xenical. Furthermore, use of a drug confirmed a perspective in which overweight was to be treated. Most participants equated a healthy lifestyle with slimness, with numerous contributions that discussed exercise, healthy eating, recipes and tips to achieve a healthy body and lifestyle. Julie accepted the notion that weight gain was associated with illness and saw losing weight as a route to a healthy lifestyle. Gemma revealed that she wanted to have children and believed that being overweight would lead to a difficult and unhealthy pregnancy.

> My primary motivating force is the desire to have children. I watched an overweight girlfriend struggle with her pregnancies, and don't want that for me. I run a small business and can't afford to have a bad pregnancy. Of course losing the weight won't guarantee a problem-free pregnancy, but keeping it on will guarantee one full of problems.

Even Xenical's side effects were co-opted to serve a normative end. Jenny admitted using Xenical while also binging on 'entire jars of hot fudge sauce, peanut butter, containers of cake frosting, multiple fast food orders and entire block of cheese in the middle of the night' before making herself vomit, although she acknowledged that Xenical was contra-indicated for people who are bulimic. Having read about how Xenical worked and the unpleasant side effects following the consumption of fatty foods, she thought these side effects would deter her from binging and enable her to achieve the goal of a slim body and healthy lifestyle:

> I read how people were learning to eat healthier and the fat intake would result in really bad consequences, I felt that would be the best choice for me… I am eating healthier and I'm afraid to binge.

In this section, we have identified how the use of Xenical fosters a biomedical approach to overweight, and this aspect of the X-Online culture was discerned in many aspects of the interactions and web materials on the site. In the discussion that follows, we consider how the online community relates to emerging discourses on patient expertise, and the extent to which these initiatives can lead to patient empowerment, or whether they sustain a dominant medical model of health and illness.

Discussion: empowerment or medical dominance?

The X-Online forum demonstrates a powerful combination of factors that sustain a community of users of weight-loss drugs, whose interactions are oriented towards self-management of their body size and lifestyle. First, the online community that has emerged is situated within a cultural context in which normative ideas about body shape, fitness and health are reflected in media images and articles on 'good' and 'bad' weights and shapes, in fashion and consumption, and in dominant medical discourses on health and illness. Second, the

community has a positive orientation towards a legitimate pharmaceutical technology that has been demonstrated to deliver weight loss effectively, when combined with diet and exercise, and which is available via medical gatekeepers as well as from Internet pharmacy. Third, X-Online has exploited a communication technology that not only can provide information about weight loss and related matters, but also facilitate discussion among users of a weight-loss technology to enable the development of individual expertise and knowledge. Together, these elements have led to a sustainable virtual community with a shared aim, ethos and norms, as has been demonstrated by the data in this paper. How then does X-Online contribute to the kinds of agenda set out in UK government policy and pharmaceutical industry papers on 'expert' and 'informed' patients?

By coining the term 'meetings between experts', Tuckett, Boulton, Olson, and Williams (1985) suggested that patient–professional interactions are based on encounters between professional expertise based in a medical model of disease and patient expertise grounded in subjective experiences of embodiment, health and illness. A generation earlier, Szasz and Hollender (1956) described three models for medical interactions, from an 'active–passive' encounter suited to acute episodes, through 'guidance–co-operation' in long-term illness such as tuberculosis or HIV infection, to 'mutual negotiation', which they saw as appropriate for chronic illnesses such as diabetes or cystic fibrosis, where patient involvement in managing a condition is paramount, and patients may end up with more understanding of a disease than their medical advisers. Recent initiatives around patient expertise move beyond the narrow experiential conception of patient experts described by Tuckett et al., yet sound resonances with the second and third of Szasz and Hollender's categories. However, these initiatives broaden the kinds of disease where this kind of patient engagement is appropriate, to cover a wider range of conditions, including 'lifestyle' problems such as body shape. However, none of these models fully encapsulate what we have described in this paper.

The expectations associated with the 'expert patient' in UK government reports (Department of Health, 1999, 2001) highlight the need for patients to take responsibility for the management of their health, as an adjunct to professional care. This involves not only researching conditions independently of medical consultations, but then using the acquired information to facilitate communication with the medical profession and foster a collaborative relationship between patient and professional. Studies have characterised the self-management tasks of an 'expert patient' in terms of various behavioural tasks. Wilson (2001, p. 134) reproduces core elements of chronic disease self-management that have informed the NHS expert patient programme, including:

- Recognising, monitoring and responding to symptoms.
- Managing acute episodes and emergencies.
- Using medications.
- Adopting appropriate aspects of lifestyle including healthy diet, exercise and relaxation, and not smoking.
- Interacting appropriately with healthcare providers.
- Seeking information and using community resources.
- Managing negative emotions and responses to illness.

