

Health identities: from expert patient to resisting consumer

Nick Fox, Katie Ward

▶ To cite this version:

Nick Fox, Katie Ward. Health identities: from expert patient to resisting consumer. Health:, 2006, 10 (4), pp.461-479. 10.1177/1363459306067314. hal-00571427

HAL Id: hal-00571427

https://hal.science/hal-00571427

Submitted on 1 Mar 2011

HAL is a multi-disciplinary open access archive for the deposit and dissemination of scientific research documents, whether they are published or not. The documents may come from teaching and research institutions in France or abroad, or from public or private research centers.

L'archive ouverte pluridisciplinaire **HAL**, est destinée au dépôt et à la diffusion de documents scientifiques de niveau recherche, publiés ou non, émanant des établissements d'enseignement et de recherche français ou étrangers, des laboratoires publics ou privés.

Copyright © 2006 SAGE Publications (London, Thousand Oaks and New Delhi)
DOI: 10.1177/1363459306067314
1363-4593: Vol 10(4): 461-479

Health identities: from expert patient to resisting consumer

Nick Fox & Katie Ward

University of Sheffield, UK

ABSTRACT This article explores the formation of 'health identities': embodied subjectivities that emerge out of complex psychosocial contexts of reflexive modernity, in relation to data on health and illness practices among groups of people and patients using medical technologies including weightloss drugs and the erectile dysfunction drug sildenafil (*Viagra*). We examine a range of health identities, from the 'expert patient' – a person who broadly adopts a biomedical model of health and illness, to a 'resisting consumer', who fabricates a health identity around lay experiential models of health and the body. The understanding of health identities is developed within a theoretical framework drawing on previous work on body/self and the work of Deleuze and Guattari. It is concluded that the constellation of health identities reflects the diversity of relations in an industrialized, technology-driven, consumer-oriented and media-saturated society.

KEYWORDS body; Deleuze; health; identity; subjectivity

ADDRESS Nick Fox, School of Health and Related Research, University of Sheffield, Regent Court, Regent Street, Sheffield S1 4DA, UK. [e-mail: n.j.fox@shef.ac.uk]

Introduction: health as identity practice

For social scientists, it has been a fundamental principle that the categories 'health' and 'illness' are not to be defined simply in terms of the anatomy, physiology and genetic make-up of an individual. Studies of the experience of sickness, disability, infirmity and pain, predominantly from within a phenomenological perspective, have established the social, cultural and psychological components that underpin how both individuals and societies understand health and illness (Charmaz, 1983; Herzlich and Pierret, 1986; Baszanger, 1992). However, social theorists have also recognized the complex interactions between the social, embodiment and subjectivity, and the 'problem' of how to avoid privileging one of these three ontological entities has predictably generated a wealth of theory and dispute (Nettleton and Watson, 1998; Williams and Bendelow, 1998; Fox, 1999). In this

article, we will draw on some empirical data to examine the ways in which health (a socially constructed phenomenon), the body (an entity that is both physical and social in character) and identity (the emergent, always 'becoming-other' reflexive sense of self) flow together in the practices of individuals and groups.

In a previous article (Fox, 2002), the relationship between embodiment and identity was theorized by an application of the work of Deleuze and Guattari. Emergent identity was 'a consequence of the confluence between embodiment on one hand, and on the other, the physical and cultural worlds which impinge and limit, yet also make possible' (2002: 349). Fox argued that we should talk of body/self, to emphasize how closely these two entities are tied together. The article examined a range of identities that are forged from the reflexive confluence of the body with its physical, psychological and emotional (affective) relations or attachments. Among these emergent identities were a number associated with relations that are constitutive of 'health' and 'illness' ('fitness', 'ageing', 'slimming' and so forth). What we come to call the 'health' of a body is the outcome of:

refracted and resisted relations, biological capabilities or cultural mind-sets, alliances with friends or health workers, struggles for control over treatment or conditions of living. Health is neither an absolute (defined by whatever discipline) to be aspired towards, nor an idealized outcome of 'mind-over-matter'. It is a process of becoming by body–self, of rallying affects and relations, resisting physical or social territorialization, and experimenting with what is, and what might become. (Fox, 2002: 360)

That article concluded that health and illness are 'political' categories, as much to do with the physical and cultural possibilities and constraints surrounding a person's body as with any characteristic of the body itself. Furthermore, identities emerge within the contexts of these possibilities and constraints. For the social scientist, this links the study of health (and illness) with identity, and means we must study 'health', 'body' and 'identity' together, as emerging from activity and practice, and located within the totality of a body's physical and social relations. Health identities are features of the clustering of relations around specific aspects of embodiment, such as sport and exercise, body modification, disability or growing old. This approach was applied in a study of ageing among people in Thailand and Australia, which explored the reflexive forging of ageing identities from 'their myriad affective, physical, philosophical, social and cultural relations (with their beliefs, their families, their life experiences, their gender and ethnicity, their care and their bodies)' (Fox, 2005: 514). The identities of older adults were the outcome of these confluences between body and milieu: hugely complex and idiosyncratic, yet accessible to empirical study through the documentation of relations and their reflexive construction. The study found that identity, embodiment and notions of health and illness were mutually constitutive within contexts of relations with the material world, culture and psychosocial engagements.

