VIRTUALLY BIOSOCIAL: IBD PATIENTHOOD AND COMMUNITY IN CYBERSPACE

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ABSTRACT

This thesis describes how patients with Inflammatory Bowel Disease create moral order through participation in internet support groups. Drawing on computer-mediated ethnography and discursive analysis of interviews with patients, I argue that the discourse of "shared experience" unites this diagnostically heterogeneous group into an idealized community. Patients describe their support practices in ways that suggest they are behaving both empirically and ethically. I then discuss how "awareness," as an ideal property of patienthood, shapes acceptable ways of being ill. My conclusion articulates the dilemmas faced by IBD patients—whose sense of normalcy is limited by their polluting and unpredictable symptoms—with theorizing on "biosociality." I suggest that the moral economy of online interaction, which involves exchanges of "experience," "information," and "support," generates sentiments of similarity and shared interest. This approach differs from much research on patient support groups, which takes patients' shared experiences as *a priori* rather than discursive constructions.

Keywords: Inflammatory bowel disease, social support, patient activism, internet use

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INTRODUCTION

The Internet and the Transformation of Patienthood

The relationship between health care providers and patients has changed in a number of ways over the last few decades. These changes include diagnostic, technological, and therapeutic innovations as well as larger-scale changes to the ways in which state-run and private systems of care allocate resources. The relationship between caregivers and receivers has been narrated in terms of a shift "from paternalistic care (with limited information given to patients) to an ethos of patient autonomy (and disclosure of whatever information the patient can handle) to realization that the complexity of issues, as well as psychological pressures, can make pure patient autonomy untenable or at best an unattainable ideal" (Fischer 2003:166). Anthropologist Annemarie Mol has noted the ways in which this presumed shift in power relations between doctors and patients sets up a dilemma positioning rational choice as an attribute of good patienthood:

> Patient choice is something nobody can be against because... the alternative is framed already there within the idea of 'being oppressed'. So this is a situation where a new ideal comes up and frames its own opposite. The only opposite becomes doubting the ability of people to choose. (Mol 2005)

Chronically ill patients, compelled to seek out information on their disorders in order to better manage illness and daily life, often find themselves struggling to negotiate between a desire for independence and their specific needs, limitations, and concerns. Anthropologists and sociologists of health have outlined some of the ways in which chronic illness is uniquely problematic for patients in the contemporary context. These include the inadequacy of biomedical models to explain persistent, diffuse conditions (Jackson 2000; Greenhalgh 2001); disapproval and punishment levelled at those unable to work (Kaufman 1988; Crawford 1984); and an intense stigma on conditions which affect mental functioning or the sufferer's ability to behave as an "agent of knowledge... autonomous and self-determining" (DiGiacomo 1992:122; also see Estroff 1993).

Examining changes to the British National Health Service, human geographer Hester Parr has described the links between "health consumerism" (Parr 2002; also see Doel and Segrott 2003; Lupton 1999) and an ethos of choice and freedom. Parr observes movement away

> from an emphasis on the state provision of medical care for the collective social body (a traditional institutional geography of doctor's surgeries, clinics, and hospitals), to an emphasis on individual consumerism of medical information, linked to choices and services for the individually healthy (and unhealthy) body (indicating a radically different geography, ranging from holistic health shops to private health clinics to gyms to telephone help lines). (Parr 2002:77)

This new geography of health-seeking is greatly facilitated by new communications technologies. The internet, a relatively unregulated social and commercial space, has become a meeting-ground for chronically ill patients, health care providers across the spectrum of orthodoxy, vendors of novel, alternative, or unconventional therapies, major pharmaceutical interests (for whom the internet presents new opportunities for unregulated, direct-to-consumer advertising [Sismondo 2004]), academic researchers, and other personally or professionally interested parties. More and more people (up to 55% of American adults with internet access, according to Bedell et al. 2004) use the world wide web to access health information. This trend has not gone unnoticed by representatives of the medical and nursing professions, who treat these new health-seeking modalities with a mix of grudging acceptance and mistrust (Bedell et al. 2004; Sandelowski 2002; Cawdron and Issenman 2002; LaCoursiere 2001).

For anthropologists studying the new realms of biological work in the West, modern citizens are increasingly "self-disciplining objects of testing regimes" (Fischer 2003:150), charged with the management of their own health, risk, and care. These new subjectivities are, in turn, productive of new socialities—social groupings and communities of practice—organized around shared apprehensions of health and illness. Anthropologist of science and technology Joseph Dumit (2004:168), drawing on Paul Rabinow's original formulation (1992), has argued for an analytic of biological commonality which recognizes the ways in which subjectivities, as much as social groupings, are reflections of large-scale changes to the organization of social relations. The concept of biosociality, Dumit argues, is a lens through which the illness-based "new social movements" organized on and through internet communications can be linked up to larger institutions, trends, policies, and discourses (Dumit and Sack 1999). Biosociality, as one manifestation of postsocial relations theorized more broadly, depends upon the phenomenon of "a disintegrating 'traditional' social universe....[a form of] sociality which challenge[s] core concepts of human interaction and solidarity, but which none the less constitute[s] forms of binding self and other" (Knorr Cetina 2001:520).

This thesis, based on an ethnographic study of the language and practice of Inflammatory Bowel Disease patienthood in cyberspace, attempts to articulate postsocial and biosocial theorizing with the literature on chronicity through an analysis of the language of ethical patienthood. This introductory chapter will begin with a synopsis of the disease category of Inflammatory Bowel Disease, lay out my research methods, and briefly describe some of the limitations of this study associated with investigating cyberspace anthropologically.

Inflammatory Bowel Disease (IBD) is an umbrella term comprising two distinct chronic inflammatory conditions of the digestive tract: ulcerative colitis, which attacks the anus and colon, and Crohn's disease (also called regional enteritis or ileitis), which can attack anywhere in the digestive tract, from mouth to anus. The etiology is unknown, although according to Loftus (2004:1504), "the leading hypotheses… emphasize genetic predispositions to dysregulation of the gastrointestinal immune system." Putative risk factors include cigarette smoking (for Crohn's disease—nicotine use is considered to provide a measure of protection against ulcerative colitis), high-fat and high-sugar diets, early childhood infections, measles vaccines, and mycobacterium paratuberculosis infection (a bacterium which causes Johne's disease in dairy cattle) (Loftus 2004:1508-1512). Though not hereditary in the classical Mendelian sense, studies indicate that close family members of patients are at increased risk of developing both conditions (Joachim and Hassall 1992). Among the research community, it is generally accepted that IBD is genetically complex and involves multiple causalities (Oostenbrug et al. 2003).

IBD, like many other chronic conditions, is considered a disease of affluence or "civilization" (Wells and Blennerhassett 2005). It is found mostly in wealthy nations, with the highest rates of incidence in the United States, Canada, Northern Europe (especially Scandinavia), the United Kingdom, Israel, South Africa, and Australia, with incidence low but rising in Japan, South Korea, Singapore, Northern India, and Latin

America (Loftus 2004:1506).[1] Onset and diagnosis generally take place in late adolescence and early adulthood, although pediatric IBD incidence is rising (van der Zaag-Loonen et al. 2004).

Symptoms of IBD are diarrhea (often containing blood or mucus due to the ulceration of the intestinal mucosa), sensations of urgency, abdominal spasm, pain, and fever. Weight loss, fissures, fistulae, anemia, skin problems, eye inflammation and arthritis are also associated with IBD, often due to blood loss or malnutrition caused by poor nutrient absorption in the bowel (Canadian Society of Intestinal Research, n.d.). Additional complications may result from the commonly used drug therapies, especially corticosteroids and immunosuppressants. Many patients report a low quality of life and develop depressive illness as a result (Irvine 2004).

Historically, IBD and other digestive disorders have held a prominent place in psychosomatic medicine, and this legacy remains a central concern of both professional and patient discourse on intestinal distress. The psychoanalytic premise is that "[i]ndividuals with characterological difficulty in expressing rage, when threatened by separation from an important object, implode the rage inward and thereby inflame and damage their intestinal lining" (Gerson 2002:381). Gerson's review of the empirical evidence for "a link between psyche and soma in IBD" (381) concludes that such evidence is minimal; however, she notes that "though the empirical literature at present

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[1] As Loftus points out, this is hardly a straightforward fact: "IBD incidence seems low in developing countries (whether this is due to low diagnostic awareness, confusion with infectious causes of diarrhea, or a truly low incidence remains unclear)" (2004:1507). Binder (2004) reminds us that "epidemiological studies have been carried out primarily in the Western world and primarily in those countries in which a public healthcare system is available" (463). Migration studies suggest that ethnic or racial differences in IBD incidence are related to lifestyle and environment rather than true genetic differences (Probert et al. 1992; Carr et al. 1999; Montgomery et al. 1999). Though people of Ashkenazi Jewish origins are considered to be at highest risk, Jews of African and Asian descent who have migrated to Israel are beginning to "catch up" (Oostenbrug et al. 2003), giving an indication of the multicausal nature of these diseases.

offers but minimal support for psychogenic exacerbation of symptomatology, patients with ulcerative colitis *frequently believe* that their psychic states determine their symptom course" (382). The recent growth of the field of neurogastroenterology has reframed traditional notions of the "nervous gut" through investigations into how different forms of stimulation (including perceptive, sensory, and emotional stimulation) can influence gut activity (Malagelada 1994; Crowell 2004; Wood et al. 1999).

The chronic nature of IBD, its lack of a clear etiology, and its association with polluting bodily processes make it an ideal candidate for study by social scientists interested in the interaction between disease course, social life, and illness experience. However, I know of only two studies of IBD patienthood that take an ethnographic approach. Christopher Adamson, a sociologist of health, published an "idiographic" case study of his personal experience of IBD and avascular necrosis (1997). His account underscores the interaction between the "clinical uncertainty" of idiopathic disease—which, at the clinical level, means provisional diagnoses, experimental treatments, and day-to-day "tinkering" (Mol 2005) on the part of medical staff—and the "existential uncertainty" experienced by the patient. In Adamson's case, clinical uncertainty meant that his "social world was defined by the precariousness of disease, but also by constant conjecturing, prolonged testing, and endless theorising about my disease" (Adamson 1997:142). He argues that "existential peace of mind and clinical certainty are complex organizational accomplishments, achieved in the face of the existential chaos that flows from illness and pain and the scientific uncertainty attached to the problem of how to treat disease" (152). His study follows many of the principles of clinical ethnography through its grounding in detailed observer descriptions of medical practice. Moreover, Adamson's highlighting of technique, technology, and taxonomy as structuring components of diagnostic work alerts us to the ways in which illness experience is intimately tied to the socio-technical context in which a disease emerges, is named, and is treated.

Anthropologist Juha Soivio (1999), like Adamson an ulcerative colitis sufferer, engages with Arthur Kleinman's (1988) "Explanatory Model" to describe how biomedical models are integrated into personal experience. He places particular emphasis on the tensions and contradictions involved in the assimilation of biomedical explanations of colitis in the context of folk theories focusing on diet, stress, and "nature cures." Soivio's data comprise 32 in-depth interviews with colitis patients taking part in an antibiotic study in a Finnish hospital. The author initially distinguished between "cultural" explanations of illness (which often link significant life events in the search for etiological coherence) and biomedical explanations. He states that he was surprised by the centrality of biomedical concepts and understandings in patients' accounts, and concludes that the distinction between these two types of models may not be that clear-cut.

Drawing on interpretive and phenomenological perspectives on chronic illness (Good 1994; Bury 1982), Soivio describes patient narratives as "synthetic processes" (100) which are continually reworked as the illness is experienced in time. He sees biomedical techniques and understandings used to render illness tangible and exterior, and states that this exteriority makes it easier for patients to choose radical treatment options such as colectomy. He argues that patients "do not just choose or accept medical knowledge, they engage in its practice" (110), and that new models are integrated when they can help establish pragmatic coping routines.

Both Soivio and Adamson focus on the narratives of *individual* patients, locating the uptake of biomedical knowledge in the individual person's cognition through experiential and narrative "emplotment" (Mattingly 1994). I am not aware of the existence of literature in any field examining how biomedical knowledge about Inflammatory Bowel Disease is interpreted, reshaped, and disputed by collectivities of patients.

Research Questions

How is it that we know that someone we've never met, who might live hundreds or thousands of kilometres away, can understand us? How do we suppose that they might be able to help us comprehend or work through severe pain, physiological dysfunction, and social unhappiness? More to the point, how do we know that they are 'like' us, that they know what we are talking about?

These important questions have gone largely undiscussed within the literature on online patient communities—what has been called "cybersupport" (Sullivan 2003). Within science studies and medical anthropology, however, an analytics of "biosociality" as an institutional technology of likeness has emerged through and around investigations into the social impact of genetics.

Biosociality works, Rabinow argues, by constituting subjects and identities around risk factors: "The target [of biopower] is not a person but a population at risk"

(Rabinow 1992:57). This constitution of identities based on a postulated genetic similarity is already at work in the wider culture. He writes,

> I am not discussing some hypothetical gene for aggression or altruism. Rather there will be groups formed around the chromosome 17, locus 16,256, site 654,376 allele variant with a guanine substitution. These groups will have medical specialists, laboratories, narratives, traditions and a heavy panoply of pastoral keepers to help them experience, share, intervene in, and 'understand' their fate (Rabinow 1992:58).

In this future, people are thrown into a world in which a particular genetic risk factor has already created the basis for a particular mode of sociality governed by particular institutions and institutional protocols, as well as appropriate experiences and codes of interpretation.

Rabinow's concept has been taken up by other anthropologists looking at genetic knowledge. There is, these writers argue, something about genes in particular that facilitates the erection of social networks on biological identity. Interestingly, many of the theorists who have adopted "biosociality" as a concept are feminist medical anthropologists with a commitment to the critical study of reproduction and reproductive technology. These writers have grafted Rabinow's concerns with institutional biopower onto an older anthropological fascination with kinship—the matter of "what makes a relative" (Rapp, Heath and Taussig 2001:384; see also Helmreich 2003). If, as they argue, scientific and popular cultures rely on a "substance model of kinship" (Rapp, Heath, and Taussig 2002:384), then it makes some intuitive sense that people believed to share substance (blood, genes) would understand one another as similar in some fundamental, primordial way. However, patient organizations and affiliation networks run along many different lines. They are not limited to genetic disorders, and indeed often flourish among people suffering from illnesses that are not understood to have a genetic link (Nguyen 2005a, 2005b) or even a known pathophysiology (Karp 1992). Dumit, for one, notes that identity politics are infinitely flexible, and though bodily substance often signifies heavily within these politics, the fundamental unit of biosocial affiliation is a *kind of person*, whether that kind is understood as genetically similar or not (Dumit 2004:162). What matters in a discussion of likeness is an understanding of a) how similarity is produced through social practices and b) why similarity is so important to Western cultural understandings of identity and relationality.

Moving beyond the gene, we can see that other organic substances, bodily states, and technologies of classification can provide the material for patient affiliation. My research engages with the ways in which "biosocial" identification manifests itself in the online talk of people with IBD. I came into this project with the understanding that the new varieties of fictive kin relationships alluded to in the biosociality literature were not dependant on the existence, or even presumption, of a genetic link. At the moment a person is diagnosed with any disease—chronic or acute, hereditary or environmental, psychological, physiological, or biopsychosocial—they have already been produced as similar, as belonging to a kind of person for whom certain symptoms, treatment options, and experiences are considered appropriate. What they do with that knowledge, how it manifests itself in their lives, is the subject of my study. For biosociality to be conceptually relevant to anthropology—as more than a loan-word from cultural studies or a new mutation of biopower—it needs to be effectively linked to social relations through close study of its appearance in and mediation of everyday life. Its position in the literature—as a sort of rhetorical "future-generating device" (Rheinberger 1994) hinting at an otherworldly dissolution of the human—may not be relevant or helpful to many people, like the chronically ill and disabled, whose social lives are, by choice or by compulsion, centred around the management of the biological. Moreover, it may not even be an adequate description of what they're *doing*.

When large collectivities of patients, separated by distance but united through their implication in a particular illness, come together to discuss their conditions, how do they establish one another as similar, and why? What can a close examination of cybersupport, as a modality of language-in-action, tell us about the politics of identification and likeness? How is IBD made collective on a day-to-day basis by sufferers?

In pursuing answers to these questions, I developed several smaller questions that helped me to chart a research course.

- What do people with IBD talk about in cyberspace?
- Who are the significant actors and institutions in social networks relative to IBD?
- How do IBD patients talk about their relationships with these actors and institutions and with each other?
- In cyberspace, how are relationships between people with IBD initiated, cemented, and reflected upon?
- What are the implications of these illness-based "virtual" relationships for our understanding of social relations more generally?

Methodology

Interview Participants – Recruitment and Sampling

In focusing on how IBD is made collective, the research upon which this thesis is based has followed an exploratory route, with open-ended questions and occasionally experimental approaches to navigating online space. Rather than studying a single, more or less bounded online community, I located a number of different patient groups in much the same way as a majority of participants found resources: by using search engines and by following links.[2]

I recruited interview participants for this study from four separate online forums for people with Inflammatory Bowel Disease. Here I will briefly sketch out the characteristics of and differences between these forums.