From the data presented here, it would appear that Xenical users participating in X-Online displayed most—if not all—of these attributes of self-management, including actively researching obesity and its management through prescription drugs, and sharing and reflecting on their experiences of overweight and its treatment. Participants tended to use the forum as an adjunct to interactions with medical professionals, upon whom many depended for prescription of Xenical, and managed side effects according to advice from other X-Online participants. They saw weight loss as a way to become healthy and avoid disease, and used the group to manage their psychological and emotional responses to obesity within a supportive environment. Exchanges of information, knowledge and experience enabled the users of Xenical to manage their condition and treatment on a daily basis.

However, a further important characteristic of X-Online concerns its cultural commitments. While participants in the forum may situate their perspectives on body shape and weight in relation to popular and media stereotypes, these normative values were mediated via a medical model of obesity and overweight. Participants saw their use of Xenical as a means to restore themselves to a body shape that is culturally acceptable in the West, but the content of discussions within X-Online were located in relation to medical model discourses concerning pathology, treatment and restoration of health and fitness. Good health was associated with slimness and weight loss; and the ethos of the forum promoted mainstream medical advice about a healthy lifestyle. For the participants in the forum, Xenical represented a medication that could help treat an undesirable condition: the objective was to return participants to a normative construct of health and body shape. Benchmarks for 'success' were defined by this medical model, rather than by experiences.

Discussions of the expert patient have identified tensions between self-reliance and compliance with medical management of disease (Thorne et al., 2000), and this analysis of X-Online suggests that this tension emerges within the reflexive processes involved in

becoming an 'expert' patient. X-Online participants were strongly motivated to self-manage their condition, and achieved this by melding medical discourses on weight loss and its treatment with their shared knowledge concerning their experiences of obesity/being overweight, using Xenical and other means to reduce weight, and coping with the side effects of the medication. 'Official' advice from doctors and others was refracted through the lens of experience, but there remained an underlying commitment to medical models of illness and treatment. For X-Online participants, the development of 'expert reflexivity' emerged from a community that reinforced the normative messages of the medical model in its ethos and its commitments. This reflexivity is perhaps critical for patient expertise.

Foucault (1980) pointed to the intricate relations between knowledge and power, and if the 'expert patient' is to be understood as a reflexive project of self-governance, then it is indeed a 'technology of the self': a disciplining of the body in relation to systems of thought. The case study of X-Online suggests how the medical model may become the basis for this discipline, establishing a reflexive self-management basis in compliance with dominant models of the body. Other writers have invoked somewhat darker versions of Foucault's analysis, seeing within government enthusiasm for expert patients, manifestations of 'pastoral power' (Wilson, 2001) and 'bio-power' (Gastaldo, 1997): projects to shine a light into the private lives of patients to assess how they govern their illness. In such a context, to be an 'expert patient' is not only to be informed and engaged, but to be open to scrutiny, normalisation and standardisation.

What then may be the various futures for the development of patient expertise? The model described in the previous paragraph perceives a project of governance that extends the medical gaze into the dark corners of people's lives. In such a model, to be an expert patient is to be empowered to manage one's health and illness, but to adopt this power from a dominant disciplinary system of thought—in this case, the medical model. The data from this case study are suggestive of this as a possible future, in which to become an expert patient is a double-edged sword. While X-Online was successful in sharing information and providing support that participants find extremely valuable, and enabled them to become 'expert patients', it may fail to facilitate a fully democratised approach to body size and shape. The 'expert patient' in X-Online, rather than becoming knowledgeable in a wide range of approaches to overweight-ness, learnt about obesity within a set of pre-defined guidelines. In other words, for these users of a pharmaceutical technology, becoming an expert patient was normative, as opposed to a radical process.

It is perhaps ironic, in the light of this model of the expert patient, that members of the medical profession have seen the move towards the expert patient as a threat, representing a *loss* of power within the consultation, in which a patient grasping print-outs from the Internet entails a time-consuming negotiation of illness management (Shaw & Baker, 2004). Even the title is redolent of a challenge, and a range of epithets have been suggested including 'involved' (Hjortdahl, 2004), 'autonomous' (Coulter, 2002) and 'resourceful' (Muir Gray, 2002) that avoid acknowledging patients as experts. A second future is thus of a much-impoverished version of patient expertise where medical dominance is not challenged within the consultation, although more use may be used of patient perspectives within policy formulation and management.

