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The Medicalization of Cyberspace

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Routledge
Taylor & Francis Group
LONDON AND NEW YORK



R
119.95
M618

HSS08/20543

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First published 2008 by Routledge
2 Park Square, Milton Park, Abingdon, Oxon OX14 4RN
Simultaneously published in the USA and Canada
by Routledge
270 Madison Avenue, New York, NY 10016
Routledge is an imprint of the Taylor & Francis Group, an informa business
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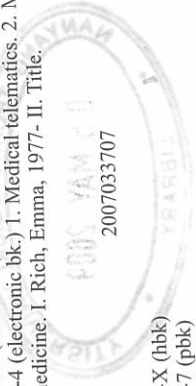
Typeset in Times by
GreenGate Publishing Services, Tonbridge, Kent
Printed and bound in Great Britain by
TJ International, Padstow, Cornwall

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British Library Cataloguing in Publication Data
A catalogue record for this book is available from the British Library
Library of Congress Cataloging in Publication Data
Miah, Andy, 1975-
The medicalization of cyberspace / Andy Miah and Emma Rich.

p. cm.
Includes bibliographical references and index.
ISBN 978-0-415-37622-8 (hardcover) -- ISBN 978-0-415-39364-5 (pbk.) --
ISBN 978-0-203-93113-4 (electronic bk.) 1. Medical telematics. 2. Medical
informatics. 3. Social medicine. I. Rich, Emma, 1977- II. Title.
R119.95.M53 2008
025.0661--dc22
2007033707

ISBN 10: 0-415-37622-X (hbk)
ISBN 10: 0-415-39364-7 (pbk)
ISBN 10: 0-203-93113-0 (ebk)
ISBN 13: 978-0-415-37622-8 (hbk)
ISBN 13: 978-0-415-39364-5 (pbk)
ISBN 13: 978-0-203-93113-4 (ebk)



various institutions (popular media, schools, doctors' surgeries, the fitness industry, etc.). While individuals are not forced to act or behave in certain ways, through a blend of disciplinary measures and control techniques, which constitute bio-power (Foucault 1990), populations are being 'facilitated' to understand 'what is good for them' (see Burrows and Wright 2006). Failure to conform to health advice or self-governance does not result in official or legal sanctions; health is not enforced or achieved through totalizing didactic forms of power. Instead, governmentality is achieved via bio-power invoking a powerful discourse of morality, which may induce feelings of shame, guilt and anxiety (see Lupton 1995; Rich and Evans 2005). This form of neo-liberalism calls upon 'the individual to enter into the process of self-examination, self-care and self-improvement' (Petersen 1996: 48–49). Medicalized cyberspace is an environment where discourses of health promotion concerned with lifestyle, commercialization and 'informational medicine' (Nettleton 2004) come together in ways that can enhance these forms of healthism.

5 Cyberpatients, illness narratives and medicalization

Health information in cyberspace is not only produced by medical authorities or commercial organizations; it is also reconstructed through arenas of lay discourse. In this chapter, we explore how Internet users have 'become significant providers of health information and advice' (Hardey 2001: 388) and how medicalized cyberspace is variously negotiated in this process. As Hardey (2001) observes, the Internet is much more open than traditional media and provides a less regulated space for the production of material. Increasingly, online users are creating websites, email groups, electronic networks, online support groups, and so on (Jadad 1999) to share experiences of health and illness. The collation of this material is part of a wider process of 'informational medicine' whereby patients can become *producers* of health knowledge (Nettleton 2004).

Much has already been written about the potential of cyberspace to enable the sharing of illness narratives and for this to act as a form of self-help (Ferguson 1997), or 'computer-mediated social support' (CMSS) (Burrows *et al.* 2000: 106), particularly in relation to terminal illness. Much less has been written about the relationship between processes of cybermedicalization and online patient use of the Internet in relation to conditions that are new or stigmatized, or where individuals may experience profound illness symptoms and yet have no clinical diagnosis (Nettleton *et al.* 2004). These are particularly rich cases through which to examine the complexities of medicalization, because those who experience such conditions have tended to rally for medical recognition, yet at the same time have tried to make public their very personal, embodied narratives of ill health. Cyberspace has been a significant feature in the formation of networks related to these conditions. We outline how cybermedicalization mediates this process by examining the case of online communities developed by women experiencing persistent sexual arousal syndrome.