The majority of my interview subjects (N=29) were recruited from a high-volume bulletin-board style web forum which I call J-pouchweb.[3] This site had over 5000 members in early 2005 and was moderated by volunteers; it also had a registered nurse working in an editorial capacity and an advisory board which included two registered nurses and four MDs. The surgical procedure for which the forum is named (j-pouch surgery, or ileoanal anastomosis) was invented in 1978 and has historically been used to treat ulcerative colitis and colorectal cancer. However, it is increasingly being used as a treatment for Crohn's disease, and some patients who have had this procedure are subsequently diagnosed with Crohn's disease after surgery (Colombel et al. 2003). As

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[2] My sense of the importance of links is borrowed from Heath et al. (1999), who see hypertext links as "vehicles for travel within and between" sites in the social world (451). Hypertext links are paths between realms that describe and consolidate their interrelationship.

[3] In order to ensure a measure of privacy for study participants and moderators, I have attempted to disguise the names of communities while preserving a sense of their unique character and goals.

such, this forum allowed me to connect with a large base of patients pre-, post-, and considering surgery, and at different stages in the surgery itself.[4] Participants from J-pouchweb ranged in age from 18 to 54 (three participants chose not to give their age). One participant was the parent of an adult child with IBD but not a patient herself.

The next largest group of participants (N=12) were members of a web forum called ColitisSucks. Founded by Bruce[5] in 1994, ColitisSucks was framed by those members with whom I spoke as an iconoclastic space (as the name suggests) free of advertising and other forms of commercial influence, and with a strong sense of community. Members of ColitisSucks held large face-to-face meetings (called "Suxfests") regularly in the Eastern United States and Canada—the weekend that I interviewed Bruce, Kristin and Liz, one of these gatherings was being held in Massachusetts. Due perhaps to this emphasis on face-to-face meetings, I was able to interview three people (one couple and one woman whose husband chose not to participate) who had married fellow sufferers whom they had first met through ColitisSucks. Many of the ColitisSucks participants I interviewed were involved in advocacy and fundraising activities related to IBD—the forum architecture incorporated permanent hyperlinks to some of these programs and organizations. Participants from ColitisSucks ranged in age from 20 to 55. One participant was the parent of a sixteen-year-old with IBD.

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[4] Ileoanal anastomosis (j-pouch) surgery is a three-step procedure wherein the colon is removed (leaving a small amount of rectal tissue, called the rectal cuff) and a loop is created from the end portion of the small intestine (ileum). A pouch is created from the loop, and an opening is made where the pouch will attach to the cuff of rectal tissue. The patient is given a temporary ileostomy and wastes are diverted to an appliance (bag) attached at a stoma (an opening in the abdominal wall). Several months later, once the pouch has healed, the ileostomy is reversed and the ileum's ends are connected. The patient is then able to defecate more or less "normally", although complications and infections are common (Scarpa et al. 2004).

[5] All participants are identified by pseudonyms. See Appendix 1 for details on each participant.

A smaller number of interview subjects (N=6) were recruited from a LiveJournal weblogging community called cureibd. All six were in their early twenties and seemed adept at socializing online (as explained below, all six chose to be interviewed through instant messaging rather than email). Because of how LiveJournal communities are set up, I was able to follow the conversations in cureibd in a way that wouldn't have been appropriate with a web forum such as J-pouchweb or ColitisSucks.[6] The data generated through this observation was enormously illuminating, as it made a large volume of patient interaction available in an easy-to-navigate format.

The final 5 participants in this study were recruited from an email listserv called SCDietsupport. This listserv was significantly different in tone from the other forums in that it dealt solely with an alternative diet therapy called the Selective Carbohydrate Diet.[7] Participants presented themselves as challenging medical orthodoxy and volunteered criticisms of both medicine and the IBD advocacy world. Selective Carbohydrate Diet practitioners were closely linked, through their use of mailing lists and other resources, to the popularizer of the diet, Elaine Gottschall. Indeed, just hours after I began recruiting from the listserv, Gottschall made contact with me through email. Participants from SCDietsupport repeatedly mentioned how important Gottschall's

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[6] I also created a research weblog with information about my project and human subjects approval, easily accessible to readers of cureibd. I felt that the networked reciprocity enabled by the interface helped eliminate some of the ethical problems inherent in doing online participant-observation (Cavanagh 1999; Ess et al. 2003; Hall et al. 2004). Cureibd readers could, in a sense, "see" me and easily gain access to my writing and contact information (see Senft 2005).

[7] This regime seeks to heal the gut by reestablishing healthy intestinal flora through the elimination of complex carbohydrates from the diet. The Selective Carbohydrate Diet's developers and popularizers claim that it is effective in treating a wide range of chronic functional, neurological and behavioural disorders, including IBD, celiac disease, cystic fibrosis, diabetes, AIDS, fibromyalgia, schizophrenia and autism. All five SCD practitioners that I spoke to were diagnosed with either Crohn's disease or colitis in addition to any other 'overlapping' disorders (see Appendix).

proximity and collaboration was, and they were effusive in praising her efforts in popularizing the diet.[8]

Geographically, thirty-one interview subjects were located within the United States. Twelve were located in Canada, three in the Netherlands, and one each in Poland, Australia, New Zealand, and the United Kingdom. One participant did not indicate her location.

Interview Data

The types of data used in this research belong to mixed genres of computer-mediated communication (CMC). The interview data itself is mixed, as I gave participants the option of answering my questions by either email or instant messaging. These two different strategies produced considerably different types of text, although the lines of questioning followed similar routes.

I tried to frame the email interviews as opportunities for extended personal narrative. Questions began with phrases like "Please tell me about..." or "What do you think..." and an introductory header on the surveys encouraged people to "answer in as much or as little detail as you'd like." In my email exchanges with people prior to sending them the survey document, I would make a point of reiterating this, and let them know that they could take as much time as they needed to answer the questions. Level of detail varied—some people answered with very few words, while many others spent days or weeks on their responses and provided me with long narrative paragraphs.

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[8] Gottschall was the author of a book entitled *Breaking the Vicious Cycle: Intestinal Health through Diet* (1994), which I was able to find easily in natural foods stores and public libraries in Vancouver. She died in September of 2005.

The surveys themselves were tailored to specific forums. If a participant had seen my recruitment post on J-pouchweb, then I would send them the j-pouch survey, but some questions remained the same across all forums. My sense was that I was trying to elicit talk about patient-patient interactions in cyberspace: how people had discovered IBD patient groups, what, if any, life events precipitated their involvement, and what they thought about these groups' benefits and drawbacks. I encouraged people to tell me about both positive and negative interactions they had witnessed online as well as whether or not they considered "friends" anyone they'd met through the group, and tried to get a picture of their level of offline involvement in patient-centred communities, organizations, and advocacy practices. All participants were asked to describe their diagnosis, level of insurance coverage (in the case of U.S. respondents) and current treatment regime. I also included a follow-up question, "Is it all right if I contact you again later if I have questions about your responses to this survey?"—to which all 50 interview participants answered yes, many appending messages of enthusiasm about my research.

Interview questions were also, to a certain extent, tailored to individual respondents. The usual routine would be that a person, seeing my recruitment post on a patient board, would send me an email offering to volunteer. The content of these initial emails often provided me with interesting leads to personalized questions. Almost all patients said something about their age, specific diagnosis, the length of time since their diagnosis and/or surgery, and level of involvement with the patient community. However, some people would provide other details: that they were the (not ill) parent of a teenager with IBD; that they had married a fellow patient whom they'd originally met online; that they worked as a hospital X-ray tech and felt their experiences helped them act more empathetically towards people coming in for colonoscopies; that they lived outside of North America and had trouble finding resources in their own language; that they were involved in IBD fundraising efforts in New York State; that they were having a hard time and wanted someone to talk to. I would use these details as leads and try to draw out more talk about these (apparently) significant phenomena. A few respondents also used the recruitment email to ask questions of me. Grant said he'd just been recently diagnosed and had found ColitisSucks by chance; he agreed to answer my questions in exchange for links to other patient groups. Another volunteer, who wound up not returning his survey, wanted me to tell him my research goals—to which end I wrote a long explanation that I then incorporated into the exegesis already on my research website.

Email interviews make up the bulk of my data, but instant messaging interviews also played a part, especially in the early stages of my research. I offered participants a choice, but most preferred the email format, as it allowed them to answer questions in their own time and eliminated scheduling and time zone conflicts. Instant messaging is particularly popular with young people, and younger participants seemed more comfortable using it than older ones. One woman in her 30s, Valerie, agreed to do an IM interview but needed her husband to set up the software first. All the other IM interview subjects were between the ages of 18 and 26.

Instant messaging (IM), as a synchronous communications technology, has certain important differences from email surveys. It allows for instantaneous feedback and permits a wide spectrum of emotive and expressive action. IM interviews were more frequently elaborated with CMC-specific linguistic codes, including what has been dubbed "paralanguage"—alphabetic pictograms intended to represent mood states and abbreviations intended to represent expressive action (Lea and Spears 1992). Though IM conversations tended to be more casual than email surveys (being "more 'spoken-like' than 'written-like'" (Yates 2001:97)), with longer conversational asides and backtracking, they also permitted long narrative sections. Noah's account of a recent severe flare ending in hospitalization ran to 72 lines, only occasionally interrupted by exclamations of horror from me. Though it might appear that IM, being more conversational and thus more like a standard ethnographic interview, would provide more natural or interactive data, this is not necessarily the case. Two IM interviews I conducted were decidedly stilted and uncomfortable, and wound up being aborted early due to the participants' reticence. These incidents convinced me that although some people, especially younger people, were very comfortable chatting in detail about their illness, others seemed to feel put on the spot (despite their willingness to participate in the study) and would be more forthcoming if given time and the opportunity to meditate on their answers. Since the patient communities from which I had recruited were asynchronous—that is, they were decidedly "written-like" forums, allowing for meditation, reflection, and revision—I feel that email interviews were of a piece with this modality of interaction. Similar communicative and rhetorical strategies were used in both email and asynchronous forums, strategies which would not necessarily translate easily into either instant messaging or face-to-face interviews.

Observational and Journal/Weblog Data

The interview data in this study are supplemented and contextualized by observation spanning from October 31, 2004 to April 30, 2005. More casual observation and data collection took a variety of forms: finding and compiling links to patient communities and making note of the links between communities; reading (but not participating in) a high-volume, ten-year-old IBD newsgroup; subscribing to (but not participating in) two different mailing lists; and reading pamphlets, drug advertising copy, and popular health and diet books targeted at patients. These practices of reading—a "hyperliterate"[9] involvement in a particular field of discourse concerning illness—mirror in many ways the practices of patients researching facts about their own bodies. As Joseph Dumit points out, "facts do not just pop into our consciousness. Facts have to find us, and we have to incorporate them as facts" (Dumit 2004:158). Keeping an eye on several different online IBD spaces allowed me to chart both the types of facts circulating amongst patients as well as the routes through which those facts seemed to be circulating.

My involvement with cureibd represented a form of participant-observation and as such was more formalized and more carefully indexed than the "casual observation"

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[9] "Hyperliteracy" is a term coined in the early years of the popularization of the internet to describe the use of "HyperText Markup Language (HTML) to communicate collective, associative thought through linking related sites or files" on the web (Fillmore 1995: digital source). Much has been written about how hypertext has changed and is changing writing practices; "hyperliteracy" also stands as a major innovation in how people read. In asking my participants how they originally located particular patient forums, I was able to draw a rough sketch of their internet reading practices in relation to IBD. I was also able to see how different spaces were connected through links and search engine ratings.

described above. As stated in my section on sampling, cureibd was a LiveJournal[10] "community"—members' personal journals ("blogs") were linked to a shared forum through which they could talk about IBD. Reading cureibd regularly, I was able to link up to the journals of Megan, Noah, and Erin and see how their "personal" representations of living with illness differed from their "public" representations in the context of the cureibd community. All posts to cureibd during the observation period were indexed thematically. I initiated couple of strategic "modest interventions" (Heath et al. 1999) in cureibd towards the end of my observation period. These interventions were questions, posed by me to the group, about specific IBD "awareness" phenomena. Members' answers to my questions—and their comments to one another in the context of the discussion thread—are integrated into the discussion of "awareness" in Chapter Three.

Other websites, journals, and testimonials created by my participants became a formal part of my data. Elizabeth and Wilf, a married couple in the Netherlands who had met through the ColitisSucks web forum, gave me access to the hypertext journal Elizabeth had kept during Wilf's many surgeries. Elizabeth described the journal as "a bit of a tear jerker drama" and felt that it would help me better understand how their shared medical histories were interwoven with their relationship. Esther, the moderator of SCDietsupport, provided me with a link to her website, which included a testimonial illness autobiography. Katherine, a member of both J-pouchweb and ColitisSucks, also had an illness testimonial on her professional website. Brandy's personal website

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[10] Social network researcher danah boyd has argued that LiveJournal should not be classed with other blogging interfaces. She writes, "LiveJournal has a particular kind of culture that has formed very distinct from the broader 'blogosphere'... its users have different needs. They typically value communication and identity development over publishing and reaching mass audiences. The culture is a vast array of intimate groups, many of whom want that intimacy preserved. LiveJournal is not a lowbrow version of blogging; it is a practice with different values and needs, focused far more on social solidarity, cultural work and support than the typical blog. It is heavily female, young and resistant" (boyd 2005).

included photos, creative writing, photos of friends, and stories about illness. Some of these illness artefacts are discussed in Chapter Three.

During my research period, I kept fieldnotes on my research weblog, which as stated above was visible only to a small number of people. Regular readers and commentators included three anthropologists (one of whom was a disability studies specialist with an interest in new communication technologies), a conversation analyst working in public health, a pharmacy student with a background in anatomy, and a study participant (Megan) who was also a psychology major. Their critique and collaboration helped enrich my understanding of how different fields of expertise positioned IBD as an object of knowledge—and also provided me with a set of practical groundings on how personal and professional relationships can be built through hypertext.

Data Analysis

This project concerns how particular types of computer-mediated "talk" position speakers as members of collectivities. I chose to integrate methods and concepts from discursive psychology into a larger ethnographic project in order to link local descriptions—produced in the context of interviews, as well as in cybersupport settings and on testimonial web pages and journals—to a broader discursive and social field. This approach has been used by other discourse analysts looking at the public construction of illness. Mary Horton-Salway, in her research on myalgic encephalomyelitis, used as her data set "extracts from interviews with GPs, the illness narratives of M.E. sufferers and carers, 'naturally occurring' discourse from a self-help group setting and from a TV talk show" (Horton-Salway 2001:182). Integrating these different types of talk, Horton-

Salway was able to identify common themes and positions relating to M.E., and to show how those positions were used to manage specific interactions.

At the end of the period of data collection, interviews and other textual sources were stripped of names, URLs, and other identifying markers as stipulated in my Human Subjects approval. These sources were read carefully a number of times, in order to identify recurring themes, patterns, and linkages and to see how my own wordings and position as researcher affected participants' descriptions. With each reading, I made note of the categories and classifications used by participants, paying particular attention to their characterizations of interactions, relationships, and types of people. Talk about illness was also examined in terms of the classifications used (for example, few participants used the term "IBD" but referred to their illness in terms of a specific diagnosis (see Appendix)) and the language with which symptoms were described.

There are those who argue, with Wood and Kroger (2000), that questionnaires and even interview data are not appropriate sources of material for discursive analysis. Questionnaires are seen by some conversation analysts and discursive psychologists as a particularly invidious manifestation of "self-report" practices generating "cartoon data" (Hopper 1999). However, even stereotyped self-representations are patterned in meaningful ways—if analysed reflexively in conjunction with other types of discourse, they can tell us something about how participants construct *idealized understandings of self and other*. When I describe "ethical sentiment" I am referring to these idealized, stereotyped, and patterned discourses about appropriate relationships. These sentiments can tell us something about how participants frame their own (and others') behaviour as morally consistent. These sentiments cannot tell us what people *believe*, *think*, or *feel*—only what they choose to foreground in particular illocutionary contexts.

My analysis of the language of ethical sentiment has thus involved paying close attention to the types of idiomatic formulations used by participants. Idiomatic formulations are utterances which reflect taken-for-granted knowledge about the world: in the case of IBD patients, such utterances might include, "If you can laugh about it, you can live with it!" or "Been there, done that." Idiomatic formulations, Wood and Kroger suggest, are difficult to challenge,

> both because of their generality, that is, their independence of the specific details of the particular situation or person to which they are applied, and because they invoke and constitute the taken-for-granted knowledge shared by all competent members of the culture. Because they are difficult to resist, they are rhetorically effective. (Wood and Kroger 2000:6)

I have seen my task in analysing this data as one of unpacking idiomatic and stereotypical formulations of IBD patienthood in order to link an idealized construct (the ethical IBD patient) to "macro" historical, political-economic, and medical transformations. It is possible—indeed likely—that more in-depth conversations with patients would have produced very different formulations of relationships and experiences. Such is the nature of language: always contextual and always oriented towards action. In representing themselves, and their cybersupport practices, to me, IBD sufferers employed particular types of descriptions. My task is thus to examine how those descriptions foreground entities, position actors, and gesture at moral order.

Limitations of this Research

The people represented in this study belong to a privileged subset of patients—those who are computer- and cyber-literate, can read and write in English,[11] and have access to the necessary technology.