In a society that is increasingly interested in all aspects of health and embodiment, from the 'cyborg technologies' (Haraway, 1991; Balsamo, 1996) of body modification by pharmaceuticals (Monaghan, 2000; Potts, 2004) or cosmetic surgery (Negrin, 2002) to genetic therapies (Le Breton, 2004) and cloning (Petersen, 2002), identity will be forged within the context of these kinds of health-related practices. Health technologies are also identity technologies, and the consumption of these technologies may forge associated health identities. An opportunity arose to explore health identities during a study of consumption of pharmaceuticals for lifestyle reasons. In this article, we report this research, focusing on the forging of different health identities and how these relate to systems of thought and expertise.

Patients, health experts and health consumers

Conceptions of patient and health professional relationships have evolved since Szasz and Hollender (1956) identified three models: 'active-passive', 'guidance-co-operation' and 'mutual negotiation' for interactions. Recent UK policy recapitulates Tuckett et al.'s (1983) description of doctor-patient encounters as meetings between experts, suggesting a future in which 'expert' patients will manage their own illnesses and conditions in partner-ship with their health and social care providers (Department of Health, 2001: 5). People with chronic conditions can now receive training as expert patients (Shaw and Baker, 2004), including:

- recognizing, 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 health care providers;
- · seeking information and using community resources; and
- managing negative emotions and responses to illness. (Wilson, 2001: 134)

Critics of the expert patient notion argue that it ignores entrenched professional power and structural constraints to do with access to resources (Tang and Anderson, 1999) and conflates experience and education (Wilson, 2001: 135). Paradoxically, patient expertise both assumes compliance and accepting responsibility for the management of health (Thorne et al., 2000). Professionals have been slow to embrace the concept, dismissing efforts by patients to theorize or explain their condition (Henwood et al., 2003). Uneasiness with associating patients with expertise has led to other proposed epithets, including 'involved' (Hjortdahl, 2004), 'autonomous' (Coulter, 2002) and 'resourceful' (Muir Gray and Rutter, 2002).

Meanwhile, a consumer movement has also affected the landscape of patient/professional interactions. Many medical conditions now have an advocacy or support network offering advice and information to sufferers.

Numerous websites, interactive forums and e-mail lists allow people to share information and discuss their condition and its treatment (Bessell et al., 2002; Mendelson, 2003; Mitchell, 2003). The validity of information on these sites varies, and organizations such as the Association of the British Pharmaceutical Industry (ABPI) argue that there is a need for 'gold standard' websites including the National Electronic Library for Health (NELH) and NHS Direct Online, which can provide trusted information to consumers. Some pharmaceutical companies are collaborating with patient groups to support dissemination of information about conditions, including potential pharmaceutical treatments (Fox et al., 2006).

This consumerist approach to health and illness has been fuelled by the development of treatments for so-called 'lifestyle' conditions, including male pattern baldness, erectile dysfunction and weight loss. Online pharmacies cater to a global market for health care products (Fox et al., 2005a), and some of the best-selling pharmaceutical products have been developed with such markets in mind. In the UK, 'e-clinics' use online consultations to assess people's suitability for medications such as sildenafil (*Viagra*) or the weight-loss drug orlistat (*Xenical*), before selling these products directly to consumers.

Thus, government policy on expert patients and the rise of independent consumers of health care both emphasize the centrality of self-management of health and illness. However, our research into health identities suggests that there is a continuum of identity practices, from a relatively medicalized 'expert patient' to an independent consumer of health information and products, often constructing notions of health and illness in contrast to a biomedical or professional perspective. In this article we draw together research data, some of which has been published more fully elsewhere (Fox et al., 2005b, 2005c), to explore this continuum and to develop an understanding of how health identities emerge in the confluence of cultural contexts and experiences of embodiment. We look at three different case studies to explore these emergent identities.

Methods

The research reported here was part of a larger study on consumption of pharmaceuticals and the role of the Internet, conducted as part of the ESRC Innovative Health Technologies programme between 2002 and 2004. As part of the study, we looked at people's use of various lifestyle pharmaceuticals, both prescription-only medicines (POMs) and pharmacy medicines (PMs). The main methods used for this element of the research were documentary approaches and 'online ethnography'.

The first of these predominantly required searches of websites devoted to information about pharmaceuticals and those enabling purchase of PMs and POMs. We focused on specific conditions such as weight loss, erectile dysfunction and depression, and located websites that would provide drugs

related to these conditions. The names of specific pharmaceuticals were entered into search engines to identify commercial websites, information-providers and other links. From these searches we were able to identify both Internet pharmacies and online clinics, and sites devoted to consumer information and interaction using online technologies such as discussion forums.

The online ethnographic work entailed observation and participation in discussion forums and subsequent interviews with participants, typically by e-mail. This is an emerging approach that has adapted 'face-to-face' ethnographic methods (Mann and 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 et al. (1998) suggest that multi-method triangulation, involving textual analysis, prolonged participant observation and qualitative interviews can provide valid and reliable data.