Online health communities

It is well documented that people with common problems often use the Internet to enable the formation of virtual communities. Drawing on a range of studies of computer-mediated support groups, Wright and Bell (2003) indicate that many of these support groups might be linked to 'weak tie' network theory.

Drawing on Granovetter (1973), they remind us that 'weak tie' relationships typically take place between individuals who communicate on a daily basis, but are not necessarily close. There are a number of resources included in these cyber-communities, including websites, blogs, email groups/and lists, discussion forums, newsgroups and chat rooms. To this end, the Internet has been utilized as a self-help resource for both sufferers and carers of the ill (Burrows *et al.* 2000; Orgad 2004; Ferguson 1997). Through the ease of accessing patients through digital networks, one can share experiences of ill health in a range of new ways. Many users of these networks believe that their own experiences of ill health are important sources of information that should, therefore, be shared with other sufferers (Pitts 2004: 46). Digital networks have become increasingly pervasive with the advent of Web 2.0, and online support groups and networks have become 'highly attractive to seekers of health advice' (Walstrom 2000: 761). For example, Ziebland *et al.* (2004), in their research on cancer patients' use of the Internet, found that users may garner a great deal of information and find forms of support that might not otherwise be available to them through conventional health care. Yet these spaces are also increasingly being used to find support of a more *emotional* or *personal* nature (see Turner *et al.* 2001) via the sharing of intimate everyday experiences of illness. Online Peer Support for Cancer Survivors, Families and Friends (OncoChat), for example, was developed to offer precisely this form of support:

Welcome to our home on the Web! OncoChat is a real-time global support community for people whose lives have been touched by cancer. We don't offer medical advice or professional counseling. We do offer lots of hugs and understanding from people who share similar experiences and emotions.

(<http://www.oncochat.org/>)

Similarly, DIPEX (www.dipex.org) is a charity patient website that hosts a database of 'personal experiences of illness', where visitors can watch, listen to or read the stories (based on interviews) of individuals experiencing particular forms of ill health. The owners of the site developed this resource in response to the growing need for patients to have access not only to medical advice, but also to embodied, experiential information.

Burrows *et al.* (2000) argue that, collectively, these resources might be considered a global health advice network or virtual community of care. These digital environments have been praised for the 'extensive range of knowledge and depth of caring participants may receive from others facing similar concerns' (Walstrom 2000: 762). Similarly, Wright and Bell (2003: 44) suggest that while real-time face-to-face support groups may provide a context within which people can find others facing similar health issues, 'they rarely have the same specificity or singleness of purpose as online support groups when it comes to discussing a particular health topic'. Online communities are particularly useful for those experiencing rare conditions where patients may be geographically distant from one another, or socially isolated, making real-time support groups

difficult to form. In this way, cyberspace can transcend geographical and temporal constraints (Wright and Bell 2003) that may impact on how people manage and experience ill health. Elsewhere, studies continue to highlight the other positive effects of these contexts in offering social support, reducing loneliness (Fogel *et al.* 2002; Pitts 2004), improving psychological well-being (Rogers and Chen 2005) and providing useful alternatives to face-to-face therapy or support groups (Walstrom 2000).

The role of these virtual communities may also be particularly important in assisting people who have health conditions that are rare, or of a sensitive nature, such as substance abuse problems (Wright 2000), eating disorders (Winzelberg 1997; Walstrom, 2000; Dias, 2003; Treseder 2003), urinary incontinence (see Sandvik 1999), mental health (Powell *et al.* 2003) or persistent sexual arousal syndrome (PSAS). This is because computer-mediated communication offers the possibility to control the level of anonymity experienced, making participation in support groups much easier than face-to-face contact for some individuals. This can help to reduce the embarrassment, shame or 'stigma' associated with particular conditions (Wright 2000). For example, virtual communities associated with mental health have been found to make it 'easier for participants to discuss their problems and setbacks' (Winzelberg 1997: 396).

These spaces can offer additional ways for people to connect and share information of both a practical and a more intimate and personal nature. The capacity to 'promote emotional involvement' (Walstrom 2000: 771) may provide particularly empathetic environments in which to foster connections. A number of studies have highlighted how these relations may develop in online health communities. For example, Macintyre's (2003) research on Internet-based endometriosis support groups found that 'respondents preferred the communication of online health communities to other resources such as books or health professionals since the sharing of personal experience indicative of these forms of health communication could not be found elsewhere'. Similarly, in her research on cancer stories online, Pitts (2004: 47) indicates that values that are generated with breast cancer websites and online networks emphasize 'connectedness and empathy over individual survival'.