Beyond questions of access and literacy, a major limitation of this research relates to a common dilemma of snowball sampling: the people who expressed willingness to talk to me about their illness may very well be representative of a particularly gregarious, cyber-sociable, and activist variety of IBD patient. Indeed, many of the people with whom I spoke were deeply involved in IBD activism, and presented their participation in my study as an extension of their duties as patient-activists. Fortunately, this sampling dilemma segues well with my interest in the ethics of patienthood and has become an important source of data on the rhetoric of awareness and support.

A significant subset of cyberliterate IBD patients that this study cannot claim to represent are "lurkers"—those who research, read, and take up the information they encounter about their illness online, but who do not participate or otherwise interact with fellow patients. It is likely that there are many more of these silent participants in cyberspace than there are active, vocal ones. However, my position as ethnographer—which often found me in the role of lurker and casual researcher—did permit me to develop some insight on the ethnomethodology of lurking as it relates to knowledge about illness. Contributions from non-patients who read my research weblog augmented this insight. A comment from an anthropologist colleague pointed to the potential of lurking as a knowledge practice:

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[11] I have located IBD cyberspaces in languages other than English—in fact, one of my participants, Kasia, is responsible for the creation and maintenance of a Polish-language ostomy web forum.

> oh—and my best friend, the one with Schrödinger's Crohn's, I talked to him tonight and was talking about your project among other things, and he told me something I didn't realize happened—that at first the doctors wouldn't test him for Crohn's because they were sure it was something else, but because he kept researching it online and reading online Crohn's groups posts he felt sure that it was a strong possibility and insisted on being tested for it, and it turns out he probably has it.

The friend mentioned here typifies the casual internet user—not involved with any particular online community, searching and sampling from the vast field of data available to him on the web, much of it the product of other patients' conversations. This casual information-surfing has, nonetheless, meaningful consequences for his diagnosis and his understanding of his own illness. Because of this study's focus on patients who participate in specific communities, his version of IBD patienthood is not available to me.[12] However, since all writers must be, at some level, also readers, the dividing line between "lurker" and "participant" may be somewhat illusory.

My perspective as ethnographer creates its own dilemmas. As a relatively healthy non-sufferer, I was not able to engage in the reciprocal "troubles telling" (Wilkinson and Kitzinger 2000) that typifies patient-patient interactions in cyberspace. On occasion, interview subjects would indicate embarrassment when they found out I did not have IBD—though more often, they expressed gratitude that I was willing to research an illness that did not affect me personally. On discovering, at the very end of our IM interview, that I was not a sufferer, Noah initially seemed surprised. He then wrote, "it's so embarrassing [talking] but it also helps."

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[12] Discursive studies of online health information, such as Parr 2002, can contribute to an analysis of how the "knowledge ecology" of info-surfing might affect patients' perceptions of their bodies.

Structure of the Thesis

I begin Chapter One by reviewing the literature on patient sociality and support groups, with an emphasis on the epistemological divide separating "applied" and "discursive" approaches to patient talk. I then outline how discursive psychological analyses of patient talk, specifically Joyce Lamerichs and Hedwig te Molder's (2003) conceptualization of "support as an accountable matter," structure my interrogation of the language of affinity in online contexts. Interview data are brought in to illustrate some of the ways "support" is deployed as an ethical construct.

Chapter Two focuses on the role of comparison in generating affect and the ways in which normality works to activate social relations. I argue that the folk empiricism of online patient forums is a testing modality commensurate with João Biehl, Denise Coutinho and Ana Luzia Outerio's framing of the affective power of technology (2001). Patients work up their engagement with physiologically similar others in ways that suggest that they are behaving empirically and rationally. At the same time, they describe the relationships that emerge from these rational-technical practices with affective force. Emotions provide a moral substrate for their interactions and help to ground their relationships (and their illnesses) as objectively real.

Chapter Three explores the materialization of ethical sentiment through a discussion of weblog/journal data and my own "modest interventions" in cureibd and the IBD advocacy world. I describe how participants literalize their online relationships through accounts of friendship, marriage, and gift exchange, and I situate the expressive character of illness testimonials within an analysis of the discourse of "awareness." I then discuss how "awareness," as a desirable property of ethical patienthood, is shaping acceptable ways of being sick. This imperative is problematic for many IBD sufferers because it forces them to negotiate between publicizing their illness for a greater good and maintaining their already fragile sense of privacy.

My concluding arguments attempt to articulate the ethical dilemmas specific to this group of patients—public illness versus private bodies; rational-empirical behaviour versus emotional relationships—with theorizing on biosociality and post-social relations. I suggest that the moral economy of online social relations, which involves exchanges of "experience," "information," and "support," produces the person in specific ways and thus needs to be taken into account in understanding how people construct and deploy their similarity in the management of chronic illness. Finally, I contemplate the different ways similarity can signify in and through "biosocial" relationships, and how these practices of signification link to shifting understandings of the connection between the body and society.

CHAPTER ONE: TALKING ABOUT SUPPORT

Literature Review

The increasing popularity of the internet as a source for health and medical information has generated a multidisciplinary literature on "cybersupport" and illness-based support groups. For my purposes, this literature can be divided into two broad camps: applied health research (much of it in psychology and nursing) which aims to improve health outcomes by assessing the therapeutic efficacy of different forms of social support, and work in the interactionist and discursive traditions focusing on the production of identity and community. Though these two bodies of work share a commitment to understanding the factors which drive patients to seek help in cyberspace, they differ in, among other things, their level of cognitive realism and their understanding of what constitutes "support." In applied health research, social support is frequently presented as a universally desirable buffer mitigating the effects of stress on the course of disease. This view is central to the biopsychosocial perspective currently prominent in some clinical circles (Sewitch et al. 2001). Discursive and interactionist writers, epistemologically agnostic on the therapeutic efficacy of social support, focus instead on self-presentation, moral ordering, and the types of claims and identities that are built through the practice of virtual communication.

Much applied health research proposes that patients seek out support in order to gratify needs arising from the interaction of disease states and social circumstances. Cawdron and Issenman (2002), writing in the field of patient education, describe the use of web-based peer support resources in a Canadian population of pediatric IBD patients. Affirming that cybersupport can be a cost-effective alternative to hospital- or clinic-based support groups, they express concerns that its potential has been unevenly realized. The authors found that while over 95% of their sample used the internet, only a very small number (fewer than 20%) had ever sought peer support or information about IBD on the web. However, around 90% of their sample expressed interest in doing so. In their discussion, the authors attempt to explain the gap between interest and activity by positing that pediatric IBD patients tend to be relatively well-adjusted and may not need support or information.

Social psychologists Davison et al. (2000) hypothesize that affiliative behaviours, including cybersocial networking, will increase when the illness in question involves "psychologically meaningful" (207) risks such as life threat or embarrassment. Canvassing four major US cities (Dallas, Chicago, Los Angeles, and New York), the authors identified over 12,000 "real life" groups. In the hopes of comparing "real" and "virtual" support venues, Davison et al. then polled 37 AOL and newsgroup support forums for a two week period. Prevalence-adjusted indices of support found that online support patterns differed in some ways from metropolitan support patterns, though in general they were substantially correlated. A comprehensive supportiveness index was created, showing the highest level of support for cancers and the lowest for emphysema and ulcers. Their findings, viewed through the lens of social comparison theory, suggest that individuals most often seek support for illnesses which are life threatening, disfiguring or stigmatizing and which have a high affective component. This study explicitly framed "supportiveness" as a function of prevalence (i.e., number of newsgroup postings), and did not address either the content of virtual forums or the reported experiences of patients.

Sheryl LaCoursiere (2001), addressing an audience of nursing theorists, argues that online health-seeking behaviour should not be understood exclusively in terms of needs gratification. The ideal outcome of online social support is “linking”: the reconfiguration of self-in-relation-to-others. Affiliation is cognitive and relational rather than strictly utilitarian, and needs related to disease states (understood as biological or psychological needs) may not necessarily be the primary motivator in health-seeking behaviour.

Claire Sullivan (2003) also argues that the needs met by cybersupport go beyond the management of disease states. She sees online groups as providing an “alternative sense of community” (83) for patients who may have limited access to traditional forms of social support. Reflecting on the fact that the vast majority of people seeking cybersupport are women, the author reviews the literature on gender and cyberspace as well as the gendered nature of support group use, concluding that the overwhelming prevalence of women in support group settings reflects gendered role expectations regarding the appropriateness of emotional expression and group participation. Comparing a large (N>2000) sample of ovarian cancer-related messages and prostate cancer-related messages, Sullivan found that the ovarian group had an “optimistic tone” and provided support in the form of compliments, prayers, and “cyberhugs.” Women established face-to-face relationships, gave advice and comparisons, and reflected on bad experiences with doctors and therapies. They also wrote expressive monologues marked as “rants” or “vents” and encouraged others to do the same. In contrast, the prostate cancer group was notably technical in style, with participants communicating in what Sullivan calls "the voice of medicine" (93); emotional and personal content was rare. Sullivan concludes that gendered styles of communication are notable features of online support groups. She argues that neither "informational" nor "emotional" styles are intrinsically more supportive, and that both modes of communication provide "a feeling of being esteemed, valued and accepted" (100) for participants.

Holly Mathews (2000), a psychological anthropologist, argues that support groups are not simply gendered, but also carry ethnic, cultural, and class markers. In her ethnographic case study of a breast cancer self-help group formed by (mostly) black, rural working-class women in eastern North Carolina, Mathews determines that members were uncomfortable with the cultural beliefs underlying the dominant oncology model of good patienthood—in particular, its emphasis on "survivorship" and "fighting spirit" and promotion of aggressive therapy. This discomfort extended to their refusal to participate in a hospital-based support group, whose membership was mostly white and middle-class and advanced a different ethnomedical model of breast cancer and an ethnically-inflected approach to life and death. Mathews argues that the "support" in the black women's group consisted of the "cultural work" (395) of synthesizing contradictory models of breast cancer through shared personal experience. She emphasizes the role of consensus-building and shared ideology in the formation and maintenance of support groups.

How "support" is conceptualized and investigated in online venues often depends upon the models of communication endorsed by authors. Joyce Lamerichs and Hedwig te Molder (2003a) have outlined the reigning paradigms in studies of computer-mediated communication, describing how their own discursive psychological approach differs. The primary target of their critique is the Social Identity Model of De-Individuation Effects (SIDE) theory, developed in the early 1990s to overcome some of the limitations of the reduced social cues perspective associated with early studies of computer-based interaction.[13] SIDE, they argue, is committed to a cognitivist realism that assumes that norms regulate behaviour. In contrast, Lamerichs and te Molder advance a discursive approach which accounts for the everyday dynamics of interaction expressed as talk. Their own research is based on data pulled from an internet discussion forum on depression aimed at senior citizens. Using participant-defined categories, the authors focus their analysis on talk about competence and incompetence. They argue that norms do not regulate behaviour but are rather used as interpretive resources to make sense of interactions with others. The identities which are presented in "depression talk" display the tensions of moving back and forth between "normative requirement[s] of being a competent member of society and ... display[ing] one's (temporary) lack of competence" (468). They feel their analysis points to a more dynamic view of identity—one which does not take statements as literal representations of inner states but rather as contextualized social actions towards others.

Galegher et al. (1998) take a similar approach to understanding online talk. As rhetoricians employing discourse analysis, the authors do not assume that statements of hardship and suffering—observed in a sample of messages from three online patient support groups—are direct reflections of inner emotions or needs. Rather, they argue that

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[13] Reduced social cues theory argues "that certain inherent features of computer mediated communication, such as a lack of social cues, lead to psychological states that undermine social and normative influences on groups or individuals. The result is deregulated (uninhibited) and extreme behaviour, as well as more polarised, extreme and risky group decisions" (Lamerichs 2002:12). I found it interesting to see the extent to which "social cues thinking" imbued the explanations of participants called upon to account for negative interactions.

the "emotional" content of support group messages needs to be understood as claims on legitimacy and authority, and that these sorts of rhetorical statements are the foundation of what appears as "support" online. Posts which received no responses—which were, as they saw it, excluded from the support community—lacked the legitimating cues provided by statements of personal experience of hardship. Examining challenges to legitimacy and authority, the authors asserted that participants rarely challenged the claims of other participants unless they tried to claim the universal applicability of their personal experience.

Similarly, linguist Ellen Barton's (1999) investigation of a "real life" support group for parents of disabled children has highlighted the use of slogans as legitimating devices. Barton argues that the repetition of slogans and sayings is used to enforce the authority of facilitators and to create parent solidarity. Utterances such as "I've been through the system" (465) are not transparent statements of fact but rather part of a larger discourse of parental authority caught in an adversarial relationship with state education professionals. Barton's work emphasizes that an understanding of the local political context of support groups is essential to grasping the interactional properties of particular sayings. Similarly, Wilkinson and Kitzinger (2000) show how "thinking positive" among cancer patients is a conversational idiom, a moral requirement, and an artefact of popular oncology discourses rather than an authentic reflection of patients' thoughts and behaviours.

Discursive approaches to support group talk explicitly reverse the emphasis, found in much applied health research (e.g. Joachim 1998; Sewitch et al. 2001), on participation as a function of emotional distress and as a strategy of adjustment. Minna

Pietilä (2002), in her study of suicide bereavement support groups, argues that though emotions are not available for research purposes, moral orders are. Drawing on Goffman's work on stigma, Pietilä reports that the bereaved subjects created a "hierarchical moral order of rights and responsibilities" (405) and constructed themselves as owning moral rights over the experience. The bereaved expected others to confirm that they were still essentially normal, good human beings, and sought the approval of others in order to construct themselves as responsible. The author sees the exchange of stories in suicide bereavement support groups as intimately wrapped up in the formation of members' experiences. Pietilä claims that emotional expressions associated with grief are not spontaneous eruptions of inner states but rather moral stagings specific to local contexts. Talking about one's authentic emotions has, in the modern West, "become the most significant way of marking one's unique individuality and the moral adequacy of one's acts" (410). People gain their experiences through the process of generalization that occurs in exchanging stories with others. Emotions, therefore, are always produced through social exchanges and are closely interwoven with moral hierarchies and expectations.

In studies of computer-mediated communication more generally, much research has engaged with the notion of "community" and whether internet communities are "real" (and therefore beneficial) or "virtual" (and potentially harmful) (Lamerichs 2002:9). This raises the question of what types of social networks, formations, or practices are "real," and whether this hierarchy of authenticity does not subsume assumptions about a natural basis of affiliation. Sociologists Nick Fox and Chris Roberts (1999), looking at an email discussion list for general practitioners in the UK, examine claims of community in terms of recent debates in anthropology and sociology about the ground of culture. Fox and Roberts argue that the distinction, commonly made by some sociologists, between "real" and "virtual" communities is untenable in a postmodern world, where even such formerly stable concepts such as "the nation" have been revealed as products of collective imagination. They argue that the motivation for constructing virtual spaces is not merely intellectual or utilitarian but also emotional and irrational (647), and can be used for the ludic challenging of real-world orders.

In this thesis, I adopt Fox and Roberts' critical interrogation of the status of "community" and extend it further, to the concept of "support." Rather than interrogating the reality of community or the efficacy of support in online IBD spaces, I treat these terms as ethnocategorizations employed by users to orient themselves towards others and create moral order. What kinds of interactional and representational work are people doing when they describe themselves as part of a "community"? What is being asked for in a request for "support"? How does talk about social relations order and activate those relations? And what does illness have to do with it?

Within illness-based internet discussion forums, talk about the body and its disorder is often mingled with talk about emotions and about social life. And "support," as I will show below, appears frequently as what Mary Horton-Salway calls "boundary work" (2001:147): practices of upholding classifications, of comparing and contrasting different kinds of person.

"Support": Contributions from Discursive Psychology

Joyce Lamerich's dissertation on the discourse of support in online communities for seniors with depression focuses on the ways in which requests for support are presented in talk as "an accountable matter"—that is, as something that has to be justified. In her analysis, Lamerichs found that

> Rather than straightforwardly asking for it, it seemed that these requests were attended to as potentially sensitive matters. That is to say, when support was requested, it was often oriented to as something to account for. ... I considered this particularly striking since we were dealing with a group that explicitly identifies itself as a support group. Why then was it so troublesome to ask for support in a straightforward fashion? (Lamerichs 2002:62-3)

Lamerichs' approach is drawn from discursive psychology, a branch of conversation analysis examining language as a social practice. This approach, which involves close readings of natural (i.e., generally not generated through interviews or focus groups) data, asks, "how is self and other constructed on a moment-to-moment basis?" (Wetherell 2003:108). Discursive psychology is strategically agnostic on the status of claims about emotions, inner states, motives, and outcomes: it views statements of such not as *representations* but rather as *avowals* towards which speakers orient action. Jonathan Potter, one of the founders of this style of language analysis, describes discursive psychology as taking "a radically *emic* view of objects (whether they be motives, gravity waves, social classes or whatever). That is, those things are understood in relation to their involvement in participants' practices" (Potter 2003:788).