During this phase, KJW subscribed to various online message forums that we considered would enable us to understand the range of patterns of health identity practice, from that of an 'expert patient' to a 'health technology consumer' (more detail of the forums is provided in the following sections). In each, a period of acculturation to the norms of the values of the groups was followed by participation in the forums, which involved asking questions of forum participants. Some participants responded to the questions via the forum, while others chose to e-mail their responses direct to the e-mail address, which provided the opportunity for 10 in-depth interviews. Participation in the forums took place over a period of months during 2003. A total of 36 interviews were conducted with participants in the forums. The forums and names of participants have been changed throughout to protect anonymity, and postings have been reproduced verbatim. For a full discussion of online ethnography, see Fox et al. (2005c).

Expert patients

The first case study we consider here illustrates an 'expert patient' health identity. 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 and Heinberg, 1999: 347). We undertook research on 'X-Online': a public discussion forum established in 2001 devoted to weight loss and the use of prescription drugs such as orlistat (*Xenical*) that disrupt the digestion of fat. It had about 500 registered users, predominantly females between 30 and 40 years from the UK, USA 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 (Fox et al., 2005b).

Within X-Online, being overweight had complex meanings for participants. Members 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. One participant had vivid memories of realizing she had a 'weight problem'. Being overweight was a family issue, and 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 20s and has kept it off for about eight years so far.

In the X-Online forum the users exchanged a high volume of information, including exercise tips, diets and progress reports. Questions about the appropriate way in which to take Xenical were frequent in the forum, while discussion in one thread was dedicated to side-effects of taking Xenical, and how to manage their diet to avoid the unpleasant side-effect of diarrhoea. Participants used an explanatory model based on a medicalized understanding of the treatment, and often made reference back to medical and pharmaceutical professionals. 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 . . . Does it really make you lose control of your functions if you should overindulge on fats? . . . 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, is it still working? I was wondering about this, am I 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???

This post received the response:

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.

One response to this posting reiterated the medical model underpinning how participants saw their use of Xenical: '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 kinds of information exchange were a first step in becoming 'expert patients', and our findings suggest that participants in this forum regarded the most highly valued expertise as biomedical, as opposed to social or experiential. 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.

Most participants had obtained Xenical from their family doctors, and regarded this relationship as important. 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" [diarrhoea], but if you stay within the limits, wont you be fine??

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 \dots 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 \dots what not to eat \dots how am I going to feel and things of this nature \dots

Engagement with the forum supported participants' self-management of their weight, working alongside the medical professional in a shared enterprise. Their use of Xenical accepted a biomedical perspective on overweight as abnormal and 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.

In summary, our analysis suggests that the participants in X-Online construct a health identity that is grounded in medical knowledge and perspectives on body mass and shape and their own culturally mediated

experiences of their embodiment. Participants were engaged in an enterprise to alter their body shape to one 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 forum promoted mainstream medical advice about a healthy lifestyle. This medicalized health identity is broadly in line with the previously described notion of the expert patient developed by Wilson (2001: 134).

Blurring identity: from expert patient to technology consumer

The second case study we researched was concerned with male impotence and treatments for erectile dysfunction. We subscribed to a number of online discussion forums including an impotence support group and lists more specifically concerned with the use of sildenafil (*Viagra*) and similar pharmaceutical treatments for erectile dysfunction. These lists had male and female respondents from the UK, USA, Canada, South Africa and elsewhere and supported an active discussion on a range of topics. We posted questions to the participants and also conducted online interviews. The impotence support list served as a broad forum for discussion of sexual function while groups such as the V-Board (our pseudonym) included an extensive 'buying guide' for purchase of Viagra and similar pharmaceuticals from Internet pharmacies and discussion boards for both men and women to describe the effects of Viagra and consider the impact of the technology for their sexual identity.

Like the other forums we have reported here, a significant feature of V-Board was information seeking and exchange. One participant wanted to find out whether Viagra would be a suitable treatment for his perceived reduced sexual function:

I'm curious about the possibility that the use of Viagra might also be helpful in speeding up the 'process' to ejaculation. It seems to take much longer to orgasm now than it used to, and I've heard that using Viagra can be helpful in that regard. Anybody have any experience with this?

Another participant wrote to get advice as a novice user of Viagra:

It sounds like there is a lot of experienced Viagra fans out there. Well, I'm about to try it out for the first time. I purchased the 100mg pills over the 'net. Does any one out there have any advice for me? I am a little worried about if I should split the pill and try a smaller dosage to start . . .

Questions to the forum sought information about both the science behind erectile dysfunction and how Viagra might counter this condition, but also how to obtain the drugs. Many posts shared information about how to obtain Viagra without consulting a physician, about the various generics

such as 'Indian Viagra' and how much these various versions cost per tablet. This participant asked about both the science and the means to access Viagra:

I don't have a clue what to believe and what not to believe. I looked up ED and this is what it said: Erectile dysfunction, or ED, can be a total inability to achieve erection, an inconsistent ability to do so, or a tendency to sustain only brief erections. I would say my boyfriend has the last of these 3 . . . the tendency to sustain only brief erections. He's already had Viagra and we both enjoyed the results, immensely, but he's not willing to go to a doctor to get it. Can anybody help me sort this all out, please?