Illness narratives

The sharing of these stories of illness via the Internet must be considered in the wider literature on health narratives, which has held a long tradition in the sociology of health (see Bury 2001; Kleinman 1988; Frank 1995; Radley 1999). Within these fields, personal narratives have generally been considered to be the 'means by which the links between body, self and society are articulated' (Bury 2001: 281). Bury (2001) notes that ill health is often considered to be a disruption to one's biography, and 'can often lead to a re-examination of personal, familial and work-related issues ... associated with the onset and unfolding of the condition' (Bury 2001: 271). For many sufferers of chronic illness, disease or ill health, narratives may be used as a strategy to cope with this

'biographical disruption' and 'maintain some sense of worth in the face of intrusive symptoms' (Bury 2001). As Frank (1995) argues, in 'the wounded storyteller' people may find healing as they make sense of their suffering by turning their illness into stories. This is borne out by Yaskowich and Stam (2003: 720), who note the importance of conceptualizing the experience of cancer as requiring 'biographical work' and who 'examine the nature of this work in the context of peer support groups'. They describe the 'process of joining, belonging, and identifying with support groups as an important process within [cancer] patients' ongoing biographical work and encompassing a search for a "separate social space"' (ibid.). Similarly, many women have written autobiographical accounts of their diagnosis and treatment of breast cancer (Broom 2001). Pitts (2004: 52) asserts that the 'technologies of writing and mapping the identity of the body-self, such as those we use on the Internet, help us feel in control'. This is partly because the sharing of one's narrative acts as a 'catalyst for recovery', which can have therapeutic benefits (Walstrom 2000: 766).

However, while there are clear benefits to telling one's story, the ability to construct particular health narratives is subject to a process of cultural politics around health and the body. This politicization impacts significantly upon what stories come to be told in particular contexts. For example, illness narratives in western societies are often mediated by the moral imperative to be 'successfully ill' (Frank 1997: 136) and to 'rise to the occasion' when sick. Indeed, Frank (1995) argues that health narratives in western society are heavily influenced by a 'restitution narrative', where one anticipates getting well again and gives prominence to the technology of cure. Broom (2001) asserts that the restitution narrative can be particularly dangerous to women's health, pressing them to construct 'obligatory success stories' (Broom 2001: 250, cited in Pitts, 2004: 37). As Pitts (2004) notes, the expectations towards a restitution narrative may lead to the silencing of other narratives associated with pain, negative feelings and changes in the body (see also Rich 2006). The significance of this is that many alternative stories of ill health may not be made public because of these moral imperatives and the 'fears and prejudices surrounding cultural conceptions of a health issue' (Wright and Bell 2003: 42).

For example, Pitts (2004: 37) suggests that '[s]ociocultural fears and expectations about femininity, women's sexuality and illness encourage a sense of shame and discrediting about breast cancer, [and] can work to "isolate and silence" (Broom 2001: 250) women about its horrible realities'. Digital environments have provided alternative spaces in which women can construct stories that are not based on a 'restitution narrative', but which focus instead on the disordered, painful and repressed feelings and experiences of illness. The incorporation of the social and emotional in these stories may be particularly important for those illnesses that carry specific cultural meanings, for example losing a breast through cancer (Pitts 2004) or living with endometriosis (Macintyre 2003), in terms not just of physical pain, but also of the cultural meanings of womanhood attached to these experiences. The array of women's voices and stories online reveal the power of what Haraway (1991: 175) refers to as 'feminist cyborg stories'. Many

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of these websites contain a mix of written text along with visual imagery as they document changes in and to their bodies. Importantly, the underlying ideologies embodied by cyberspatial conduits reflect the mediatory nature of cyberspace as it challenges and reframes biomedical constructions of health that may define the body in deeply gendered ways. For example, Batt (1994: 279, cited in Broom 2001) suggests that if many of the stories of the embodied physical experiences of cancer were to be made public, 'we might as a society, move beyond phobia and fantasy to assess what medical research can realistically do and which problems are beyond its scope'.