A discursive psychological approach does not ask whether patient communities are effectively supportive (in other words, whether they help people adjust to difficult social, psychological, or physical circumstances) but focuses instead on how talk *about* support is attended to by participants. Lamerichs notes that, in her own study, talk about support was closely linked to emotion discourses and mental state avowals (2002:111). Seniors' requests for support were accounted to through avowals concerning the authenticity of the emotional drive behind support needs. Moreover, these authentic emotional drives were worked up as deeply moral and normative:

> [T]alking about your feelings is attended to as something you (must!) do for others, rather than for yourself. By presenting talking about your down feelings as a moral obligation, Betty not only creates space for Naomi to talk about what she feels, but also for herself, by putting forward a normative order in which it is required. (Lamerichs and te Molder 2003b:297)

As "an accountable matter," support is mutually constructed by participants as necessary both for the individual and for the health of the group as a whole. This moral ordering of support as collective informs my interpretation of IBD sufferers' descriptions of their reasons for participating in online patient communities. I will here describe how the moral ordering of support as collective relies on an accounting to bodily and emotional states, highlighting the links between the two and working up the suggestion that ethical patients take responsibility for the well-being of (frequently anonymous) others.

Negativity – An Accountable Matter

All users of ColitisSucks see the following message, in bold, red, capital letters, before they click the button marked "Post My Message": **"THINK BEFORE YOU CLICK THE BUTTON. IS THE MESSAGE YOU ARE ABOUT TO POST SUPPORTIVE? THERE IS NO GOOD REASON FOR POSTING IT IF IT IS NOT."**

In this context, supportiveness is presented as an ethical imperative: a way of behaving towards others, requiring an accounting for one's actions. This warning message, and the ethical reasoning behind it, has a history which I was able to partially reconstruct from my conversations with ColitisSucks users and the bulletin board's creator/moderator, Bruce. In their representations of how "support" ought to manifest itself, how people with IBD ought to relate to one another, and how certain types of conversational practice are unaccountable, these participants draw attention to a set of values which suggest that patients' interests—psychological, biological, and political—are intimately linked to the way people talk. This resonated with something I had observed in other online IBD spaces: that people in "support communities" will "be supportive" is seldom taken for granted. The need for supportiveness is, rather, an overarching value that is constantly declared, reiterated, and policed.

In focusing, at the outset of my thesis, on accounts of negative interactions, I do not wish to give the impression that such interactions were a typical feature of interview subjects' accounts. The majority of IBD patients I interviewed disavowed having experienced "negativity" in support communities (questions about negativity were a standard feature of my interviews) and almost all—even those who had witnessed conflict—expressed enthusiasm about the value of these "positive" or "supportive" environments. However, the rare accounts of conflict that I received can help generate valuable insights about how an ethic of support is constructed in patient talk. "Negativity" is one of the things that the ethic of support is intended to counter.

Bruce founded ColitisSucks in 1994, after a period of involvement in a large, high-volume Crohn's and colitis newsgroup. The web board was "immediately popular" and attracted a large number of users, some of whom were still active at the time of our interview in January 2005. Bruce had been diagnosed with Crohn's disease in 1969 and had a resection in 1978; since that surgery, he told me, he was "pretty much in remission" and therefore "didn't feel any need for a [face-to-face] support group." He stated that many other long-time users are no longer seriously ill, but "seem to hang around for the social aspects of the forum, although many of them still are dealing with the variety of problems related to IBD."

When asked about the problems he faced as a moderator, Bruce provided a long and detailed explanation of how "interpersonal squabbles" and "troublemakers" had threatened the cohesiveness of the community. He wrote,

> These fights would blow up and then die down, and blow up again, sometimes simmering for a year or more between flare-ups. And then someone would say something that someone else would take offence at and the whole thing would ignite again. Sometimes with the same old parties involved, and often with new folks sucked into it as well. For one reason or another, these troublemakers have seen fit to leave us alone for the most part for a while now, although it's evident to me that a couple of them log in occasionally.
>
> From the outset, I made every effort to make clear to everyone that I was not going to be sucked into the role of referee in any sort of fighting that occurred. It seems that people want someone to be "Dad," or "Judge," or "God" or whatever, and to enforce the rules. More importantly, they want someone to punish whoever they think is persecuting them. I refused to do this, and a lot of people, particularly the troublemakers, didn't like this.

While refusing to play "'Dad' or 'Judge' or 'God'," Bruce nonetheless altered the architecture of the forum, placing messages about desirable, normative, and inappropriate forms of interaction at various places around the website. On one page, users see a message that explains that ColitisSucks members have "No particular axes to grind, beyond the idea that suffering shared is suffering lessened." Another statement warns that the site is a place where users "share our common burdens and thereby lighten our own.

We do this in a variety of ways, including but not restricted to what may seem a bizarre sense of humor to the uninitiated.... If you are easily offended by 'bathroom humor' then perhaps this is not the place for you."

Other long-time users of the forum described how unsupportive talk was dealt with by Bruce and the rest of the group. Nancy wrote that ColitisSucks had been shut down for a while because of arguments. She explained:

> You have a large number of people here who are suffering in their daily lives, putting them on emotional edge (not to mention drugs like pain killers and prednisone that can greatly affect someone's mood/thinking.) And because you can't see the one you are 'hurting', that makes people freer with their comments than they would be in 'real life'. There have been situations with people making up new screen names in order to snipe at people too. Unfortunately, there's no way to stop that. Normally things eventually die down after everyone has had their say. But I can think of one case where someone had to be denied access to Sux by IP Address (because there's nothing to stop people from choosing a new name if their old one is deleted.) And as I said, Bruce did shut down Sux totally once. That was very painful to a lot of people (besides Bruce), particularly those in need that had nothing to do with the problem. And several of those involved in that argument ended up leaving Sux and opening their own site.

The lead troublemaker in this incident was never named, but Jason mentioned him as well, saying "he and his group went off to establish their own board (where, apparently, they ended up fighting with each other)."

Notable in the accounts of negativity that I collected from ColitisSucks users were avowals of determination to ignore unfriendly or argumentative posters. Bree said that she had witnessed fights and felt that "[t]hey are handled very positively. It is an open community and extremely supportive. Negative comments/arguments will not be tolerated and are dealt with in an understanding and comprehensive manner." Liz, on the other hand, indicated that while she knew that these sorts of things happened, her usual reaction was to "run and hide. This place has been such a source of friendship and solace for me that at the first hint of negativity, I sign off for a while and stay away." Veronica estimated that "some folks online just want to cause trouble. Have had people create identities, come to ColitisSucks and try to sell their religion, politics, etc. to the members.... Generally after 1 or 2 postings, they are booted off. If a new identity is created, and remarks continue, members generally ignore them." Pita said that she had "witnessed the odd flame war, though not often. The site administrators when they become aware of such activities remind people that the environment is supposed to be supportive (ever more forcefully, including removing posts occasionally)." Elizabeth suggested that ignoring troublemakers was a shared ethic—"Most of the old-timers on Sux subscribe to the mantra: ignore, ignore, ignore"—and Leah, a member since the beginning, attributed a recent decline in negativity to the hard-line tactic endorsed by the group.

Why is negativity such a serious charge? "Flaming" and "trolling" are familiar practices in online spaces of all types—critical scholars of cyberspace often have to stretch to imagine the internet without them (Gurak 2001). In the case of IBD communities, however, it is often suggested that negativity increases levels of stress on individual participants, discouraging healing.[14]

Stress, Etiology, and Inter-patient Ethics

Dan was, chronologically, my first interview subject. A 24-year-old computer programmer from Australia with ulcerative colitis, he was a member of the cureibd community. Our first IM chat focused on his diagnosis (ten years previously), drug intake

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[14] Similar sentiments, articulated differently, are common in recovery communities focused on, for example, child sexual abuse or eating disorders. Users self-police for "triggering" images and words and employ a variety of hypertextual practices to shield others from the potentially regressive effects of being exposed to them.

and side effects, and the differences between online illness communities and computing communities. When I asked how he would account for these differences, he mused, "I think the people within are more humbled, or perhaps it's the bond of a common ailment. We're not competing to be the sickest." He affirmed that cureibd was "indeed a very supportive environment" and could only remember one argument—"but everyone was essentially friendly about it."

About a week later, Dan sent me an instant message. Briefly mentioning that he had just been diagnosed with a hiatus hernia, he initiated the following exchange:

> dan: I was wondering if you'd seen the cureibd community lately?
> barbara: yeah... i read it about once a week
> dan: Did you see the post I did a few a days ago?
> barbara: yeah! trying to remember what it was but i did see it...
> barbara: oh i remember
> dan: It was about the term "GI"
> barbara: the GI thing! yeah i noticed that
> barbara: there was an actual argument!
> dan: Yes!

We discussed the incident: Dan had posed a question, at the beginning of a post about a recent colonoscopy and some new changes to his diet, about the use of the abbreviation "GI" to mean Gastroenterologist. Another user had taken issue with his question and a long thread of nitpicking and argument ensued. Dan eventually got the last word, but in his conversation with me he expressed amused exasperation at how the discussion had unfolded.

> dan: Well yeah, here I am using actual facts to support my standpoint, and he's just throwing around his theories and opinions... people who do that just shit me
> barbara: it seems like a weird place to start a fight
> dan: I agree. One person made the comment that the fighting is counter-productive and we could all use less stress... Which I TOTALLY agree with, but I wasn't about to sit back and let this guy tell me I'm wrong when I know I'm right.

Here, the third party's interposition of a claim about a collective responsibility to decrease stress is acknowledged and affirmed, in spite of the fact that Dan chose not to attend to this ethical imperative.

Allan Young has argued that the discourse of stress "make[s] use of analogy and ellipsis in order to link together what would otherwise seem to be disparate sets of events" (1980:133). Young's analysis, based on a review of early stress researchers' accounts of physiological mechanisms, focuses on how this research "reproduce[s] beliefs about man's social nature" (135). His argument is too dense to be fully summarized here, but for my purposes, a few crucial points can be drawn out. Among the beliefs subsumed into stress research are, firstly, that the individual is the fundamental unit of society with fixed dispositions and needs; secondly, that participation in social life is voluntary and utilitarian, explicable in terms of individual dispositions and needs. "Stress" emerges as a "patterned mystification of [patients'] life situations" which produces "conventional knowledge of a wholly decomposable society" (142) wherein all life events are equally capable of producing stress and social analysis stops at the individual. Elsewhere, Young compares "stress" with concepts such as "'coping mechanisms,' 'life styles,' and 'socioeconomic status,' which, having been raised out of the culture of the middle classes into the halls of science by empiricist sociology and social psychology, desocialize sickness" (Young 1982:260).

"Stress" emerges in the talk of IBD patients as simultaneously elliptical and accountable: as shorthand for a variety of unpleasant (often interpersonal) life events; and as an accountable uncertainty linked to emotion or personality discourse. By linking "support" and "stress" together, a string of moral imperatives are activated. Rather than desocializing illness, stress resocializes it by inciting reflection on types and relationships.

I asked all my interview subjects to describe what they thought caused their IBD. From the very beginning, I was surprised by the differences in level of detail and commitment people brought to answering these questions, from a curt "don't know" to a page and a half of scientifically-inflected musings. Some patients implicated stress in their illness' etiology, often as a "triggering" life event that potentiated a prior disposition (genetic and/or personality-based). Patricia's response is fairly typical of this sort of explanation:

> I think that there is an element of "fluke" involved and I also think that my personality played a part. I am a worrier and very high strung and this coupled with my stress level I think led to my getting UC. I have yet to meet anyone who has UC that is not a high strung person or someone with a "type A" personality.

Tanith, another self-described Type A personality, wrote:

> I believe that it is genetic but is aggravated by stress, poor eating habits, etc. I have a high stress job with this year being a particularly hard year for my company. I am in upper management with a company that announced it was in CCAA [bankrupt] this last Jan. ... Someone on J-pouchweb recently said that it seems that a lot of j-pouchers were type A personalities. I think that may be true. Type A personalities feel like they have to be in charge all the time and weakness embarrasses them.

Candace used "stress" to modify an expression of uncertainty: "No Idea, perhaps stress." Valerie mentioned stress *and* genetics, but seemed not to settle on either one, settling for a 'fluke' explanation not unlike Patricia's:

> People think it is stress, I'm also Jewish, and I've heard IBD is prevalent among Jewish people. I was/am under stress, but who isn't, I think it is like cancer or any other disease... I just got it.

Stress doesn't stand alone in these accounts; rather, it helps to compose an explanation by connecting personality traits, genetic predispositions expressed as risk, or life circumstances to the development of disease. However, it is also elliptical in the sense of compressing a complex set of causal and predisposing factors, and in signalling the presence of uncertainty—a rhetorical shrug.

A couple of participants framed stress—or, to be more specific, Post Traumatic Stress Disorder—as potentially a trigger *and* an outcome of their illness career. Veronica answered that she thought that her illness was caused by a "TRAUMATIC & chaotic childhood paired with genetics" and mentioned elsewhere that her mother had "multiple mental problems including hypochondria." Wynne explained that she thought that PTSD was underdiagnosed among people who had had j-pouch surgery:

> I know I probably suffer from it...I think because of the medical trauma. I also have felt like my body was not my own...I have read this is a common occurrence amongst people with disabilities.

Some participants emphasized the difference between triggers and causes in their accounts. Wilf wrote, "Stress *triggered* my disease, but I don't know what *caused* it" (italics in original). Others denied that a cause existed: "I understand that it is hereditary and there is no real cause" (Mike); "I do not know what caused my IBD – there is not a known cause" (Pita). These statements suggest an appeal to the state of scientific knowledge about IBD; they work up the "out-there-ness" of causes through the use of impersonal externalizing devices (Potter 1996:150). Here, the uncertainty of the speaker (expressed through clauses such as 'I understand' and 'I don't know') becomes a virtuous deferral to medical fact.

In these different narrations of causality, kinds of person are being accounted to. Often, these kinds of persons are rhetorical membership categories ("type A personalities"; "people with disabilities"; "j-pouchers") to which the speaker claims affiliation or similarity. Stress helps to sediment typologies by providing a ground for similarity rooted in personality as a form of biologically-based experience. This can be viewed as an example of what Joseph Dumit calls "objective self-fashioning": "an ongoing process of social accounting to oneself and others in particular situations in which received-facts function as particularly powerful resources because they bear the objective authority of science" (Dumit 2004:162). Stress, in its role as causal ellipsis, rhetorically brings people together.

Therapeutic Politics

Patient conversations in IBD spaces delineate a set of interlaced therapeutic politics. As there is very little literature on these politics and how they influence patients' avowals about needs and desires—as well as their narratives of hope and understanding—I have attempted to reconstruct them from my observations in IBD cyberspaces, from patients' "personal" writings in weblogs, and from interview data. Here I will give a brief overview of the technological interventions and therapies most talked-about among the patients I observed.

Stoma Surgery and Ostomies

For many patients, removal of the colon or ileum and permanent resort to a stoma for elimination represents the utmost limit of their imaginings. Life with an ostomy is often described in terms that make equivalences with death, as, for example, Noah did when he suggested “if it wasn’t for Dr. Tenner, and my family experience, i’d have a colostomy bag or be dead now.” Patients with successful j-pouches—where the stoma represents a temporary bodily event in the narrative past—often describe their time with the ileostomy as lonely or alienating. They report, as Brandy did, a visceral, abject embarrassment that closed them off from other people:

> brandy: well, when i had the ostomy bag for a semester.. that was rough
> barbara: yeah
> brandy: it was really embarrassing
> brandy: and i didn’t tell any of my friends because i thought they would think it was gross
> barbara: did you know any other people who had [ostomy] appliances?
> brandy: no, i was in denial i think
> brandy: i kept a lot to myself

Tropes of trauma and repression imbue some patients’ accounts of the emotional sequelae of past stomas. Erin, whose transition to a j-pouch was successful, wrote a story in her personal weblog about going to an oral surgeon for wisdom teeth extraction, and finding herself crying during the consultation.

> It should have been no big deal, really. Pop in and see the surgeon for an update, things are going well blah blah, goodbye. How was I to know that seeing the surgeon would cause me to burst into tears? But there I was, in his office, crying like a baby. And you all thought I was strong.
>
> As it turns out, even though I got rid of the stoma, I still have baggage.... I don’t even think about it all that much. I know it’s there, barely suppressed by the movies and books that fill my spare time—but I never think about it or dwell on it. It’s just there, waiting to be useful or dealt with—or both. And I’m not ready to do either.

Though many patients considering future or past stomas reflected on the “boundary breach” (Manderson 2005) with disgust or embarrassment, those with permanent proctocolectomies or ileostomies often defended of the procedure and the opportunities it gave them for renewed independence and control. One member of cureibd, who had a permanent proctocolectomy, aggressively questioned users who made equivalences of the type made by Noah above, and on one occasion moved the conversation to an ostomy community that he ran. It appeared that he did this in order to "vent" his frustration in a more "supportive" environment populated by physiologically similar others. His movements between communities, and conversations in each, highlighted and explicitly challenged the way in which ostomies were described as a "last resort" by people who had, as yet, not been required to resort to them.