A third, more positive future may be discerned by recalling the rather different formulation developed by the ABPI in its report *The Expert Patient* (Illman, 2000). This body is an advocate for commercial organisations and their conception reflects a view of patients as informed consumers, and the UK pharmaceutical industry has set up an Informed Patient Initiative Taskforce to 'create new relationships between patients and healthcare professionals and ultimately between patients and the pharmaceutical industry' (Illman, 2000). Beyond the UK, market forces have freed pharmacy from the medical profession to an extent, and direct-to-consumer advertising in the US and New Zealand reflects the global consumerist movements that are developing in the healthcare sector. Our research set out to explore consumerism in relation to pharmaceuticals; clearly, Internet pharmacy is having an effect on access to drugs that may in due course transform the relationship between patients and professionals more than government policy. While consumerism raises issues of equity and social exclusion, it also has the potential to challenge power structures in societies. Informed patients are also informed consumers, and may wish to engage with providers of health technologies freed from the constraints of professional control and governance (Fox, Ward, & O'Rourke, forthcoming).

In conclusion, we have argued that participants in X-Online emerge as expert patients within the kind of model envisaged in UK government policy. We have used this case study to question some notions implicit in initiatives to create patient expertise, to ask what expertise is being created here, and how alternatives to the medical model of health and disease may be fostered when the dominant discourse is biomedical. We have suggested that the expert patient is a reflexive patient, contextualising her life-story and experiences within available systems of thought, which—at least in policy formulations—are biomedical. The growth of a consumerist approach to healthcare may, however, offer an

alternative basis for an informed 'patient', who resists biomedical formulations of health and illness, and uses the kinds of community described in this paper to develop expertise that empowers rather than constrains.[5]

References

Abraham, S., & Llewellyn-Jones, D. (1997). *Eating disorders: the facts*, Oxford: Oxford University Press.

Beck, U. (1992). *Risk society*, London: Sage.

Bessell, T. L., Silagy, C. A., Anderson, J. N., Hiller, J. E., & Sansom, L. N. (2002). Quality of global E-pharmacies: can we safeguard consumers? *European Journal of Clinical Pharmacology*, *58*, 567–572.

Bordo, S. (1993). *Unbearable weight: feminism Western culture and the body*, Berkeley, CA: University of California Press.

Coulter, A. (2002). *The autonomous patient—ending paternalism in medical care*, London: Nuffield Trust.

Department of Health (1999). *Our healthier nation—saving lives*, London: The Stationery Office.

Department of Health (2001). *The expert patient a new approach to chronic disease management for the 21st century*, London: Department of Health.

Després, J-P., Lemieux, I., & Prud'homme, D. (2001). Treatment of obesity: need to focus on high risk abdominally obese patients. *British Medical Journal*, *322*, 716–720.

Foucault, M. (1980). The eye of power. In C. Gordon (Ed.), *Power/knowledge*. Brighton: Harvester.

Foucault, M. (1988). Technologies of the self. In L. H. Martin, H. Gutman, & P. H. Hutton (Eds.), *Technologies of the self*. London: Tavistock.

Fox, N. J. (1998). "Risks", "hazards" and life choices: reflections on health at work. *Sociology*, *32*(4), 665–687.

Fox, N. J. (1999). *Beyond health. Postmodernism and embodiment*, London: Free Association Books.

Fox, N. J., Ward, K. J., & O'Rourke, A. J. (forthcoming). A Sociology of technology governance for the information age. The case of Pharmaceuticals, Consumer Advertising and the Internet. Submitted to Sociology.

Gastaldo, D. (1997). Is health education good for you? Rethinking health education through the concept of biopower. In A. Petersen, & R. Bunton (Eds.), *Foucault, health and medicine* (pp. 113–133). London: Routledge.

Giddens, A. (1991). *Modernity and self-identity*, Cambridge: Polity.

Gordon, R. A. (2000). *Eating disorders: anatomy of a social epidemic*, Oxford: Blackwell.

Grogan, S. (1999). *Body image*, London: Routledge.

Henwood, F., Wyatts, S., Hart, A., & Smith, J. (2003). 'Ignorance is bliss sometimes': constraints on the emergence of the 'informed patient' in the changing landscapes of health information. *Sociology of Health and Illness*, *25*(6), 589–607.

Hine, C. (2000). *Virtual ethnography*, London: Sage.

Hitchcock-Noel, P., & Pugh, J. A. (2002). Management of overweight and obese adults. *British Medical Journal*, *325*, 757–761.