Cyberspace provides contexts for intriguing and diverse expressions of ill health through new ways of writing text and representing oneself through video and pictures. In some of these virtual narratives and web pages, expertise is no longer medicalized, but derives from experiential knowledge of living with a particular illness. As Hardey (2002: 37) notes, we see a 'blurring in the distinction between the private world of the self manifest in the home page' as it collapses the boundaries between medical expertise and the experiential knowledge of the patient. This brings to the fore the cultural politics of health where medical knowledge 'has "escaped" into the networks of contemporary info-scapes where it can be accessed, assessed and reappropriated' (Nettleton 2004: 674). More intimate, embodied knowledges of the body are no longer necessarily hidden or marginalized by the institutional domains of medicine. In this sense, the 'ill' body can be relocated in cyberspace, and culturally represented in a variety of ways.

Persistent sexual arousal syndrome and the contradictory culture of cybermedicalization

Much of the literature outlined so far has celebrated the capacity for cyberspace to allow patients to develop support networks and construct alternative knowledges of health that challenge biomedical frameworks of meaning. Yet while the Internet offers a less regulated context for the production of alternative narratives, a complex and contradictory process of cybermedicalization tends to infuse online narratives, particularly those that are oriented towards conditions that are stigmatized or undiagnosed. Earlier chapters outlined how the medicalization of many features of social life has become more apparent over the past few decades. Thus, it is hard to find many human experiences that cannot be categorized through medical language. Despite this, there are conditions where individuals may experience profound illness symptoms and yet have no clinical diagnosis (Nettleton *et al.* 2004). The non-regulated nature of the Internet provides a capacity for users to mobilize knowledge of conditions that might be stigmatized or rare, or where treatment or medical understanding of the condition is limited. These include mental illness, AIDS/HIV, chronic fatigue syndrome, attention deficit disorder, Gulf War syndrome, excessive daytime sleepiness (see Kroll-Smith 2003) and persistent sexual arousal syndrome (PSAS). Many of the dissident or marginal discourses constructed by those

experiencing these conditions may be seen to lie outside of medical discourse and can be silenced in mainstream contexts. The Internet has played a significant role in the cultural politics of these conditions, operating as a 'form of media activism, to raise the private troubles of people with health problems as public issues through a revitalisation of the public sphere in contemporary post-industrial societies' (Gillett 2003: 608). However, such mobilization is often infused by a process of cybermedicalization that is neither liberatory nor oppressive.

We develop this argument by drawing on the case of networks and support web-sites for PSAS, which is both a rare and a stigmatized health condition whereby women may experience a form of persistent genital arousal that is unrelated to sexual desire. It is a condition that is often unreported by those experiencing it and provides an interesting illustration of the complexity and ambiguity of personal health narratives online. Many of the women utilizing the Internet for support around this condition have attempted to challenge the way in which PSAS is often stigmatized. One strategy has been to rally for the medicalization of PSAS, so that it may be seen by medical authorities as a legitimate health condition. The role of lay discourse in vying for recognition in this way makes the processes of medicalization increasingly complex. The particular case we examine is a website and support group established by a woman experiencing PSAS who goes under the pseudonym of Jean Lund (see Lund 2002). Having felt isolated and frustrated by the lack of support and acknowledgement of her condition, she set up her own website to chart her experiences, and subsequently took part in a series of media interviews. This website, along with the online support group linked to it, at the time of writing this text was one of the few online resources available to women with PSAS. On her website, Jean describes PSAS in the following way:

There has been a lot of focus the past few years on diminished sex drives. The causes have varied from daily stress and fatigue to the side effects of medication. But there is a new phenomenon affecting women that has never been discussed. In fact the majority of the medical field itself has little, if any knowledge of it. It is called Persistent Sexual Arousal Syndrome (PSAS). The symptoms are the complete opposite of FSD [female sexual dysfunction] in that women are complaining of a constant need for an orgasm.

(Lund 2002)

One of the first significant features of her narrative, is her quest to investigate this condition for herself: 'Feeling as though I were a freak of nature I started my own research on the Internet trying to find information that matched what I was going through' (ibid.). Jean takes active steps in challenging the pathologization of her condition and goes in search of information that will connect with her embodied and experiential construction of PSAS. By searching for information and by looking for that which 'matched with her', she is simultaneously the informed and critical health consumer while also attempting to resist her pathologized subjectivity. Much of her narrative centres on the need to make public the forms of inequality she experienced. Jean's online story details how she felt stigmatized by

the medical community, impacting both on the social construction of PSAS, and also on the way in which she learned to manage it:

My symptoms began in mid 1995; almost a year after untreated Thoracic Outlet Syndrome (TOS), a compressed nerve in my neck began. During that year I suffered with a lot of trigger points in the lower back of my head, the neck and the scapula area. I also had high anxiety and panic attacks from the pain. Four months before I had surgery for the TOS I noticed an increase in my sex drive. It wasn't a big increase at first but within two months it suddenly became out of control. As soon as I reached an orgasm, it was only a matter of minutes before I felt ready for another. No matter how many I had, I still felt the usual way. Alarmed, I made an appointment to see my gynecologist. He ran the same battery of blood work, checking hormone levels and testosterone levels and did a paps exam. All the tests were normal. He snickered and told me I was 'every man's dream.' Angry and disappointed in his reaction I never went back. (ibid.)

Stories like this reveal social inequalities in medical treatment and interactions. These encounters are shaped by cultural discourses of gender, heterosexuality, illness and the body. The explicit sexualizing of the condition as 'every man's dream' not only belittles her condition, but reflects how health problems are sometimes constructed through forms of 'disordered femininity' (Broom 2001: 256).¹ PSAS is constructed in a similar way in the popular press. For example, a recent storyline in the British press on one woman's experiences of PSAS was accompanied by the headlines 'sexy Ellie Allen is a girl who just can't say no – because she's too busy saying yes ... yes ... YES!' (Acton and Spencer 2006: 45). Jean claims she experienced a similar reaction from the media, and utilizes the Internet as a context in which to critique these experiences:

Media from all over the world were clamoring to get an interview and contacted the Globe wanting to get in touch with me. They wanted interviews on how women suffer from PSAS, what it is, how it affects women's lives etc. Although a few other women (who remained anonymous) were quoted in the Boston Globe report, as far as I know, I was the only woman who did further interviews and certainly the only one who had allowed her identity to be known. Did I do it for my 'fifteen minutes of fame?' Hell no! All you have to do is see some of those sensationalized stories and pictures that took hours out of my life for photo shoots and interviews only to be printed with rather embarrassing headlines screaming '**Woman has 800 Orgasms a Day and feels like a Sexual Freak**' to know that I did it only for the attention that PSAS would get. (ibid.)

These are significant narratives that reveal the inequalities women may face not only within the medical encounter, but also in other features of their daily lives. For these and other women, cyberspace can serve as a vehicle through which to make

public the social outcomes of the medical encounter. For many of the women experiencing PSAS, there is a continued stigmatization attached to this condition because of the perceived association between sexual arousal and sexual desire, and the idea that PSAS may be a psychological problem, or a manifestation of being 'oversexed'. On her website, Jean offers an explicit counter narrative to this:

Over the course of the next six years I saw an internist, four more gynecologists, a neurologist, and a urologist, each suggesting I see a psychologist or psychiatrist. ... [T]his is indeed a true medical problem, not a psychological problem. The only psychological problems we face are the ones caused by the frustration of not being able to make it stop, from the drastic changes it makes in our everyday life and from the ridicule we face if we openly discuss it, specifically with men. Even other women quietly turn on us treating us like we are perverts. (ibid.)

In the extract above, Jean rejects the idea that PSAS may be an imagined condition, or one that may be purely 'psychological'. Efforts are made to mobilize alternative explanations of PSAS deriving directly from the *experience* of the patient:

[W]e have not found any help or solution and have a hard time getting doctors to listen to us that it is NOT something we are thinking about but our BODIES need continuous orgasms. (ibid.)

These are significant experiences that 'publicly relate stories about navigating health care' (Pitts 2004: 44) and Jean actively negotiates the meanings associated with PSAS. However, the representation of 'psychological' issues as less important than physical, organic or, in Jean's words, 'medical' explanations, is the means through which a medicalized discourse is reified and constructs a particular subjectivity. Therefore, the presentation of these narratives in cyberspace is an embodied process, as it is 'contingent upon specific health needs' that can 'profoundly impact upon both the emotional and pragmatic aspects of illness experience' (Nettleton *et al.* 2004: 550). Jean uses cyberspace to construct a narrative to explicitly challenge the invisibility of her condition, and reasserts the need for the legitimization of alternative explanations of PSAS that are grounded in the embodied experience of having PSAS:

The one thing we do all have in common is that none of us are thinking sexual thoughts. PSAS is not brought on by the mind. It is an actual physical disorder and all of us would rather never have another orgasm as long as we live, than live like this. Several think it is something neurological in the brain, I being one of them. (ibid.)