Lenore Manderson has written eloquently about the tension that exists for people who,

> on an everyday basis, have to deal with their bodies as objects, caring for the stoma, preventing lesions and infections, changing bags and so on. The tension is both to establish a routine such that the stoma does not intrude in everyday life, and despite the artificial management of faeces and/or urine, to establish an illusion of normalcy. Individuals' sense of themselves, and others' perceptions of them, are informed by presumptions of a link between the physical body and the self, and managing a stoma impacts on self-image and sexual/social relationships. Individuals need to separate self from substance—the subject (the ''real'' self) from the object (body-with-stoma). The challenge for many is to establish, or re-establish, a sense of identity unrelated to the body, so that they are recognised for ''themselves,'' despite and apart from the barrier to this that their non-conforming body might present. (Manderson 2005:406)

"Ostomates" and "baggies"—as people with ostomies sometimes call themselves—have a slang vocabulary and set of somatic description practices which are broadly shared. They name their stomas (often with diminutive or infantilizing names), iconically represent them with graphics (in online forums that use graphic avatars or other visual images), point out their resemblances, and assign them gender. These turns toward personification can be read as attempts to separate the subject from the object and to manage the disgust that caring for the stoma evokes in others. Referring to the stoma as though it were a dependent child or cartoon character also eases the difficulties of talking about elimination and stoma care with unaffected family members, friends, and coworkers. In the places where stomas are collectively personified—for example, on ostomy web sites—there is also a sense in which ascribing personhood, moral qualities and agency to the apertures does part of the political work of defending radical surgery. "He saved my life," people will say, referring to their stoma. In saying things of this nature, patients challenge the construction of stoma surgery—by other patients and by non-sufferers—as a fate worse than death and a sign of surrender.

Ileoanal Anastomosis

Concomitant with the politics of stoma surgery are the specific politics surrounding ileoanal anastamosis (j-pouch) surgery, a relatively novel procedure that is desperately desired by many of those with ileostomies because of its promise of reestablishing a more or less "normal" physiology of elimination and improving quality of life for patients with severe ulcerative colitis (Scarpa et al. 2004). However, the procedure is also controversial and has a high rate of complications. Many of my interview participants described having to "work hard" to get their doctors to perform the procedure, often by doing their own research online or switching physicians. (Kasia's story about navigating the Polish healthcare system and her report of how the procedure inspired regional factionalization among practitioners is discussed in Chapter Two.) Patient representation seems to be a strong factor in the procedure's spread—both through advocacy efforts and through participation in needs-assessment and quality of life research.

I was struck, in my attempts to locate participants through postings on patient websites, by the immediacy, number, and enthusiasm of volunteers from the J-pouchweb site. Despite the site's very large membership, I don't believe this pattern is merely a reflection of proportion. (After all, the number of active members at any given time is significantly smaller than the total number of registered users.) Their participation was often framed as a part of the political work of showing, in Geoffrey's terms, "the side of the successful pouchie" and to demonstrate the procedure's value.

In discussions with members of J-pouchweb, negative language was framed as sufficient grounds for being banned. Participants tied the policing of negative speech to an imperative to "represent" the procedure in appropriate ways. Kim told a story about a disgruntled, post-op member who tried to dissuade people considering the surgery.

> kim: Ive only experienced one big fight... the person ended up being banned from the site because she was telling everyone who came on not to have the surgery and was just being generally mean
> barbara: had she had problems with her surgery or something?
> kim: yeah she had some complications and ended up with an ileostomy, which she didnt like... she took great lengths to get information about other people on the site (emaill addresses, phone #s, etc) to tell them that the jpouch is a terrible thing... which its not.

Though this user's etiquette would have been considered poor in most other online forums, illness-related or otherwise, it is significant that her behaviour is oriented towards discouraging other patients from pursuing a j-pouch.

Prednisone and other Drugs

Prednisone is a corticosteroid used to reduce inflammation and to repress immune response. It is one of the drugs most commonly prescribed for treatment of IBD. Observing online patient conversations I was stunned by how sufferers talked about this drug—its effects were described in tones of horror. The most unpleasant, and most discussed, of these were its emotional and neurological effects (anxiety, depression, feeling "like someone else," and, rarely, steroid psychosis), unwanted weight gain (especially changes to the shape of the face), and osteoporosis. Web forums exist that have "bitching about pred" as their entire raison d'etre.[15]

Discussions about drugs and their side effects appear to comprise the bulk of the conversation on many IBD online forums. Of the over 400 messages I indexed from cureibd, about 150 were direct queries about drugs—more than any other topic. Some participants emphasized the power of comparison in helping them justify their decisions about drug therapy. As Nancy said, referring to the positive aspects of her involvement in ColitisSucks, "It has strengthened my resolve to avoid pred at all costs." Others found that the ability to compare their side effects with others made enduring them more tolerable, and cherished the opportunity to "vent" the negativity that the drugs inspired. Being able to cite the neurological effects of the drugs in explaining negative talk was one of the ways in which patients were able to manage their negative feelings in a context otherwise characterized by an ethic of "positive thinking" and "being supportive."

Remicade (infliximab) is a relatively novel immunological treatment for IBD that operates by impairing the production of tumor necrosis factor-alpha (TNFa) (van Hogezand and Verspaget 1998; Serrano et al. 2001). Some patients I spoke to narrated it as a "miracle drug" or "life saver," especially in relation to previous experiences with prednisone.

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[15] One of these, which I followed for several months, was called Death to Pred. Its participants included IBD sufferers as well as people with other autoimmune and inflammatory diseases—for example, asthma, rheumatoid arthritis, lupus, diabetes, and Guillain-Barré syndrome. More anecdotally, Google searches for the terms "prednisone + mirror" produce a fascinating array of testimonials across disease categories.

Other drugs appeared in patient conversations and in interviews, almost always in the context of queries or "rants" about side effects (Sullivan 2003). However, it was clear that drugs were sometimes the locus of patient sociality because of the way in which quests for information on particular pharmaceuticals tended to end in "communities" of one kind or another. Megan, for example, described her path from diagnosis to internet involvement:

> barbara: so once you were diagnosed where did you get most of your info about UC from?
> megan: asacol comes with a really useful info package
> megan: then i went to the internet
> barbara: oh like a pamphlet[?]
> barbara: i noticed you link to the asacol site from your userinfo page
> megan: and then ... i came accross the cureibd and [another] community
> megan: yes
> megan: i do because i think they have a very useful site

Search engine queries for drug information tend to bring up commercial and "medical information" sites, most of which repeat the same information. Many patients argue that they prefer "communities" because the information found therein is "more realistic" or based in "actual experiences." In reaction to this trend, it appears that many pharmaceutical companies are remaking their information to incorporate patient testimonials ("real" and synthetic) or even creating (carefully moderated) communities for consumers.

Dietary Therapy and Probiotics

As mentioned in my Introduction, five interview participants were members of a listserv for a particular form of diet therapy, the "Selective Carbohydrate Diet." These participants expressed criticisms of mainstream gastroenterology and even of major patient advocacy organizations such as the Crohn's and Colitis Foundation of America. I had the impression that they felt that their duty, as interviewees, was to advocate on behalf of the diet to me. In answering my questions about diagnosis, four of the five emphasized how well they were and how few symptoms they had. The fifth, who had a number of overlapping disorders, said that he felt the biggest problem faced by IBD sufferers was "physicians not recommending the SCD."

The Selective Carbohydrate Diet is difficult to follow—it requires the elimination of all sweeteners (except honey), starchy tubers, and grain products, along with most dairy products and processed meats—but those who had been successful in implementing it in their lives worked up the rewards associated with this hard work. Often this required community-building in "real life" as well as in cyberspace, because of the difficulties involved in maintaining a viable social and public existence with such a restricted diet. I discovered websites detailing regional "dinner clubs" held in the private homes of SCD users, which promoted a sense of locally-grounded, familial togetherness.

Other dietary and supplementary treatments were popular topics in patient spaces. The SCD is one particularly strict version of a variety of "probiotic" therapies which seek to encourage the reestablishment of healthy intestinal flora. Other participants, who were not willing or able to undertake major dietary changes such as those mandated by the SCD, ingested yogurt, lactobacillus, or patented probiotic therapies to this end (Tamboli et al. 2003; Fioramonte et al. 2003; Lucas 2002).[16]

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[16] One ColitisSucks user quipped on his message signature file: "What I learned at the CCFA conference today: We are 10 times more bacteria than human. Thus, tho you may not have a date on Saturday night, you are never alone."

In 2004 and 2005, probiotic foods began to be advertised on television, and to appear in major supermarkets in Canada (Beck 2005:A17)—an interesting mainstreaming of a well-established alternative diet trend.

Just Information: Support Needs and Competency Avowals

In many studies of illness-related internet use by patients, "support" is distinguished categorically from "information" and the distinction between these two types of interaction forms the basis of an interrogation of patients' needs. This dichotomy is rarely questioned. Sullivan (2003) comes closest to unearthing the roots of this divide, employing a gendered lens to examine group differences in discourse styles between men using a prostate cancer mailing list and women using a breast cancer mailing list. Women, she argues, appear to express "emotional" support to relative strangers with greater ease; men, on the other hand, employ a variety of rhetorical and discursive tactics in order to manage and downplay emotional stake and enhance the objectivity and facticity of their accounts. Though Sullivan is quick to point out that neither form of interaction is inherently more supportive—each gender-appropriate modality can generate a sense of "belonging" for participants—my own research suggests that many internet users distinguish between "support" and "information" in ways that underline their own competency. This distinction appears to cross gender lines. By declaring that they "just need information," chronically ill individuals are able to suggest that they are managing their illness well—unlike rhetorical others, who go unnamed but hold an important positioning function in their avowals of competency.

"Traditional," face-to-face IBD support groups, often organized through large advocacy organizations such as the CCFA/CCFC[17] and UOA[18], are one of the routes through which professionals dealing with IBD engage with the patient population. This engagement involves multidirectional flows of different kinds of facts. From the patients and their families, these facts can takes the form of participation in clinical or needs-assessment research—as, for example, in Joachim (1998), where the researcher collaborated with a local branch of the CCFC in order to create a pilot nurse-facilitated support group. Within this research matrix, patient participation helps to generate new data about patient preferences, needs, and dispositions which then becomes the basis of future research. From the professionals (among whom I include physicians, nurses, representatives of pharmaceutical interests, and researchers) facts take the form of different kinds of patient-targeted literature, advice, statistics, and synopses of the current state of scientific knowledge about disease. I began this research project with an interest in tracking the movement of facts between the many different parties with a stake in the illness. As such, I supposed that many of my interview subjects would have been involved with face-to-face support groups, or would have been urged to become involved by their clinicians.

The impression that some of my participants gave me was that face-to-face support groups were excessively emotive, uninformative, and, for them at least, unnecessary. Only a few had been involved in face-to-face groups, and fewer still had made such groups a regular and lasting part of their social networks. Even those who had

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[17] Crohn's and Colitis Foundation of America/Canada, founded in 1965 (Rosenthal 2001). Similar groups exist in most Western countries.

[18] United Ostomy Association. Not strictly an IBD organization, but one which caters to many patients in different disease categories who have to make use of ostomy technology after radical surgery.

never been involved in face-to-face support groups expressed (mostly negative) opinions about them: namely, that they were for *other* people, those who "couldn't cope," who needed more than "just information." The stereotype about face-to-face groups, one which I heard expressed a number of times, was that they were populated mostly by older people, especially older women, who were unconcerned with upgrading their knowledge or being "proactive" about illness—in Liz's words, "a bunch of old ladies chatting about ostomies and eating popcorn and blockages."

I present the following short exchanges because they demonstrate some of the ways in which declarations of "just needing information" help to construct a particular type of subject—an active, "Type A," self-managing subject:

> Barbara: Have you ever been involved in a 'face to face' support group?
> Todd: No. I haven't primarily because I don't have the time, and also because I haven't really needed the support. I consider myself well-balanced and very capable of coping with the problems I face.
>
> Barbara: Have you ever been in a face to face support group?
> Felicia: Yes, I was involved in a local information and support group from about 1978-79 to 83-84. My gastroenterologist and I would set up meetings and arrange for speakers. We kept it up for the five or so years and then I gave it up.... In both groups I found that too many people wanted to sit around and complain and were not interested in being proactive about their health.

What I found most interesting about statements disclaiming the need for support groups was that many of the participants who made these avowals would, in the same interview, declare how valuable and necessary their online interactions were. When asked whether her participation in J-pouchweb had helped her with her illness, Patricia wrote,

> Not really. I just read the boards to see if what I am experiencing is similar to what other people are experiencing. I have concluded that I have had a very positive experience so far with my j-pouch. There are some people who are still very sick and need people to talk to about it. I read the boards a lot when I was pregnant because there is a very limited group of people who have experienced pregnancy with a j-pouch. Even my gynecologist had never had a patient with my anatomy. This was the only place where I could communicate

> with anyone who TRULY knew what I was feeling. It also gave me hope that I could have a normal pregnancy and delivery.

This paragraph contains an interesting contradiction. Positioning herself as unlike "some people who are still very sick and need people to talk to about it," she still emphasizes that the board is "the only place" where she (and her anatomy) are understood. Her "needs" are presented as limited, situational, and pragmatic, while, at the same time, her relationship with (pregnant) j-pouchers is described with affective force.

Other patients modified their statements about needs by talking about kinds of relationship that cross-cut or extended beyond disease categories. In one case, a J-pouchweb member disclaimed his need for "support" through describing a more meaningful affiliation that, for him, took priority: his allegiance to the US Armed Forces. Mike told me that he only initiated private conversations about illness with j-pouchers who were military personnel.

> I was wondering if the surgery would end my career and I corresponded with a Marine who had been through the surgery and was still on active duty. I also corresponded with, and encouraged, a lady who wanted to join the Coast Guard but was unsure because of her j-pouch.

He had never been involved in face-to-face support groups, he told me, and "If I did, I think I would be a supporter, not the supported. I've never felt a need for support through this process."

"Happy to Help!" Ethical Patienthood and Experiential Authority

I was chatting with Noah only a few days after he was discharged from the hospital. After what he described as "about 6 weeks of unbearable agony"—a major ulcerated fissure that was not responding to either corticosteroids or immune suppressants, and which had required a blood transfusion—he had been flown out to New

York from his home in California. With the help of his sister and her gastroenterologist, he was granted an audience with "the God of Crohn's/colitis," Dr. Arthur Kornbluth, at his Manhattan practice. Dr. Kornbluth, Noah told me, "decide[d] right off the bat to give me Remicade," and after a TB test to ensure compatibility, he was given the drug in concert with IV painkillers and antibiotics. The change was immediate and dramatic, and he began to recover.

It was under these circumstances—fresh out of the hospital, slowly recovering but, in his words, "weak as a kitten" and "loopy on meds"—that Noah subscribed to cureibd. At the time of our chat, he had been reading and participating in the community for less than a week. He had decided to subscribe to cureibd, he said, because he wanted to help.

> i mostly joined because at this point i've been through hell and back, and wanted to make my experience available to help others avoid the 4 years of pain and bullshit i went through ... i didn't have any specific questions, it was mostly to do research to learn more, as well as to try to be someone to help out

This sentiment—the desire to help others suffering from similar afflictions by "mak[ing] [one's] experience available"—was echoed by other participants. Tom, a 36-year-old man from Toronto who had had a successful j-pouch surgery about ten years previously, had become a regular participant on J-pouchweb long after his near-total recovery from ulcerative colitis. When I asked if anything in particular had brought him to the forum, he wrote, "Nothing in particular, I simply wanted to reach out to others effected by this rotten disease, and try to help them if I could, and I have, many times over, the internet is really a wonderful thing!" Tom volunteered further that he considered helping fellow patients one of the duties of his job as an x-ray tech at a Toronto hospital.

> If I can help someone's journey a little easier, than why not, I know it helps me to talk to someone who knows how I feel, but I [had] no one aside from the doctors to talk to when I had my surgery, now that it is so much more out in the open, I'll be damned if anyone has to go thru this all alone.... Generally, I'll share my story with the patients and it tends to relax them. I think it's very important to let them know that there is someone who understands what they are going through, and someone who can give a first hand account of what it's like to have these tests preformed, I don't lie either, I'll tell them it's going to be uncomfortable, but I'll also tell them it's really not that bad, and that it is necessary to do these tests in order to properly treat them (I also mention that it was a barium enema that finalized my diagnosis and lead to my treatment).

Geoffrey, another j-pouch success story, offered an altruistic rationale for participating on j-pouch related websites in spite of feeling better than "since I was a teenager."

> The main reason I still frequent these forums is to hopefully add a little balance. By their very nature these boards are visited by people who are having problems and looking for help, it would be a strange person who popped in and said 'Hi, I've had pouch surgery and feel great, can anybody help?'. This can be quite off putting for somebody who is about to have surgery to see, I'm there to put the side of the successful pouchie, tell them what I did to help me recover so well, and what they can do. I've become quite knowledgable on the subject and can correct people's misconceptions and often point people in the direction of any information they may be looking for.