For many participants, information seeking concerned the impact of drug interactions, perhaps because they were using other medications such as anti-depressants or blood-thinning drugs. Some participants had become expert on using cocktails of drugs to increase sexual arousal:

I'm thinking about taking 50 mgs of Viagra one hour before sex and 150 mgs of trazodone/Desyrel 2 hours before sex. The dosage and timing of the Viagra are obvious, regarding the dosage of Desyrel, I read that it would be the best and safest dose to increase potency. I would take it 2 hours before sex because then peak plasma levels are obtained. I don't know however if it would be adequate to take the Desyrel only on days you plan to have sex. . . . By the way, I live very close to an emergency room and or not very priapism-prone.

These participants were using pharmaceuticals within a medical context, to address a lifestyle problem perceived by them as a deviation from normal sexual function, or to address a loss of performance as a consequence of illness or ageing. For example, the following participant on V-Board used tadalafil (*Cialis*) to enhance a perceived reduction in arousal:

I for one am very excited and impressed, and we are trying as a husband and wife to discount or not let the 'placebo effect' influence our experience with Cialis. I don't feel that I have extreme ED, but sometimes I am amazed at how 'dead' my part can be . . . so to have anything work well – and as well as Cialis, I am ready and willing to use it.

Pharmaceuticals such as Viagra have also created potential for recreational uses, often by males and females who from a medical point of view would not be considered to be sexually dysfunctional. The discussion forums included postings that reflected this alternative, non-medical use of the drug as a 'cyborg technology' to enhance sexual performance beyond physiological or psychological constraints. The following participant sought information from the forum on how Viagra might artificially enhance arousal:

I hope I am not offending anyone here with my question. I am a 23yo female and I want to know if my male gay friend can get an erection while with me after he takes the pill. He is very curious about straight sex and I have assured him I would be understanding and careful with him. By the way, I think he is so

gorgeous so I am thrilled about this opportunity! But because he is gay, I am kind of wondering if he will be able to get hard with me-I am hoping Viagra will be a great catalyst ... any suggestions or similar experiences will be extremely helpful.

Another forum focused on these non-medical uses of Viagra and similar drugs. One participant described how he had used Viagra to sustain erection:

Now i realise this great medicine should not be abused and I don't want to start any competitions but can i just say that after sneaking off with a long time friend of mine for a enjoyable weekend, i racked up 12 hours of non stop action on day one, 16 hours on day two and only 4 hours on day three due to the fact my supply had run out (I ate 8 of those blue M&M's that weekend). The only side affects i suffered was the fact I tore all my stomach muscles and could not walk or laugh for 3 days.

While drugs such as Viagra are not licensed for prescription to women, a theme on some forums was its impact when taken by females. A female contributor posted the following:

Just wanted to let all you unbelievers out there know that I tried Viagra and it certainly DOES work for women; at least it worked for me. I was wet and more abnormally swollen than usual. Not only did I want my partner constantly, and with a kind of insane intensity, but when we went out to a bar afterwards, I was also almost irresistibly sexually drawn to other men in the bar. It was an effort to pull myself away. So Viagra definitely FEELS like a drug. We both didn't take more than half, and I wouldn't recommend more than that. He was hard for over 24 hours, and I also experienced effects for about that long.

In summary, the impact of pharmaceutical technologies for erectile dysfunction has enabled both the effective treatment of a medical condition and the exploitation of the technology for non-clinical uses. These discussion forums perform a number of functions, from enabling the sharing of experiences of sexual function and the use of various technologies to treat problems, offering personal testimonials to different treatments, through to about how to obtain pharmaceuticals without medical consultation. Like other medications for 'embarrassing' conditions, Viagra has benefited from the rise of online pharmacies such as 'ShytoBuy'. There is a consumerist orientation to the postings on these message boards, and while erectile dysfunction is a psychologically devastating disease for sufferers, the opportunities to purchase an effective treatment can blur a health identity as patient, and open up potential to engage actively as a consumer of what Potts (2004: 27) describes as a 'tool' to achieve a particular desired outcome, which may or may not be clinically indicated.

Resisting (anti-)consumers

The final case study we report upon explores health identities forged and sustained through their explicit opposition to a medical model of disease and treatment. Anagrrl (our pseudonym) is one of a number of semiunderground 'pro-anorexia' or 'pro-ana' websites and discussion forums. This movement supports those in an anorexic condition, but unlike mainstream support groups for people with eating disorders, regards the condition as sustainable and survivable. Like similar groups, Anagrrl had been persecuted by the media as supporting a dangerous and potentially fatal condition, but at the time of the research was a thriving community that provided a comprehensive website and message forum, where participants exchanged ideas, provided support and shared experiences, achievements and perceived failings. The site included recipes to promote healthy anorectic eating, advice on nutritional supplements and 'thinspiration': photographs of slim celebrities to inspire and sustain anorectic behaviour.² Participants were predominantly from the USA, UK, New Zealand and Australia, overwhelmingly females between 14 and 42 years, with the majority around the ages of 17 to 20 and in full-time education.