This case illustrates what Nettleton and Burrows (2003: 177) identify as a juxtaposing of 'diverse types of discourse', as Jean simultaneously emphasizes the importance of aetiology, of understanding 'causality', and of finding a cure to PSAS:

All I could think of was that maybe now; maybe finally I will get help. Maybe there is a doctor out there that does know what this sexual arousal is caused from and how to treat it. (ibid.)

Pitts' (2004: 44) work on women with breast cancer is particularly useful for making sense of some of these accounts. She argues that some individuals may, ironically, reinvoke a medicalized discourse, making efforts to demonstrate 'mastery over medical language' and 'establish their credibility' for them to be able to define their own meanings and understanding of health and illness. Part of this involves the process of

arming themselves with information as they try to negotiate the world of high-tech medicine, in a process which not only helps them understand and choose the best treatments available to them, but also to demand that doctors share the power over their bodies and health care. (ibid.: 43)

Thus, medical language is paradoxically drawn upon to frame the experience and gain legitimacy, albeit to challenge biomedical constructions of their conditions. As Broom and Woodward (1996: 359) note, in contemporary western society 'many individuals and organizations (including employers and insurers) are unable or unwilling to take a person's own word for the fact that they are "really" ill. Some kind of authority is often required to validate a person's claim to illness'.

Within these accounts of PSAS, one can observe a process of cybermedicalization that is taking place in Jean's construction of the management of PSAS. As Pitts found in her study of breast cancer patients in cyberspace, Jean similarly 'appropriates medical discourse to embody her virtual space, presenting her body through the revelations of a medical lens' (Pitts 2004: 45):

Well it meant they changed the referral from Dr. Jordon to a 'urologist' within their group!! I was pretty pissed off but have been through this all before. In the past I always gave up out of frustration. This time I decided to play their game ... and it wasn't a fun one. I saw their urologist, armed with my print outs on PSAS and Pudendal nerve. He looked at me and asked why I came to see HIM with THAT. I could have been insulted but instead I threw it back in his face. 'Well because I was FORCED to come see you with THIS, that's WHY! I didn't WANT to come see you, I asked to see Dr. Jordon.' He shook his head and sent me away writing a referral to see Dr. Jordon. A week later along came an approved authorization for me to seek mental health!!! (Lund 2002)

The case of this particular PSAS Internet resource demonstrates particularly well that illness narratives are neither wholly liberatory nor oppressive. The construction of online narratives of illness is mediated by various commercial, medical and cultural discourses around health and the body. For example, consider how a restitution narrative (Frank 1997) is drawn upon in a manner that is ambiguous, complex and often contradictory within Jean's account of her experience of PSAS. In some instances, her story explicitly deals with being successfully ill (Frank 1997), of putting on a brave face:

I carried on with my daily routine of holding a full time job, running the support group, and focusing on more media attention. (ibid.)

At the same time, these websites are infused with accounts that emphasize the anger, frustrations and difficulties of experiencing PSAS:

Just one more doctor I had to set straight. I am NOT bipolar. I even researched it on the web. I'm not. I have a perfect right to the emotions I have been going through. Frustration with the HMO system, frustration towards all the doctors and the time I spend repeating myself to each new one, and then I have trouble going on in my personal life that is causing suppressed anger, rage in fact, that really relates to very hurt feelings caused [by] family members.

I felt absolutely helpless. My lifestyle has changed dramatically. Where I was once a very sociable person and loved outdoor activities, I have become a recluse. I only go to work because I have to support myself. Working is very difficult because I am constantly distracted by the urges ... I rarely socialize because I am constantly distracted and in discomfort. (ibid.)

Jean's narrative offers a counter-discourse to the traditional medical discourse, which distinguishes the personal/subjective/patient from the scientific/objective/doctor. She constructs a narrative grounded in a patient's experience, from the point of view of the lived body, expressing what it feels like to experience PSAS. This conflicts with the health professional's approach, based typically on the need for health, disease and illness to be understood theoretically on the basis of signs and symptoms. These stories offer some challenge to the dominance of medical knowledge about these conditions. Conversely, Jean also recognizes the need for her condition to be medicalized in order for her to receive some recognition in the form of support and treatment.