All of these "helpful patients," downplaying their own needs in favour of a model of ethical expert patienthood, happen to be men. This appears to fit with Sullivan's assertion that support practices are gendered and that women are more comfortable communicating in "needy" ways. However, close readings of these men's accounts tell a different story. Noah was strikingly vulnerable in his interview with me; he talked about his own weakness, fear of death, embarrassment and physical pain in graphic and emotive detail. He reasoned that his recent fissure had been triggered by an argument with a close friend whom he "feel[s] strongly for." In talking about his anger with the medical treatment he had received, he wrote,

> noah: i also got this really bad impression from my doctors
> noah: basically, because i was not responsive to treatment
> noah: they seemed to take offense at me

> barbara: hmm... interesting... like you're their 'personal failure' or something?
> noah: like i was some lemon car that they had to keep fixing, and not a person...walking away when i'm crying, look, i know i'm a 26 yr old big guy, but it's fucking hard

Noah, in expressing a desire to help, was not denying that he himself had emotional needs—rather, he was attempting to enter into an ethical relationship based on shared experience of a particular kind of suffering.

In patients' talk about illness, shared experience is presented as a natural ground for affiliation. The naturalness of this relationship is summarized in Wilf's words, who told me, speaking of his relationships with IBD patients he met during a hospital stay, "I would say that we support each other, but that comes naturally from shared experiences; it's not a support-group per se." This move uses the naturalness of empathy to suggest that patients' relationships are noncontingent and apolitical (Shuman 2005:82). Ethical relationships between patients are characterized by the fair exchange of experiences: "It's also a give and take, if you give good, you get good. The Karma thing." (Liz)

The richness and detail with which interview subjects described the "information" they had obtained through exchanging experiences with fellow patients is the focus of Chapter Two. Their characterisations of information obtained from peers are examined in relation to two themes: medical authority, and the affective power of comparison.

CHAPTER TWO: COMPARISON AND AFFECT

This chapter engages with participants' descriptions of the information they have obtained through online peer support and suggests that their representations of this information are imbued with affective force. By linking "support needs" to a pragmatic empiricism—a day-to-day testing and tinkering with the body—participants emphasize their own competency and ability to cope. At the same time, these representations enhance the authority and value of relationships with biological peers. The embodied and experiential knowledge of fellow sufferers is contrasted with the passive knowledge of doctors or others who "don't know what it's like." Out of these comparative relations are drawn avowals of likeness and shared interest. In Brandy's words, "Doctors have studied the disease and they find new things for us to try, but people with the disease can relate."

In the previous chapter I outlined a discursive psychological approach to talk and how it informs my readings of patients' statements. Here, I would like to re-iterate my understanding of this approach and how it ought to be applied to that ubiquitous and unavoidable term, "experience."

"Experience" is a concept with deep roots in modern understandings of the self, personhood, agency, and the foundations of social and political life. That individuals "have experiences" which form the basis of their unique personhood through the absorption and application of knowledge is an ethnopsychological verity that is extremely difficult to challenge, or even talk past. Experience requires a knowing, self-aware subject that is able to use knowledge for the purposes of self-improvement.

In much qualitative research on health (including certain brands of medical anthropology), where a "patient-centred approach" or a critique of power relations is often central, "experience" epistemologically grounds the investigation of how patients are implicated in systems and practices of health care. In these models, experience is produced through the assimilation of the world (which is external to the self) into the individual's cognition and psychology. The ethnographer's task—that of describing a social world—means "collecting experiences": his/her own through engagement in particular social worlds; others' through the narratives of informants.

As Mary Horton-Salway has pointed out, "[f]rom this perspective, the self and identity are treated as residing within the individual, whilst being affected by outside influences, life experiences, and one's own perception" (Horton-Salway 2001:162). Discursive psychology's approach to "experience" is generally more cautious. Practitioners examine "experience" in terms of its deployment in talk, often as a particularly *strong* and *effective* category entitlement which helps to position the speaker as an eye-witness (Potter 1996:165; Shuman 2005). This does not mean that, in using this approach to the analysis of language, practitioners of this method deny the truth value of subjects' statements about particular experiences—on the contrary, they are not concerned with confirming *or* denying the truth value of anything subjects say. Rather, they emphasise what is done with talk and how authority, facticity, "emotional flavour," and "patterns of investment" (Wetherell 2003:101) are built up through acts of communication.

I approach claims about "experience" primarily as category entitlements that work to sediment categories. They do so by positioning others as "knowing" or "not knowing" and by linking bodily processes to emotions, which are then worked up as an authentic and natural ground for relationships.

The Mirror of the Self: Identification and Affect

In many IBD sufferers' accounts, the value of cybersupport lies in its ability to make them feel "normal": it reassures them that their body's functioning, however abnormal in relation to the general population, has precedent among fellow sufferers. As Wynne wrote, in response to my question as to whether J-pouchweb had helped her with her illness,

> I don't think it has helped with my illness, however, it has helped me cope with my illness. I can see that I am not alone, I can ask ANY questions and usually get a fairly quick answer. For example, someone recently posted an article about how 2/3rds of j-pouchers have osteopenia which was a shock to me - I thought it was just me!! Also, I saw someone post about lower back pain after surgery - again I thought it was only me with that problem!! And I recently asked a question about the possibility of chrone's [*sic*] disease and got a reply almost the same day! In this way, it helps. You don't feel like some freak of nature that seems to get every disease known to man! You start to see the similarities between yourself and others out there. It gives you hope.

This mode of talking to others is presented as affectively forceful: emotions like shock, loneliness, and hope are evoked through discussing symptoms, diagnoses, side effects, and the problems of living with IBD. Identification with relative strangers helps the subject to re-vision herself and her problems.

In the Introduction to this thesis I quoted Michael M.J. Fischer's characterization of healthy modern subjects being governed by "testing regimes" (2003:150) which encourage self-monitoring, producing what Biehl et al. (2001:90) have described as "automated forms of governmentality and subjectivity." "Testing regimes" take many different forms—Biehl et al.'s study specifically concerned a free HIV testing clinic in Bahia, Brazil—but they can be united through their reconfiguration of the relationship between medical authority and patients' emotional drives. Here I will describe the Bahian study's theorization of "technology and affect" and use it to address the question of normality.

Biehl et al. found that the clients who tended to use the free HIV testing service were categorically at low risk for contracting HIV. Most were middle-class Bahians who used the service in order to establish a new, biologically-based "truth" about themselves and their sexual partners. The practice of testing creates a new form of identification in which the individual becomes subsumed within a specific epidemiological "risk group":

> At stake is no longer the influence (suggestion) of others, a large number of people, upon the individual, but the work of each individual upon him or herself via a testing technology that works as a new ideal of the ego, and his or her 'group participation' in epidemiological profiles (anonymous and epistemic populations). (Biehl et al. 2001:98)

The authors' psychoanalytic orientation focuses attention on the ways in which the automated governmentality of the testing clinic reshapes "ideal agency" and "instinctual and moral economies" (Biehl et al. 2001:96). Self-testing helps clients understand themselves as behaving in morally accountable ways. One client told the authors, "'The test helps me to understand that I might have it and might die. It is difficult, but the test reveals that. So, I prevent'" (Biehl et al. 2001:115-6). Testing, prevention, and identification with "risk groups" are some of the primary ways in which "rational-technical management of health and of a biologically based identity… are reified and absorbed" (Biehl et al. 2001:89).

Interview descriptions of "information" obtained through participation in cybersupport groups often emphasize how learning, teaching, and experimentation are wrapped up in processes of self-other comparison. Michael's answer to a question as to whether J-pouchweb had helped him with his illness is quoted at length:

> I found out about rinsing my pouch with a water enema, which for me helped the most of anything, even more than most medicines. I also tried psyllium (although it irritated me) and may try loperimide (anti-diarrhea), although I've been doing absolutely great for the past month, except for that one flare-up. Besides recommending treatments, it makes you appreciate where you are at because there's so many more people who aren't doing as good as you, so it shows you how fortunate you are. Also, it makes you feel more normal, cause on a day-to-day basis, I feel like I can't relate to most people. I have also been isolating myself a bit since the discovery of my food allergy and the diet change, cause I can't eat what most people can. So often times I can't eat what others want to eat, or if I do I really regret it later...I haven't found others who have these diet restrictions, although I know they're out there.

This paragraph begins with a description of "tinkering" with different treatments learned from peers—treatments that help more than "most medicines"—and then moves into a discussion of how normality is established through comparison. The final sentence in this quote suggests that "finding others who can relate" to particular types of medical difference is a desired outcome of talking with fellow patients. Brandy, also a member of J-pouchweb, expressed similar sentiments in our IM chat:

> barbara: so when you first joined the j-pouch group, were there any particular questions you had, or experiences you wanted to learn more about?
> brandy: I basically wanted to know more people that went through the same operation as me. I wanted to know everything I could about living with a j-pouch and to hear of other people's experiences. Even possibly, giving advice to others who wanted to have the surgery. I feel that my surgery was a success. I've never had any major problems. The first topic I posted about was minor rectal bleeding.
> brandy: If it meant I had pouchitis...or if something else was wrong with me. A few people reassured me that it was normal as long as I didn't have a huge amount of blood.

Managing the anxieties and uncertainties of a surgical procedure through the interrogation of "people with the same experiences" simultaneously reassures patients that they are "normal" (in relation to a particular triangulation of diagnosis and therapy) and reshapes their sense of membership. More pragmatically, it also provides them with a template for action: the bodies of others become the predictive substrate of an experimental practice. Testing the self against others creates a rational-technical body that can be acted upon by the patient as "proactive" reworker of the self.

In the case of J-pouchweb members, these practices were often related to the management of complications related to surgery, pharmaceutical use, and testing procedures (especially invasive procedures such as colonoscopy). With SCDietsupport, where the specific technical focus was on following a strictly regimented diet and ideally excluding the use of drugs or surgery, agency is reshaped through iteration and documentation of good dietary behaviour (or, as they're called in SCD discourse, "legal" and "illegal" foods). Practitioners, following the advice of the diet's developers and promoters—who, as noted, were relatively proximate through their interpellations of the email listserv—kept "SCD diaries" in which they noted their food intake and monitored their own progress.[19] Participation in collective conversations through email lists and other online resources provided sufferers with techniques for self-surveillance and management. Alicia described to me her own methods for sticking to this very challenging diet:

> In my first year of following the SCD I read every email on the list and kept a notebook of "SCD Advice." It helped so much with following the diet fanatically and with ideas of things to prepare and ways to handle flare-ups. At those times that I would feel particularly down or discouraged with my progress, someone else would send in an email with my exact problem and how they got through it. Also, hearing of others' progress and healing who had been on the diet longer than me was so encouraging. And, I have to add, that the author of [*Breaking the Vicious Cycle*], Elaine Gottschall, was also posting on the list during my first year of the diet so having her input was so wonderful and exciting.

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[19] I was able to locate a number of publicly accessible "blogs" (weblogs) and "flogs" (food logs) created by SCD practitioners. On blogs which permitted commenting (such as those using the LiveJournal interface), users were able—and encouraged—to monitor one another's behaviour as well as their own.

Monitoring the self—through iterative practices of reading and writing—is successful, in Alicia's description, because it involves others in the process. To borrow from Biehl et al.'s Lacanian conceptualization, the community of practice becomes the "new ideal of the ego" (2001:98)—a mirror of the self which "reveals the subject to him/herself as a piece of unfinished business composed of ever new lacks" (Knorr Cetina 2001:527). The unfinished business of remission—the ideal goal of all IBD sufferers—requires constant self-awareness.

Standardization, Empiricism, and Embodied Knowledge

Accounts of tinkering—of employing practical empiricism in the management of IBD—were often qualified by comments about how doctors and other medical professionals "didn't know," "didn't mention," or "didn't care" about potentially helpful interventions. Doctors' knowledge was worked up as detached, standardized, and abstracted from the real-life experience of illness.

After stating that "there's also a big disconnect between the patient community and the medical one," Noah elaborated:

> noah: the doctors prescribe enemas, either steroidial or 5-asa ones
> barbara: right
> noah: they can be more effective and more targeted than oral medications
> noah: anyhow
> noah: i've never been told by anyone, doctor or pharmacist
> noah: to warm the enema up, i mean, otherwise you can't hold it, it's fucking cold
> barbara: right!
> noah: and you already have pain down there and an extreme urgency to go to the bathroom
> noah: so they hand you this stuff, and don't give you any tips on making it more comfortable
> noah: they just aren't in touch...

Doctors and pharmacists are literally "not in touch" in this formulation—their lack of embodied, experiential knowledge is framed as mitigating their authority on matters of intimate concern to patients. Shortly after our interview, Noah, who as stated in Chapter One had only recently joined cureibd out of a desire to help, exchanged this piece of advice about enemas with another new member. In the context of web forums, where interactions are structured around question-answer formats, "personal experience" can become a form of social currency, providing entrée into a community.

Brooke's descriptions of tinkering foreground "other peoples' experiences" as more real, informative, and embodied than the types of care provided by doctors. She writes, of her involvement in ColitisSucks:

> It has also helped me to learn a lot about the disease—reading other peoples' experiences is a lot more informative than reading a book written by doctors! It has given me ideas for ways to cope with issues that the doctors don't talk about—like how to prevent skin irritation during a bowel prep (and how to best deal with bowel prep, for that matter—for example, what to use as a "chaser" for GoLytely [a bowel lavage solution used before exams]).

Tanith, discussing the online resources she used during a hospital stay, contrasted the information found on patient sites (specifically J-pouchweb) with the standardized information found on more professional medical sites.

> While I was hospitalized, my husband would search and print off any info he could find so that he could bring the info to me in the hospital. Many were from medical sites. These had the technical aspects of the disease and of course the standard, you can't eat this or this or this. I found most sites were basically the same info that I received from the surgeon on the pamphlets he gave me. The discussion group gives you a chance to hear what it is really like.

Doctors' approaches to care were occasionally described as being illogical, scholastic, and non-empirical. Brooke's narrative of joining ColitisSucks positions her doctor as "not listening" to her symptoms and his treatment practice as irrational.

> I was experiencing my second (and worst) flare, and was having a difficult time communicating with my doctor. He wasn't really listening to my symptoms, and I didn't see the logic in his treatment plan for me (he was switching medications, adding several new medications at once, and I didn't see how we would be able to tell which one was working–I didn't want to take unnecessary medication; he wanted me to take whatever worked, without really understanding *how*. My dad told me that I was being more logical than most doctors, who practice "medicine by witchcraft."). I came online looking for information on what the doctor was prescribing, stumbled across IBD Sucks, and out of sheer desperation, joined so that I could ask if anyone else had been prescribed that particular combination of drugs, and if they thought my doctor actually knew what he was doing.

This narrative positions the doctor as irrational and non-empirical through a number of distinct rhetorical turns: by describing him as "not listening" or observing the patient's symptoms; by working up his prescribing practice as chaotic and experimentally unsound ("how we would be able to tell which one was working"); and by citing doctors in general as practicing "medicine by witchcraft"—not only non-empirical, but non-modern. Brooke's decision to do her own research on medications positions her as a self-improving (if desperate) patient seeking better information.

Language Ideology and the Mediation of Realness

Patient interactions in the IBD cyberspaces I observed were marked by a distinct mode of talk about shit. The indexing category I gave for these types of conversations was "scatology." This is my term, and as such it carries some of the baggage associated with my analytical orientation: it implies a modality that is systematic and scientistic, based in scrutiny and categorization of natural processes.[20] What I call scatology was all these things; it was also playful and, generally, humorous.[21] In talking about shit,

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[20] A category more faithful to patients' wordings might be "TMI" ("too much information") or "bathroom/toilet talk," depending on their age and/or location. Cureibd users, who as stated in the Introduction were generally younger, used TMI regularly—it is a pop culture term that has become a part of internet slang.

[21] Abject scatology—a more expressively negative and self-deprecating form of talk—was rarer in patient discussion forums but quite common in personal weblogs.

participants used humour to downplay emotional stake and to create a sense of collective, *experienced* knowledge of the body. Scatology gives patients a shared language and a language ideology. IBD slang describes symptoms and symptom course ("flares"; "butt burn") but scatology, as a modality of interaction, establishes experience as a site of similarity. It also enables a disparate group of patients—with different diagnoses, understandings of causality, and treatment regimes—to be rhetorically united through an accounting to the objective reality of shit.

Floating in and out of my discussions with patients were questions about the real as it related both to sociality and to reading biological signs of illness. Frequently people would say something along the lines of "How could a doctor not see this?", alluding to the disorderly waste emblematic of IBD. Biological peers knew how to read these signs correctly; they had experienced them in the same way; and what I dub scatology is a way of indicating familiarity with the appropriate indexes of a real, serious condition. IBD's continued association with psychosomatism and its diagnostic uncertainty (most patients I spoke to had been misdiagnosed at least once—with sometimes gruesome results—before their disease was correctly identified) made establishing realness an important part of the work of patienthood.

There was a sense in which biological peers had seen—or, to be rather more faithful to patients' wordings, experienced—the signs of illness that doctors, by their very nature and by the nature of the clinical encounter, *could not see*. The irony in this formulation is that the people interacting with one another, claiming the authority and knowledge that derives from biological identification, were frequently considerably more distant from one another, in a spatial sense, than doctors usually are from patients. Humorous scatological conversations elicited sentiments of intimacy and proximity.

In our interview chat, Megan described a friendship with a classmate with Crohn's disease that was characterized by scatology—"inside jokes" that could also be seen as a form of comparative testing. "It can get kind of gross," Megan noted dryly, "but we find it entertaining :)." It helped her cope, she said, because "the things that others might find strange (ie. looking at your stool when you have a BM) isn't strange to someone who has it too—they know you have to check it out to make sure everything's kosher." Normality is activated in scatological humour—a playful/serious method of establishing difference and similarity in everyday talk.