Hjortdahl, P. (2004). 'The informed patient'. Rapid Responses. *bmj.com,* 24 March 2004. Accessed at: http://bmj.bmjjournals.com/cgi/eletters/328/7442/723#54602.

Illman, J. (2000). *The expert patient*, London: Association of the British Pharmaceutical Industry.

Jones, T. (2000). Foreword. In J. Illman (Ed.), *The expert patient*. London: The Association of the British Pharmaceutical Industry.

Kleinman, A. (1980). *Patients and healers in the context of culture*, Berkeley: University of California Press.

Luck, J., Morgan, J. F., Reid, F., O'Brien, A., Brunton, J., Price, C., et al. (2002). The Scoff questionnaire and clinical interview for eating disorders in general practice: a comparative study. *British Medical Journal*, *325*, 755–756.

Lupton, D. (1994). *Medicine as culture: illness, disease and the body in Western societies*, London: Sage.

Lupton, D. (2002). Consumerism, reflexivity and the medical encounter. In S. Nettleton, & U. Gustafsson (Eds.), *The sociology of health and illness reader*. Cambridge: Polity.

Mann, C., & Stewart, F. (2000). *Internet communication and qualitative research: a handbook for researching online*, London: Sage.

Mendelson, C. (2003). Gentle hugs: Internet listservs as sources of support for women with lupus. *Advances in Nursing Science*, *26*(4), 299–306.

Mitchell, C. (2003). Autism e-mailing lists. *Health Information on the Internet*, *33*, 3–4.

Muir Gray, J. A. (2002). *The resourceful patient*. Oxford: eRosetta. Also available at http://www.rseourcefulpatient.org.

Nettleton, S., & Gustafsson, U. (Eds.) (2002), *The sociology of health and illness reader*. Cambridge: Polity.

Rothblum, E. D. (1999). Contradictions and confounds in coverage of obesity: psychology journals, textbooks, and the media. *Journal of Social Issues*, *55*(2), 355–370.

Shaw, J., & Baker, M. (2004). Expert patient: dream or nightmare? *British Medical Journal*, *328*, 723–724.

Szasz, T., & Hollender, M. (1956). A contribution to the philosophy of medicine. *Archives of Internal Medicine*, *97*, 585–592.

Tang, S. Y. S., & Anderson, J. M. (1999). Human agency and the process of healing: lessons learned from women living with chronic illness—re-writing the expert. *Nursing Inquiry*, *6*, 83–93.

Thompson, J. K., & Heinberg, L. J. (1999). The media's influence on body image disturbance and eating disorders: we've reviled them, now can we rehabilitate them? *Journal of Social Issues*, *55*(2), 339–353.

Thomsen, S. R, Straubaar, J. D, & Bolyard, D. M. (1998). Ethnomethodology and the study of online communities: exploring the cyber streets. *Information Research*, *4* (1). Accessed at http://informationr.net/ir/4-1/paper50.html.

Thorne, S. E., Ternulf Nyhlin, K., & Paterson, B. L. (2000). Attitudes toward patient expertise in chronic illness. *International Journal of Nursing Studies*, *37*, 303–311.

[5]Elsewhere (Ward et al., forthcoming), we look at how some users of weight-loss drugs have subverted the medical model, to use the drug to radically reduce weight in ways that the medical professional regard as un-natural and dangerous. These 'expert patients' do not adhere to a medical model of health, but have established a rival, subversive approach and support this culture through their own Internet environment.

Tuckett, D., Boulton, M., Olson, C., & Williams, A. (1985). *Meetings Between Experts*, London: Tavistock.

Ward, K. J. (1999). The cyber-ethnographic (re)construction of two feminist online communities. *Sociological Research Online*, *4* (1). Accessed at www.socresonline.org.uk/socresonline/4/1/ward.html.

Ward, K. J., Fox, N. J., & O'Rourke, A. J. (forthcoming). Pro-anorexia, weight-loss drugs and the Internet: anti-medical resistance and the subversion of technology.

Turner, J., Grube, J., & Meyers, J. (2001). Developing an optimal match within on-line communities. *Journal of Communication*, *51*(2), 231–251.

White, M. H., & Dorman, S. M. (2000). Online support for caregivers: analysis of an Internet Alzheimer mailgroup. *Computers in Nursing*, *18*(4), 168–179.

Wilson, P. M. (2001). A policy analysis of the Expert Patient in the United Kingdom: self-care as an expression of pastoral power? *Health and Social Care in the Community*, *9*(3), 134–142.