An anti-medical and 'anti-recovery' ethos underpinned the site, with anorexia regarded as aspirational, contributing to a positive pro-ana identity among its members. Lily, the founder of the website, described the movement as the means for people with anorexia to take an active role in living with what society considered a debilitating, dangerous and shameful disease. Anorexia, she suggested, was defined by insecurity and vanity on one hand, and the relentless striving for perfection on the other. Becoming pro-ana was complex, risky and obsessive, entailing a stringent regime of eating, fasting, purging and exercising to restrict calorie intake to a 'survival level' of about 700 calories per day, but with the aim of safely sustaining this regime. Unlike pro-recovery groups, anorexia was not seen as abnormal or inherently pathological.

Using a combination of text and photographs, participants in the group framed their bodies to reflect and re-create the values of the pro-ana movement. These photographs seemed to have been selected to present a deliberately staged version of the self, with close attention to hair, make-up and clothes. Other members would compliment the pictures, noting that the subject was exceptionally thin and beautiful, and a source of *thinspiration*. Other identity strategies included creation of a 'signature', which often contained the user's current and goal statistics and measurements. Participants appeared to apply a standard format, incorporating their height, current weight (cw), high weight (hw), low weight (lw) and goal weights (gw). For example, this was Jenny's signature, 'H:5'2; cw:100 down five lbs; hw:120; lw:75lbs; 1st gw:90lbs; 2nd gw:80; 3rd gw:70lbs ~ I always was told to test the limits~'. Marcy used as her signature a lyric from the Manic Street Preachers' song 4 stone, 7 pounds: '... i wanna be so skinny that i

rot from view ...' Participants' analysis of anorexia was overwhelmingly social. They located the causes within the beauty industry, media obsessions with celebrity lifestyle, and the equation of slimness with being considered beautiful, successful, happy and healthy. For one participant we interviewed, comments by a peer had led to her becoming anorexic:

I've always been 'thin' or so they've told me. But what triggered me was my best friend's boyfriend. He always used to criticise me and make fun of me and call me ugly. It hurt so much I contemplated suicide. Then it was probably May when my ED [eating disorder] started, I think it was because I thought, Well, I'm skinny, I have that much going for me, Maybe if he notices how skinny I am he won't bother looking at the rest of my imperfect body. I was 89 pounds then and now I'm 94, I think in July I noticed I had an ED, I started researching things on the internet about Anorexia, and everything applied to me . . . It was scary But I thought I would take control and show that fat ass a thing or two!

For participants in *Anagrrl*, low body weight was less important than the underlying pain and alienation that had driven them to adopt a pro-ana identity. Many saw the process of becoming and sustaining this identity as a place in which control and purity could be found. Jenny described how anorexia represented a form of security and comfort in an often-disordered environment:

I think of my ed [eating disorder] as a sanctuary from the pain that I've lived through. I have control over myself when I restrict, and I have control over my body when I purge and that is what has got me through the hard times in my life, the times when there was no control or stability in sight.

'Recovery' from anorexia was not a desired option for most participants in *Anagrrl*. In contrast to medicalized explanatory models of anorexia, the website and discussion forum devoted most of its space to exploring the safe management of a dangerous condition, to sustain both low body weight through tips and advice on use of weight-loss drugs, and also a pro-ana identity. The site offered support 'in a non-judgmental way', rather than a 'politically correct' approach in which support was given to achieve recovery, said one respondent. *Anagrrl* enabled its members to play out a health identity that was valued and provided, as Charlotte remarked in an interview:

I joined a pro-recovery anti pro-ana site and they were all politically correct and trying the proper support in a recovery type position – but they had an article on pro-ana and I looked into it – at first just to get some triggering pics and stuff, but came across this site and have found on the whole that the support I receive on there is much better than the support I received on the other \ldots maybe one day I will be 'ready' for recovery but i certainly am not yet – and I am sick and I like to know there are people out there who feel the same way as me.

Both Amy and Emily commented in interviews that they proactively sustained their ana health identity, and that their ability to choose an identity was crucial:

I would recover if I were pregnant, which will never happen due to my anorexia. I would also recover if I reached the point in my life where I wanted to marry someone close to me. It's not fair to put my life in danger when I am so valuable to someone else.

I will only recover when I truly want too. last time I was forced. I could've fought back harder but I felt badly doing that to my parents. my dad wouldn't sleep cause he worried about me, and relatives kept calling my parents asking if I was okay. but now I seem to have a problem with binging and no one seems to give a damn. anyway that's a whole other long story. moral of story . . . don't change for anyone else, only for yourself.

In summary, these data demonstrate the emergence of a health identity that is not only grounded in an assertion of self around particular values, behaviours and cognitions, but is highly resistant to conventional models of health, be they inspired by biomedical, social or psychological explanations of anorexia (Bruch, 1973; Grogan, 1999; Berg et al., 2002; Luck et al., 2002; Gremillion, 2003). Elsewhere, we have argued that the pro-ana movement constitutes a coherent anti-medical explanatory model of anorexia capable of offering explanations of the aetiology, epidemiology, prognosis and management of the condition. It is perhaps because of this coherence that a self-actualizing health identity manifests. In place of the expert patient whose identity we noted earlier emerges in the confluence of a medicalized embodiment, we see a resisting consumer (consumption of weight-loss drugs, low-calorie recipes and thinspiration; non-consumption of food), who rejects the medicalized body and conventional cultural values concerning body shape.