As mentioned in Chapter One's discussion of ColitisSucks, the use of scatological humour was frequently elevated to the level of a language ideology. Bruce, the moderator of ColitisSucks, had created a page entitled "Sux-iquette" that included a statement about bathroom humour and its appropriate uses. When I asked him if users had objected to the language policy, he wrote,

> I have heard from people that other web forums have much stricter limits on language, and that this is one reason why they felt limited in what they could talk about there. Early on there were a couple of complaints about the name of the forum, in fact. I always responded to the complainers, that while I appreciated their concerns, I felt that the explicitness of the name was its strongest selling point. It almost never comes up for discussion within Sucks.

Here, a language ideology that celebrates frankness and humour is used to distinguish the particular web forum and its associated community from other, "stricter" forums. Elizabeth and Wilf, a married couple who were longtime members of ColitisSucks, followed their assessment of the forum's value with a statement about the importance of humour in living with IBD:

> when you first learn there's more people out there that have the same experiences, problems and fears that you have, it's such a big relief. Common belief is still that "it's all in your head," and sometimes you're almost going to believe that. To learn that it's not, is the best thing.
> And then there's the humor-folders! If you can laugh about it, you can live with it!

Besides generating realness and establishing normality, scatological humour is also oriented to by patients as a way of resisting the "polite" euphemizing of their conditions for the benefit of unafflicted others. Though they acknowledge that shit is "gross," it is also "normal" (even when disordered and disorderly)—and they express feeling as though the disgusted reactions of people with normal elimination are used, deliberately or not, to further isolate sufferers. When I ran into Erin one day on a crowded bus, she loudly and almost defiantly discussed missing the ability to "write [her] name in the snow" since her ileostomy had been replaced by a j-pouch. This defiant scatology seemed out of character with her otherwise reserved personality.[22]

Counter-Expertise and Ethical Patienthood

Patient collectivities (whether formal or informal) can be counted among what Linda Hogle calls "counter experts": groups which "may have complicated collaborative relationships with experts or groups in power and who may selectively identify with these groups rather than with the 'depoliticized, disorganized groups' on whose behalf they are working" (Hogle 2002:237). In the case of the four support groups studied in this project, relationships with expert groups were indeed complicated and difficult to track. Almost all online IBD resources maintained hyperlinks to the major advocacy organizations, the CCFA/CCFC and the UOA, which act as major knowledge brokers and gatekeepers

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[22] Her comment was apropos of nothing (that I can recall), which makes me think that she was alluding to my research, which she knew was ongoing, without directly talking about it—or alternately, testing my reactions.

between the medical profession and the patient population. J-pouchweb was the only one of the four groups studied that maintained a formal, advisory relationship with medical professionals. However, all groups, whatever their relationship with medical authority, had prominent legal disclaimers to the effect that peer support was *not* a substitute for proper professional care and that all information found online was "for educational purposes only."

Though I witnessed interactions that indicated that some patients use online support groups in ways that are explicitly forbidden—for example, in order to trade pharmaceuticals, establish a secondary diagnosis, or give and receive medical advice—most patients framed their conversational practices as "exchanges of experience." The line between "experience" and "advice" is a blurry one, to say the least. In online conversational practice, a hierarchy of value obtains to modes of talk, just as it does in offline contexts: personal experience enhances the authority of claims, grounding it in practice and observation. A small fragment of my IM conversation with Sadie indicates how value accrues to experience:

> barbara: can you give me an example of the kind of advice you've given?
> sadie: hm, today i replied to someone who was asking about 6-mp
> [mercaptopurine, an immunosuppressant]
> barbara: oh so that was something you'd experienced
> sadie: yeah, i wouldn't respond unless i had something worthwhile to say.

In examining the worthiness of types of speech, we come to a place where patient's rationales for the use of online resources intersect with their critical observations on the medical professions. Though often critical of *specific* doctors', nurses', and pharmacists' practices, many patients presented their online search for solutions as an accommodation of doctors' busy schedules. Candace, describing how J-pouchweb had helped her with her ulcerative colitis, wrote,

> Once in a while I have questions I don't want to bug my doctor with so I post them on the site. It can be intimidating in the doctor's office and easy to forget certain questions or it's too embarrassing; sometimes I need clarification but don't want to monopolize their time so I post the questions instead. I always check back with my doctor if I am unsure but at least it gives me a jumping off point and peace of mind.

As Richard Gwyn has pointed out, discourses of "empowerment" and "patient involvement" are not anti-professional in the sense of representing a direct challenge to medical authority; rather, "the movement for 'patient power' which asserted itself in the 1970s to a large extent reflects a burgeoning consumerist mentality" (Gwyn 2002:73). By becoming counter-experts, some patients are able to create new socio-technical coalitions—with doctors, researchers, and fellow sufferers. The surgery narrative of Kasia, a 37-year-old woman from Krakow, Poland[23], illustrates some of the ways in which the availability of internet resources can both enhance patient autonomy by creating such coalitions, and give form to moral normativities about entitlement to care and the appropriate basis of professional expertise.

Kasia was diagnosed with ulcerative colitis in 1996, after approximately ten years of unusual symptoms. Four years after her diagnosis she had an emergency colectomy; two years after that, her j-pouch was created. At the time of our interview she was preparing to go under the knife yet again—this time for a rectovaginal fistula.

After her emergency colectomy, which left her with an ileostomy (and its attendant ostomy device and associated problems), Kasia started doing research on the

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[23] Poland has universal health insurance, though private care is available. As Kasia told me, "Theoretically this is very egalitarian but in fact there is a serous shortage of money in the system and if you really need help quickly you very often have to go to a private clinic and pay for that help."

internet. In the process, she found J-pouchweb and began reading about the procedure—a procedure which her doctors in Krakow had never mentioned. The research wasn't easy; "it was rather difficult to find all the information, especially that they was only in English, and I even didn't know if such surgeries are done in Poland and if I qualify (Polish medical information is very poor in the Internet)."

The information she was able to find she took to her doctors. Their reaction was unexpected:

> It turned out that here in Krakow, which is not a small town and is a university city, where we have many clinical hospitals, doctors are not convinced to the j-pouch surgery. Firstly they didn't tell me about the possibility and secondly, when I asked directly, they told me that this is not a good idea and that they do not do such operations. But they also don't tell that I can have such surgery in Poland. I find [out] myself that I can be operated in Poznan—6-7 hours driving distance from Krakow. After some hesitation I decided for the surgery. It wasn't an easy decision because I heard the different opinions from the doctors: those in Krakow said it was a bad idea, those in Poznan were very in favour, and a professor in Warsaw was rather against.

Intrigued by the question of why doctors in different Polish cities would have differing approaches to the procedure, I emailed Kasia again with a follow-up question. She explained in some detail the rationales that the Krakow doctors had given her—namely, that incontinence was frequently a problem after surgery and that patient satisfaction was low. She then suggested another explanation:

> What is really behind? I suspect that the Krakow clinic (This is a general and gastrointestinal surgery clinic) has its own specialization, they are very good in cancer surgeries, surgeries made on stomach and maybe they don't want to make experiments which not necessarily will be successful at the beginning.

While describing the Polish medical system to me, Kasia inserted an interesting bracketed aside, which I include here in order to illustrate how doctors' interests are framed within the context of a public health care "shortage":

> [This is something I have to put into brackets - treat this as my personal complain, not the official statement ;-)
>
> There is also very serious problem of corruption. I'm very ashamed to say about that but I must say that this is rather common that people pay bribes to be admitted to the hospital or to have a surgery. The most painful thing for me personally is that when you know that your doctor expects money from you despise him/her and on the other hand you have to rely on him/her, you have to "give your life in his/her hands." Terrible. People justify that by the fact the medical staff is very underpaid and they deserve to have more. Maybe, but I also may say that I deserve more...]

These formulations present doctors' professional interests as misaligned with patients' needs. The topic of professional corruption links Kasia's concerns about the availability of *her* care to a general sense that doctors in Poland have unethical interests, interests that are fundamentally at odds with her own. Kasia describes herself as using the information she'd obtained through J-pouchweb in order to get around a system that placed roadblocks in the way of her recovery. By becoming an active researcher involved in her own care, Kasia was able to get the surgery she wanted and deserved.

This, however, was not the end of the line for Kasia: though she had taken care of her own needs, she now turned to taking care of others'. After her emergency ileostomy, she had started up a Polish-language website targeted at "ostomates"—people with surgically-created stomas for elimination—and now she reworked the site as a clearinghouse for j-pouch information. Kasia was now a counter-expert to whom other Polish speakers undergoing intestinal surgery went with their questions. Visitors to her site undertook group discussions regularly in her chat room and met face-to-face on occasion. "I think we are friends now," she wrote.

Kasia's story describes the origins of a particular virtual community and that community's very visceral consequences for Polish patients. It is relevant to my discussion of affect and comparison because it demonstrates how patient groups position their status as "communities" in relation to medical authority. Kasia's representation of unethical doctors suggests that she had no option but to take matters into her own hands; and her decision to spread the word about j-pouch surgery shows how sentiments of duty and friendship emerge out of the technical coalitions initially framed as utilitarian and self-interested.

Sentimental Resemblances

The affective force of comparison is activated through particular ways of talking about illness—recounting symptoms, exchanging advice, and describing feelings. Sufferers' emotional reactions to the experiences of biological peers are deployed to ground their similarity and to rhetorically bolster an ethic of sharing.

Recent research analysing emotion discourse has challenged the conventional interpretation that emotional content necessarily undermines the out-there-ness and objective flavour of entities. Hopkins et al. (2005), examining emotion discourse in a UK anti-abortion campaign, have observed that emotional content can often *enhance* the out-there-ness of entities by constructing peoples' "instant" reactions to them as bodily, pre-linguistic, and therefore natural and authentic. This, as Catherine Lutz (1990:69) has pointed out, is a modern, Western formulation of emotion premised on a distinct model of psychophysical function. Hopkins et al. elaborate:

> Emotions are typically 'conceived to be natural bodily experiences and expressions, older than language, irrational and subjective, unconscious rather than deliberate, genuine rather than artificial, feelings rather than thoughts' ... and this multidimensionality allows for considerable flexibility in working up any number of versions of reality.... Thus, just as emotion can be contrasted with thought so as to appear 'irrational' (and charges of emotionality used to discredit others' positions); so too, emotion can be construed as 'unmediated' and 'authentic' (and

> constructions of emotional reaction employed to ground particular accounts as objective). (Hopkins et al. 2005: 395)

The authors argue that naturalized emotions are particularly potent representational resources when deployed in the description of *contested entities* such as fetuses, whose status (as independent persons versus maternal tissue) is considered to be of great political importance. In the case of IBD we have a number of different versions of reality operating in patient and professional discourses: multicausal etiological models; an intellectual history of psychosomatism; diagnostic uncertainty; and complex therapeutic politics. Establishing the disease, a contested entity, as "real"—and particular triangulations of realness, such as an "autoimmune condition" or a "genetic condition" or "a dietary issue"—often requires a considerable amount of representational labour. That labour draws on affect as much as it does scientistic descriptions of objective biological processes. Because they share emotional experiences (the logic goes), sufferers are naturally concerned for one another's well-being and will understand that they have a shared political interest. Because their experiences are affectively grounded, they are real, as are their relationships with one another.

This is an important point to stress. Within popular framings of internet sociality, concern is regularly expressed about the anti-social potential of online communication. The internet is broadly portrayed as a place where people talk to strangers—strangers who are often predatory, untrustworthy, or just pathetic. Relationships which are mediated by technology or separated by large distances are seen as being less authentic, and people who initiate friendships or marriages through computer-mediated communication are frequently held under suspicion (e.g. Constable 2003). A hierarchy of intimacy privileges "face to face"-ness, with the most proximate forms of conjunction—

the mother and child, or the conjugal couple—representing the core of realness and the epitome of relationality. Despite their critique of the "myth" of disembodiment, much of the scholarly literature dealing with cyberspace replicates some of these assumptions about the asocial or antisocial nature of computer-mediated communication (Porter 1997; Gurak 2001).

In contrast, framings of sociality *within* cyberspace are often intimate, utopian, and oversocialized (boyd 2003; McKinnon 1995). What, then, do we make of patients' assertions that they "naturally" know, understand, and empathise with one another? How do we parse political claims about similarity outside of their illocutionary context? Can the emphatic defence of cybersociality be untangled from an equally emphatic identification with an epistemic population?

Chapter Three attempts to answer these questions by examining the performances that IBD patients undertake in order to literalize their relationships. Moving beyond online talk about understanding and identification, I describe how the sentimental resemblances built through participation in patient groups are deployed as the basis of public patienthood, and how sentiments of ethical patienthood circulate materially outside of cyberspace.

CHAPTER THREE: PUBLIC AND PRIVATE PATIENTS

This chapter moves away from a focus on the discursive analysis of interview materials in order to reflect ethnographically on the ways in which patients deploy notions of similarity in enacting, describing, and accomplishing the “political” work of patienthood. My usage of political is both commonsensical and specialized: it refers to the blending of advocacy practices with support practices, the literalization of links between advocacy, support, and professional communities, and the ways in which ethical sentiment works to build idealized “public” patients. It is, in a very specific sense, *bio-political* sentiment, raising certain types of symbolic action towards fellow-sufferers to the level of filial (or fraternal) duty and troping explicit parallels between patient duty and family duty. This familial troping is, I argue, what makes the concept of biosociality so enticing (especially to anthropologists) and also so problematic: “kinship” is a powerful interactional resource with not-insignificant political effects.

I argue that certain modes of expressivity, including textual acts of positing similarity, are political performances staged within a larger context of disease advocacy—and not, necessarily, spontaneous eruptions of unmediated fellow-feeling (or signs of a pernicious biomedicalization of social life). Many of the IBD patients I interacted with during my research period described a duty to raise awareness. Many stated outright that they were participating in my research because of just such a duty. They also reflected upon their public performance of patienthood in ways that suggested that they had a responsibility to cultivate others by bringing them out of the closet. If these characterizations sound familiar, it is likely because they are mimetic of, and consistent with, forms of disease advocacy now common throughout the West. Yet many patients expressed discomfort with having to publicize their IBD; though unanimous that there was a need to raise awareness, they frequently found identification problematic. The moral ordering of ethical patienthood—as an *identity* requiring public iteration and display—came into conflict with sufferers' feelings of abjection and alienation from their own bodies, as well as with the pragmatics of navigating everyday life.

"Awareness": A Difficult-to-Challenge Formulation

Awareness is a term almost as ubiquitous as "experience," and one which is similarly difficult to challenge. It is a term that travels alongside patient activist movements, one with which they attempt to penetrate public discourse and mobilize sentiments of individual, familial, and collective duty. Yet awareness is in some sense multivocal. Barbara Ley (n.d.) has noted the different "awarenesses" signified by the opposed parties in the American breast cancer movement—an ecofeminist awareness of industrial pollution and corporate greed, in the case of the environmental breast cancer movement; and a personalized, prevention-and-screening awareness on the part of "mainstream breast cancer culture." As the mainstream version of breast cancer activism is more publicly visible (due in large part to its corporate backing and its success in tying the disease to matrilineal relationships), its version of awareness has achieved hegemonic status.

In Ley's account of these opposed political perspectives on breast cancer, she outlines the influential critique posed by Barbara Ehrenreich (2001), which framed mainstream breast cancer culture as individualistic, sentimental, and hyper-commodified:

> For Ehrenreich, this "cult of pink kitsch" is embodied by corporate PR campaigns encouraging women to purchase items such as cosmetics, jewellery, teddy bears, and tee-shirts whose proceeds will go towards finding a breast cancer cure; by breast cancer organizations which strive to empower women by encouraging them to get a mammogram; and by breast cancer websites that seek to inspire afflicted women with quotes such as "Don't Cry over Anything that Can't Cry Over You." (Ley n.d.)

Though Ehrenreich and other activists are horrified by what they see as a political "pinkwashing" of breast cancer, this mode of symbolic engagement—the creating, selling, trading, and gifting of "awareness" items between patient organizations, individual patients, and their significant others—is not asocial or apolitical in an absolute sense. In order to untangle the specific registers of "awareness" and its materialization in patients' lives, it is important to examine *why* people participate in this field of action and how they represent their actions to one another. Observing the IBD awareness gift culture can help us to understand what awareness means to people and how it is caught up with ethical sentiments surrounding illness. Few patients in any disease category would reject outright the idea that awareness is necessarily a good thing that advances their interests. Awareness is, by its very nature, always positive. But what is it?

The Awareness Economy

In mid-December of 2004 word started circulating on cureibd and a high-volume IBD newsgroup about products being sold by the Crohns and Colitis Foundation of America: dark blue silicone rubber bracelets, sold in packages of ten, embossed with the words "Got Guts." Advertising copy on the CCFA website enthused, "Express love &

support, show courage & bravery." These items were received enthusiastically by the participants of cureibd, some of whom started gifting them through the community forum. One participant posted an announcement saying that she had purchased ten—keeping two for herself and her boyfriend—but would give the remaining eight to the first takers. Backchanneling[24] ensued, and a few weeks later the community was full of messages of enthusiasm and gratitude directed at the gifter.