These virtual environments provide a context within which it is possible to rewrite social and cultural meanings of certain health conditions.² Such cultural negotiations not only are significant for the individual patient, but, in cases like PSAS, have a wider implication for the cultural construction of 'highly political aspects of the body, gender and illness' (Pitts 2004: 33). In addressing forms of

inequality, Jean's story of PSAS and other Internet sites on rare or stigmatized conditions may have an 'activist orientation consistent with prior forms of media activism' (Gillett 2003: 619). Networking with others is an important feature of this form of activism:

I started one [discussion board] on Yahoo and moved her posted messages to my board. So in addition to putting my face out front in media print, I took on making a safe place for women to converge to discuss their PSAS. ...

In the mean time a woman with PSAS and I began e-mailing back and forth. She is not part of the support group but had already found Dr. Leiblum on her own and had been very busy doing research. Dr. Leiblum pointed her in my direction and it didn't take long for us to have a wonderful emotional connection. ...

She asked and I agreed to join her in her research as we began comparing notes. I started her treatment of using prescription **5 per cent** Lidocaine ointment for a couple of days, then using prescription liquid Atropine on a patch in the genital area for a couple of days and then a combination of using both together for a week documenting each day's results. (Lund 2002)

This sort of exchange of experiential health knowledge has been documented in online support groups for other conditions. For example, in her research on online endometriosis support groups Macintyre (2003) revealed the significance of online communities to build 'collective knowledge' concerning the management of endometriosis. In particular, she found that having experienced frustrations with the medical profession, women used advice from other members of support groups to 'protect their reproductive health'. Collectively, patient-led Internet resources can therefore bring forth 'the prospect of a renegotiated relationship between medical knowledge and lay experience based on shared learning' (Loader *et al.* 2002: 53). Patient-led Internet resources concerned with conditions such as PSAS can take on an ambivalent and contradictory form, and reveal the complexities of cybermedicalization as experienced by various individuals. On the one hand, they publicize experiences that are intimately connected with the cultural politics of gender, the body and health. Yet, in order to gain legitimacy and recognition for these conditions, increasingly these narratives are medicalized by patients themselves. In the specific case of the PSAS networks, online users experience contradictory subject positions, where there is an emphasis on the experiential aspects of PSAS, alongside the use of demonstrable medical knowledge. The emergence of these ambivalent narratives within cyberspace would appear to reflect Green *et al.*'s (2002: 284) observation that decisions and practices of both lay-women and health professionals reflect a 'complicated mixture of health knowledge and advice and embodied cultural experience'. Therefore, these stories might be considered a reflection of the presence of a 'new medical pluralism' (Cant and Sharma 1999) within cyberspace.

In building on some of the earlier considerations of medicalization work in Chapter 3, one is reminded of the difficulties with making ethical claims about the impact of medicalization on behalf of patients. Indeed, there is some evidence elsewhere that suggests how medicalizing 'a condition can have constructive outcomes, especially for people with chronic and refractory conditions such as chronic fatigue syndrome' (Broom and Woodward 1996: 359). As Conrad and Schneider (1980: 247) observe, 'there are many instances in which people have sought to redefine a condition as an illness in order to reduce the stigma and censure that are attached'. Nevertheless, cyberspace serves as a critical artefact in the renegotiation of cultural meanings associated with these conditions, which have these particularly complex relationships with medicalization. In conclusion to Part I, we draw attention to a series of our main points, which should assist the development of our thesis. First, we have outlined the competing expectations that the Internet will bring about categorical changes for the practice and consumption of medicine and health. The medicalization of cyberspace presents a complex series of narratives that frustrate the attempt to neatly discuss its effect. Second, we have considered how discussions about medicalization themselves have undergone a series of complexities that make it difficult to isolate as a static thesis. Medicalization is characterized as a series of illegitimate and legitimate attempts to shape and fashion health from the perspective of institutions and professions, but it is also a process that is endorsed intentionally or unintentionally by patients and medical tourists.

In Part II, we explore in further detail how the body is inscribed through cybermedicalization processes and how this process should inform the theoretical approach to cybermedicine, considering a number of bioethical issues it presents. We outline a number of cybermedical moments that offer further detail to our medicalization thesis and what this means for a range of literatures that have developed theoretical work on posthumanism, public engagement with science, cyborg theory, legal studies of cybermedicine and the relationship between ethics and cultural studies. Many of these debates are pertinent to what some authors have described as an emerging biomedicalization (Clarke *et al.* 2003), though we stop short of using this term, since our study is located less in biological modifications and more in considering how the digitization of biology is the context for this imminent future of lifestyle medicine.

Part II

Cybermedical bodies