Health identities: what can a body do?

We chose to describe here three different types of engagement that individuals had with medical knowledge and expertise, with health technologies and with their embodiment practices. In the X-Online case study, we see people engaged in body modification (weight loss) using a pharmaceutical technology within the framework of medical expertise on fat metabolism. For these people, their own expertise in applying a technology towards a body objective paralleled a medical model, in which slimness was desirable and 'healthy'. They adopted a health identity located within relations with medical knowledge in which they were foremost 'patients' and secondarily 'expert'.

Individuals in the second case study manifested a range of relations with biomedicine in their exploration and use of a 'cyborg' technology (Haraway, 1991; Balsamo, 1996). Both weight-loss drugs and pharmaceuticals to treat erectile dysfunction are grounded in biomedical models of physiological function and both serve to treat a condition that is culturally defined as abnormal. However, in part because of the economic relations surrounding

the use of Viagra, in part because of the wish by some individuals not to label themselves as impotent by consulting a family doctor, and in part because of the potential for the drugs to achieve 'hyper-normal' sexual performance and to enhance or extend normal sexual function, the relation with medical knowledge diverges from that in the first group. Health identities within this category are located along a continuum from the expert patient to an independent consumer, operating outside medical guidance.

The third group that we reported in this article are in some ways the most remarkable. The pro-ana movement has also drawn upon medical technologies in their application of weight-loss medications, although this is by no means central to their health identity. The relations that forge proana health identities run counter to medical perspectives that consider anorexia as quintessentially unhealthy. In contrast, anorexia is regarded by those in the movement as a 'healthy' response to an underlying malaise that inheres in the social relations with family, friends or wider society. The objective of pro-ana is to sustain an anorectic health identity emotionally and physically while the anorexic addresses these underlying problems in her relations and affects. 'Recovery' in a medicalized sense has no part in the ethos, although they accept the possibility of life after pro-ana, once other problems are resolved. They stand at the extreme end of the continuum of health identities we have outlined, rejecting medical and other conventional models of extreme weight loss, appropriating and subverting technologies intended for the obese to sustain their condition.

These three cases suggest a dimension upon which we might map health identities, from expert patient to resisting consumer. This offers explanatory power to the exercise, enabling an analysis in terms of how identifications emerge in relation to or in opposition to biomedicine. It extends the kinds of modelling of patient identities first conceived by Parsons, Szasz and Hollender and others, suggesting both that health identities can be forged independently of medical conceptions of health, yet also acknowledging the continuing power and significance of biomedicine. This locates health identities in relation to a dimension of autonomy/dependence and such a dimension can serve to map a variety of possible health identities. However, it is quite possible to develop further identity dimensions, for example in relation to ideas of natural or holistic 'health' versus intervention and technology, or in relation to physical well-being versus spiritual integrity. Indeed, there are endless dimensions that could be posited, and any mapping of health identities would need to be within a multidimensional space rather than a single dimension. While identities do in part emerge in relation to dominant cultural systems such as biomedicine, their forging cannot be reduced to such a deterministic analysis.

In the introduction to this article we suggested that in order to grasp the character of health identities, we must study 'health', 'body' and 'identity' together, as emerging from activity and practice, and located within the totality of a body's physical and social relations. Health identities are

features of the clustering of relations around specific aspects of embodiment, such as sport and exercise, body modification, disability or growing old. In this anti-essentialist, Deleuzian interaction, none of these elements of health, identity and body is prior; each is constituted in relation to the others. Potts contrasts biomedicine's model of health as grounded in the stable homeostasis of the body, with this way of thinking, so that

... in opposition to medicine's contention that the organic body functions through the monitoring and regulation of its various systems and processes, Deleuzian bodies come into being in a kind of chaotic network of habitual and non-habitual connections, always in flux, always reassembling in different ways. (Potts, 2004: 19)

Deleuzian scholars suggest that the question 'what can a body do?' is a useful way to explore embodiment and identity (Buchanan, 1997; Fox, 2002; Potts, 2004). The confluence of body/self is processual, constituted from the relations and affects that the material body has with its natural and cultural context. Body/self comes into being only in its relations to physical forces of nature, to cultural and social expectations and constraints, emotional attachments and reflexive understandings. What this body can do depends upon the confluences with these myriad relations. They provide the capabilities and potential but also the limits to what it can do. 'Health' paradoxically is both a characteristic of this emergent body/self, and the conditions or relations that in part define body/self (alongside the many other relations that contribute to identity).

We can apply this understanding to the people we described in this article and their health identities. For the weight-losing body/self, there are confluent relations with medical definitions of normal body shape and the dangers of overweight, and the emergent health identity is the recovering (expert) patient. For the sexually potent, physiology-defying Viagra body/self, relations with medical, pharmaceutical and cultural dispositions upon normal sexual function and behaviour foster a health identity as cyborg lover. For the pro-anorexic slimming body/self, whose relations are pained and oppressive, the health identity is anti-social, anti-medical, resisting (anti-)consumer.

In this analysis, health identities are neither prior, nor are they determined. Rather they emerge from concrete embodiment practices in relation to material, cultural, technological and emotional contexts. We can draw three conclusions.

First, that if there are myriad health identities, then there are as many possible individualized conceptions of 'health' itself. Just as we have noted the 'slimming-body' of a weight loser or anorexic, the 'moving-body' of the athlete or dancer, the 'enhancing-body' of the body-builder or cosmetic surgery enthusiast, the 'diseasing-body' of the chronic sufferer and so forth, we can see all these as 'healthing-bodies'. A health identity is an emergent identification for an individual, but because it is the outcome of the confluence of body/self with its relational contexts, it also structures what

'health' is for that body/self. For example, for the 'weight-watching' body of the slimmer, the health identity emerges from the confluent relations (physical, emotional and symbolic) with food and its ingestion, and with the cultural contexts that associate overweight and obesity as antagonistic to health. Health for our respondent Julie (see earlier) is structured by her relations to her slimming-body, to her desire to live a 'healthy' lifestyle. Health for pro-ana Jenny (see earlier) was about psychological and physiological control and stability.

Kleinman (1980, 1988) used the concept of 'explanatory models' to describe the narrative frameworks used by lay and professional people, western and non-western, modern and pre-modern, to make sense of disease or other abnormal experiences or behaviours. Our analysis suggests we can extend this notion of an explanatory model by recognizing that these narratives contribute to health identities (and thereby to people's conceptions of health itself). However, we see culture as only one component of the relational contexts within which health identities and ideas of health emerge. Alongside these cultural contexts we must also recognize the confluences of physiological capacities and limits of a body, the sum of psychic and emotional lived experiences, the valuations, beliefs and attachments that a person holds, and the reflexive and social expectations of what a specific body can do. Fox (2005) found all these elements affected the health identities of older people: that health was as relational and individualized as the body/selves were.

For social scientists, this means that rather than seeking a single 'master' theorization of health (for example, as an evaluation of capacities in comparison with norms or ideals, as an assessment of fitness, body tone, as emotional well-being or whatever), health must be acknowledged to be a highly contextualized outcome of the lived body/self and its relations with its material and psychosocial environment.³ The second of our conclusions flows directly from this. Health identities (and thus health itself) are legion, constituted from both the biological and the social, the material and the psychic forces that define what a body can do. But these phenomena are amenable to empirical study, as we have shown in this chapter and elsewhere. Simply by asking 'what can a body do?', we can seek the relations and affects that structure health identities and conceptions of health and illness held by a person, whether for reasons of research or in practical or therapeutic settings. There is potential from such maps of identities for understanding much more about 'health' behaviour, 'health' beliefs and patterns of morbidity and health care provision and consumption. Furthermore, this approach firmly establishes embodiment as a key element in the way we understand the social organization of health and illness. It offers a way forward for an empirical sociology of the body: a fertile area for research that has up to now been strong on theory and weak on practical application.

Finally, the research that we were able to conduct with these disparate associations of individuals has contributed further examples of health

identification in the 21st century. Some respondents were pursuing traditional health activities, while others were forging anti-medical identities as consumers of technology and of the body's potential to supply pleasure or control. There is a substantial agenda here for the exploration of health and illness practices, expert patients and body consumers, using the health identity as the starting point for analysis. In an increasingly industrialized, technology-driven, consumer-oriented and media-saturated global health and illness economy, longevity, fitness, body shape and size, youthfulness and so forth will continue to be significant for the emergence of health identities. The body's relations with its physical and psychosocial environment will refract endlessly, producing multiplicity and diversification of bodies, identities and healths.

Notes

- 1. ESRC project L218252057, funded within the Innovative Health Technologies programme.
- 2. Examples of 'thinspiration' may be viewed on websites such as http://looking glasssupport.com/StarvingForPerfection/
- 3. We have not made too much of this here, but it is worth pointing out that this way of thinking about bodies and health overcomes the criticisms of many theories of embodiment as reductionist, either to the biological or the cultural realm. In this analysis, physical, psychic and cultural relations are all constitutive of what a body can do, and thus of its 'health'.

References

- Balsamo, A. (1996). *Technologies of the gendered body*. Durham, NC: Duke University Press.
- Baszanger, I. (1992). Deciphering chronic illness. *Sociology of Health & Illness*, 14, 181–215.
- Berg, K.M., Hurley, D.J., McSherry, J.A. and Strange, N.E. (2002). *Eating disorders: A patient-centered approach*. Abingdon: Radcliffe Medical Press.
- Bessell, T.L., Silagy, C.A., Anderson, J.N., Hiller, J.E. and Sansom, L.N. (2002). Quality of global e-pharmacies: Can we safeguard consumers? *European Journal of Clinical Pharmacology*, 58, 567–72.
- Bruch, H. (1973). *Eating disorders: Obesity, anorexia and the person within*. New York: Basic Books.
- Buchanan, I. (1997). The problem of the body in Deleuze and Guattari, or, what can a body do? *Body & Society*, *3*, 73–91.
- Charmaz, K. (1983). Loss of self: A fundamental form of suffering in the chronically ill. *Sociology of Health & Illness*, 5, 168–95.
- Coulter, A. (2002). The autonomous patient: Ending paternalism in medical care. London: Nuffield Trust.
- Department of Health. (2001). The expert patient: A new approach to chronic disease management for the 21st century. London: Department of Health.
- Fox, N.J. (1999). *Beyond health: Postmodernism and embodiment*. London: Free Association Books.
- Fox, N.J. (2002). Refracting health: Deleuze, Guattari and body/self. health: An

- *Interdisciplinary Journal for the Social Study of Health, Illness and Medicine,* 6(1), 347–64.
- Fox, N.J. (2005). Cultures of ageing in Thailand and Australia (What can an ageing body do?). *Sociology*, *39*(*3*), 501–18.
- Fox, N.J., Ward, K.J. and O'Rourke, A.J. (2005a). The birth of the e-clinic: Continuity or transformation in the governance of pharmaceutical consumption? *Social Science and Medicine*, 61(7), 1474–54.
- Fox, N.J., Ward, K.J. and O'Rourke, A.J. (2005b). 'Expert patients', pharmaceuticals and the medical model of disease: The case of weight loss drugs and the Internet. *Social Science and Medicine*, 60(6), 1299–309.
- Fox, N.J., Ward, K.J. and O'Rourke, A.J. (2005c). Pro-anorexia, pharmaceuticals and the Internet: Resisting the medicalisation of body shape. *Sociology of Health and Illness*, 27(7), 944–71.
- Fox, N.J., Ward, K.J. and O'Rourke, A.J. (2006). A sociology of technology governance for the information age: The case of pharmaceutical consumption. *Sociology*, 40(2): 315–34.
- Gremillion, H. (2003). Feeding anorexia: Gender and power at the treatment centre. Durham, NC: Duke University Press.
- Grogan, S. (1999). Body image. London: Routledge.
- Haraway, D.J. (1991). Simians, cyborgs and women. London: Free Association Books.
- Henwood, F., Wyatts, S., Hart, A. and 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.
- Herzlich, C. and Pierret, J. (1986). Illness: From causes to meaning. In C. Currer and M. Stacey (Eds.), *Concepts of health, illness and healing*. Leamington Spa: Berg.
- Hine, C. (2000). Virtual ethnography. London: Sage.
- 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
- Kleinman, A. (1980). *Patients and healers in the context of culture*. Berkeley, CA: University of California Press.
- Kleinman, A. (1988). The illness narratives. New York: Basic Books.
- Le Breton, D. (2004). Genetic fundamentalism or the cult of the gene. *Body & Society*, 10(4), 1–20.
- 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, 755–6.
- Mann, C. and 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 emailing lists. *He@lth Information on the Internet*, *33*, 3–4.
- Monaghan, L. (2000). Drug taking, 'risk boundaries' and social identity: Bodybuilders talk about ephedrine and nubain. *Sociological Research Online*, 5(2). Accessed at http://www/socresonline.org.uk/5/2/monaghan.html
- Muir Gray, J.A. and Rutter, H. (2002). *The resourceful patient*. Oxford: eRosetta Press.

- Negrin, L. (2002). Cosmetic surgery and the eclipse of identity. *Body & Society*, 8(4), 21–42.
- Nettleton, S. and Watson, J., Eds. (1998). *The body in everyday life*. London: Routledge.
- Petersen, A. (2002). Replicating our bodies, losing our selves: New media portrayals of human cloning in the wake of Dolly. *Body & Society*, 8(4), 71–90.
- Potts, A. (2004). Deleuze on Viagra (Or, what can a Viagra-body do?). *Body & Society*, 10(1), 17–36.
- Shaw, J. and Baker, M. (2004). Expert patient: Dream or nightmare? *British Medical Journal*, 328, 723–4.
- Szasz, T. and Hollender, M. (1956). A contribution to the philosophy of medicine. *Archives of Internal Medicine*, *97*, 585–92.
- Tang, S.Y.S. and 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. and 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), 339–53.
- Thomsen, S.R., Straubaar, J.D. and 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. and Paterson, B.L. (2000). Attitudes toward patient expertise in chronic illness. *International Journal of Nursing Studies*, *37*, 303–11.
- Tuckett, D., Boulton, M., Olson, C. and Williams, A. (1983). Meetings between experts. London: Tavistock.
- Williams, S. and Bendelow, J. (1998). The lived body. London: Routledge.
- 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), 134–42.

Author biographies

NICK FOX is Reader in Sociology of Health and the Body in the School of Health and Related Research at the University of Sheffield. His research interests are in postmodern social theory; health technologies, embodiment and subjectivity; and the social impact of information and communication technologies on health and health care. He directed the Pharmakon project for the ESRC Innovative Health Technologies programme, and has contributed articles to Sociology, Social Science and Medicine and Sociology of Health and Illness. His latest book Beyond health: Postmodernism and embodiment was published by Free Association Books in 1999.

KATIE WARD is a Research Associate in the School of Health and Related Research at the University of Sheffield, where her research work focuses on the emergence of 'e-health' and the 'informed patient', and eating disorders and the body. She has published articles about health in a new media context. Before joining ScHARR she was engaged in research with the EMTEL II network, where her main interest focused on the consumption of media technology in the domestic context. She is currently co-editing a book on the 'domestication' of media technology.