This flurry of gift-giving took me a little off-guard. The bracelets were not particularly attractive, in my opinion, and the slogan embossed on them was so subtle as to be difficult to see. However, shortly after learning about the bracelets from reading these online groups, I started seeing something else: yellow bracelets. In a period of about a week, I saw three people at my university wearing bright yellow wristbands, not unlike the Got Guts product.

What I didn't know at the time was that these blue bracelets were a takeoff on a wider cultural phenomenon: yellow bracelets, by far the most common, were being sold and traded to support professional cyclist Lance Armstrong's "campaign to crush cancer." Marketed and distributed by Nike on Armstrong's behalf, they were widely visible in the popular media. Megan, more in tune with pop culture than myself, estimated that they had been around since at least the summer, "based on seeing celebs wearing them on TV and in magazines." *The Globe and Mail*'s fashion section, picking up on the trend, reported that they were launched in May 2004, and in the intervening

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[24] "Backchannels" are the routes through which people connect public internet discussions with private internet discussions. Requesting someone to email you and providing a private email address (or IM username) in a public forum has backchanneling as its aim. (It is generally considered unwise to post one's home mailing address in a public forum.) Backchanneling is interesting but frustrating to a virtual ethnographer because it points to the social interactions and transactions that go on *outside* and *between* public forums.

time "more than 33 million had been sold to people around the world" (von Hahn 2005:L3). And the phenomenon was not limited to cancer and colitis:

> Anti-bullying awareness bracelets are red. Purple is for cystic fibrosis, green helps the environment and orange benefits lupus. Autism awareness wristbands are light blue, while a darker blue has been used by anti-Bush activists, prostate cancer research and the anti-abortion movement.... Tsunami bands say Strength and come in many colours. Support Our Troops bracelets are army green. (von Hahn 2005:L3)

Knockoff bracelets, with funds going (apparently) nowhere except to the distributors, were also available on the internet and through clothing chain stores popular with teenagers, in a rainbow of different colours. Within a few months, I had seen them on thousands of people on the streets of Vancouver. By the end of the summer, they were ubiquitous features of daily life in both its "real" and "virtual" forms. The association of disease categories with colours initiated a striking psychogeographical transformation for me: walking or biking down West 10th Avenue in Vancouver (where Vancouver General Hospital and other biomedical research centres are located), I suddenly became "aware" of bracelets, ribbons, flyers, balloons, posters—all of them invoking specific awarenesses. These campaigns, through their use of viral and memetic advertising tactics, made illness into part of the sensory fabric of everyday life.[25]

In my research weblog, I wrote up my speculations on possible approaches to the phenomenon: were the bracelets simply a fad? Items in a gift economy? Identity markers? The Got Guts bracelets were obviously mimetic of an already-established (and

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[25] "Viral" marketing both uses a transmission model to incite the adoption of products within small social networks, and partakes of "viral" semantics in describing economic behaviour (for example, through the use of terms like "inoculation" in reference to consumer resistance to ubiquitous advertising) (Compton and Pfau 2004). "Memetic" exchange in cyberspace follows similar routes but deploys an evolutionary logic—practices, ideas, or products are understood as adaptive traits that advance the interests of the network. I use "mimetic" in the more conventional sense of "imitative"; "memetic" to refer to the deployments of meme theory by marketers, evolutionary psychologists, and theorists of cyberspace (including study participants).

very successful) fundraising campaign, as well as a fashion trend especially popular with pre-teens. When worn, they attracted the eye and elicited questions. But was that why people were wearing them? At first, I assumed that they appealed to patients because they gave them a means for identifying biological peers, or at the very least sympathetic others. A story that one young woman posted in cureibd seemed to back this up. She wrote,

> went to a new rock climbing gym today, just to check it out. As I was climbing around, I noticed a guy who is probably one of the best climbers I've ever seen (plus, he's super buff and cute). At one point when I was bouldering around, he came up to me and asked what my blue bracelet said. I said 'Got Guts, it's for people with...' and he goes 'Crohns and Colitis. Yea, I think I left mine upstairs.' We both had the moment of understanding, then started conversing about our diseases. He said he had colitis, and I asked for how long, and he said he'd HAD it for four years, and I knew what he meant–he lifted up his shirt to show me the scar from where he got his colon removed (not to mention his niiice 6 pack). We climbed around for a bit and talked about having UC, and then he had to leave. But we did exchange numbers to go climbing again, and above his number he wrote his name, '(no colon)'.
>
> It was so awesome!!! We were both like the first people we'd met in the city who had UC or Crohns, or at least that we knew of.

In this forum participant's case, the bracelets are a technology pressed to the service of identification. The "moment of understanding" she describes is a social shorthand, enabling each person to make an empathetic guess about the other person's medical history and relationship to a thing called ulcerative colitis. The bracelets summarized, to a certain extent, the wearer's location in a network of practices, technologies, and knowledges making up Inflammatory Bowel Disease: either as a patient, ex-patient (in the case of the rock climber),[26] or "supportive" and presumably "understanding" peer or kin.

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[26] People who have had a colectomy consider themselves 'cured' of ulcerative colitis—no colon, hence nowhere for colitis to live. The story reports that the rock climber "said he'd HAD it for four years, and I knew what he meant"—the emphasis on the "HAD" is understood as shorthand for major surgery.

Though this young woman's story of meeting a cute rock climber with no colon fit my theoretical concern with identification and likeness, I realized that the social life of these objects didn't begin at the moment they were worn. Conversations with Megan forced me to think and rethink what was going on. A month or so after the bracelets' first appearance in cureibd, Megan's boyfriend ordered her ten bracelets, and she mentioned the transaction in her personal weblog. When I expressed my interest in this (she had already read the musings in my research journal about the items), she offered to send me one once they arrived—she would be, she believed, the first person in the Lower Mainland to have one. I asked her for her interpretation of the bracelets: were they "fundraising" or "awareness" products? She wrote back,

> i kind of got the impression that it is almost a chain letter type thing after reading through some of the posts in cureibd. my own intentions were to give them to family and friends to wear in order to show their support and to increase awareness...basically, i want to get them into circulation up here.
>
> from what i gather, the purpose of the CCFA's sale of the bracelets is similar to that of the lance armstrong yellow cancer bracelets. when you purchase them, the money goes to the ccfa (i'm assuming for research) and wearing them both shows support and increases awareness.

In what follows, I will attempt to describe the logic that connects "support" to "awareness" and "fundraising" via an ethics of circulation and dissemination. I will move outwards from the Got Guts bracelets to examine how other awareness commodities move through and beyond IBD cyberspaces. These commodities also link different IBD cyberspaces together. Though much of my analysis here could be applied to any object or technology related to illness—especially mainline pharmaceuticals, alternative medicines, and ostomy technologies—I am focusing on these items because their role in the cultivation and maintenance of patient sociality and "awareness" is made so explicit by the people who create, use and share them.

Public and Private Illness

Browsing through various patient communities one day, I came across a website selling t-shirts reading "I am stronger than Crohn's Disease." Cureibd had been busy with conversations about the need to raise awareness (Megan had recently started an email campaign to get Oprah Winfrey to do a show on IBD), so I decided to post in the forum and test the waters. Up until this point, I had been a fairly silent participant, posting only in order to recruit interview subjects. In keeping with Heath et al's approach to the ethnography of networks, I see my interpellation of the group as a "modest intervention": an active engagement in order to render "links between different domains visible. These interventions reveal how knowledge practices arise from the intersections among the people, places, and electronic artefacts that make up and are brought together by these networks" (Heath et al. 1999:451).

Posting an image of these t-shirts with a link to the online shop selling them, I asked, "What do you think? Would you wear one?" Responses were immediate and contradictory. A few participants agreed with one young woman, who stated, "they are cool, but personally i don't want a shirt that invites people to ask me questions or announces that i have a disease." She then clarified, "i don't mind telling people what i have at all, just that i mine being approached by random people and asked questions ya know." Another woman, in her negative assessment of the t-shirts, focused on the embarrassing aspects of explaining Crohn's Disease to outsiders:

> god it took me enough to even admit to my family (extended, obviously my parents knew) that i was getting a colonoscopy
> why dont i just open myself up for a million more jokes about things being shoved up my ass???

Others emphatically disagreed: one wrote, "Public understanding, public awareness=more funding for research. Also, shorter bathroom lines, and I don't have to physically remove people in my way." Another expressed uncertainty about wearing a t-shirt "in public" but said that s/he would buy one "and wear it around the house and on hospital visits and what not." In all of these comments, there is an explicit concern for the appropriate place in which to reveal one's disease status. Participants who had elsewhere ranted about the problems of "misunderstanding" seemed reluctant to wear a shirt that invited comment, speculation, or queries about their condition, and some were clear: they'd buy the shirt, but they wouldn't wear it around non-sufferers.

The t-shirt discussion had ramifications besides inciting debate about the relative value of privacy versus awareness: it illustrated the connections between different IBD cyberspaces. One day after my original post and question, the designer of the shirts found my inquiry and responded. This was unexpected, as I had found the link through a forum I had considered to be spatially and demographically very "distant" from cureibd and which seemed, unlike cureibd, to have very few young people participating. The t-shirts' designer interjected in the thread, responding to some of the uncertainty about publicly claiming Crohn's Disease. He wrote,

> Hi everyone,
>
> These t-shirts are my doing. I suffer from Crohn's Disease (for over 4 years now) and I thought it would be good for awareness.
>
> The concern is "people will ask questions..." Well, that was the point. Every time someone asks you a question about your shirt, you have the opportunity to educate someone. It may make you uncomfortable at first, but that is the way each of us can make a difference.

Responses to his interjection were conciliatory and enthusiastic, and, interestingly, mostly from ulcerative colitis sufferers who wondered whether he could make a version of the shirt specifically for them. One sufferer wrote, “I would be very proud to order and wear one of your T-shirts for UC. I would just have to wear it on days that I don’t mind getting a lot of questions from strangers!” The speaker here is offering a bargain, attempting to mediate between personal discomfort and patient duty. Another commenter agreed, adding,

> Right on. I’m all for education and awareness—the more people know about Crohn’s and UC, the better a chance we get for funding to try and fix these evil, evil diseases. Not only that, awareness provides an opportunity to help overcome the discrimination most of us have encountered—whether it’s people thinking we’re “doing it for attention” or that we “don’t look sick enough.”

Fundraising, Circulation, and Empowerment

In the course of my research, I had the opportunity to interview a number of people involved, to greater or lesser degrees, in the IBD advocacy movement. These people differed from “ordinary” patients in their explicit commitment to generating and cultivating patient sociality. Such individuals often seemed eager to answer my questions, and their surveys were marked by exceptional detail and elaboration, creating the impression that they had deeply reflected on their answers and were used to giving them.

The IBD activists I interviewed spoke as though fundraising, the economic value of their awareness efforts, was epiphenomenal of the “real” goal of awareness—making patients. Leah, a patient-participant in ColitisSucks, was a volunteer organizer for two awareness projects—a quilt project (mimetic of the better-known AIDS Quilt) and a bike marathon. She spelled out for me her understanding of the relationship between “awareness,” “support” and “fundraising”:

> The current sole purpose of [the quilt] is awareness and support, not fundraising... I personally believe that [the bike marathon]’s most important purposes are (1) awareness raising and (2) giving the IBD community an empowering event through which they can connect to others with this disease

> and get personally involved in the cause. The empowering nature of events such as this one cannot be overstated.
>
> Fundraising is also very important and good fiscal management (wasting no dollars) is crucial. So as to not misunderstand - while I rank fundraising somewhat behind awareness and community empowerment, I do not put it all that far behind. The three are very much linked.

Leah's position as an organizer, which has made her responsible for locating donors and sponsors, may motivate the second half of her statement, wherein she retracts a little on her subordination of fundraising to awareness. In an audit culture such as the one that increasingly pertains to non-profit advocacy groups seeking the goodwill of potential donors, "good fiscal management" has become an important rhetorical and practical ethic. However, the first half of her statement (it was a response to a direct question from me about the relationship between fundraising and awareness) illustrates a logic of circulation and involvement that would appear, in modified form, in other interviewees' talk about awareness.

Leah presents awareness as a matter of cultivating patients. An aware patient is one who is connected to other patients, involved in the common cause. An aware patient is also empowered through her knowledge of and involvement with other patients. Making *patients* aware is more crucial than cultivating the knowledge and support of outsiders, although I will return in more detail to this later. Liz, Leah's co-volunteer at both projects, sent, to my great surprise and delight, a parcel full of brochures and t-shirts to my departmental address. (I assume she found the address through my website.) When I emailed her thanking her for the gifts I asked her where she thought I should distribute them. I should give them, she told me, to "those IBD friends of yours. We'd love to have a [quilt] square from any of them."[27]

Misunderstanding, Discrimination and Awareness: Ethnotheories of Patient Sociality

Building on some of the models developed within medical sociology, Sue Estroff (1993) has outlined the social processes producing the American experience of chronic schizophrenia. Her outline is broadly applicable to other chronic conditions, both "mental" and "physical." Estroff envisions chronicity as a series of nested disruptions and reformulations of the patient's identity. This disruption necessarily occurs within social, familial, institutional and sociopolitical settings:

> Chronicity and disability are thus constructed by: the temporal persistence of self and other-perceived dysfunction; continual contact with powerful others who diagnose and treat; gradual but forceful redefinition of identity by kin and close associates who observe, are affected by, or share debility; and accompanying loss of roles and identities that are other than illness-related. (Estroff 1993:259)

The chronically ill person—particularly when afflicted by what Estroff describes as "I Am" illnesses: schizophrenia, epilepsy, diabetes—undergoes "a fusion of identity with diagnosis" (Estroff 1993:251) as their social world constricts to accommodate symptoms and treatment. This tendency is fossilized and exacerbated, Estroff argues, when the person is unable to contribute to productive labour. The surrounding community, through agents of social welfare and health delivery, scrutinizes the sick individual and allocates moral judgement based on perceived willingness to work. Estroff describes the "can't versus won't" controversy as underlying

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[27] This was an indirect reference to a statement on my website, where I mentioned that although I did not suffer from IBD myself, I had friends who did.

> much of the apparent ambivalence in the West about persons who are chronically ill and disabled. We cannot reward role refusal, but must assist inability borne of innocent, impaired functioning. We cannot invite or tolerate large scale, protracted defiance of functional requirements, but we should not punish and neglect those who are *actually* unable to contribute at expected levels. (Estroff 1993:252)

The scrutiny to which the chronically ill are subjected extends from their productive capacity to the ontological status of their disease. Estroff sees this as a "profound Western cultural problem" (1993:252): establishing the visible, verifiable reality of the illness. A virus, a gene, a lesion—the indexical presence of dysfunction must be identified to validate claims to inability.

Estroff's outline of chronicity conceptualizes the reformation of identity as a social process whereby the patient is forced into stigmatized social roles, experienced subjectively as a tension between self and non-self. In order to preserve the culturally-mediated expectation of an intact, functioning self, the patient objectifies his or her illlness as "not-me," stepping away from the possibility of moral responsibility for disease. This pattern is observable in cases of acute, sudden affliction; however, "a more profound and exaggerated process occurs when the affliction is severe and long-lasting" (Estroff 1993:256). As the illness extends its presence in the patient's life in time, it becomes harder and harder for the suffering individual to maintain the otherness of the affliction.

I mention this approach to chronicity not to validate or debunk its applicability in the lives of IBD sufferers, but rather to engage with sufferers' own theorizations of their predicament. The ethnotheories of stigma and discrimination expressed by the patients I spoke to had points of similarity with early sociological thinking on chronic illness and frequently used tropes associated with other stigmatized identities (such as “in the closet”). In activist formulations of patienthood, it is the shared experience of stigma which organizes and makes meaningful patients’ experiences of identification with fellow-sufferers. Though none of my research participants used the word “stigma” specifically when talking about unpleasant interactions with non-IBD sufferers, they did sometimes use a different word: “discrimination.” This is the word that one cureibd participant above used in referring to the “awareness” t-shirts that I had mentioned. The idea of discrimination was deployed in patient conversations and interviews in order to make arguments about the importance of awareness.

The symptoms of IBD, most of which relate to bowel habit and control, are socially polluting (Soivio 1999; Manderson 2005) and cause immense social discomfort in addition to their physical and emotional toll. However, the disease label is not a barrier to social integration, as is often the case with conditions such as HIV/AIDS, schizophrenia, or intellectual disability. In patient talk, “discrimination” and “misunderstanding” are products of the disease not being known.[28] It is this misunderstanding or lack of visibility which is the source of much of the social suffering that patients describe. Clearing up misunderstanding is one of the goals of awareness and thus patient sociality in general.

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[28] To be more specific, they are not known by the general public. A very different set of dynamics emerge when doctor-patient interactions in relation to bowel conditions are taken into account. Many of my participants described interactions with hostile doctors who believed their conditions were psychosomatic, factitious, or “just nerves.” A very common trajectory involved an initial diagnosis of Irritable Bowel Syndrome, a functional bowel condition “not associated with any known biochemical, serologic, or structural disorders” (Olden 2003:S10) and then a rediagnosis of IBD following a crisis or hospitalization. These trends are also described in the health psychology literature on bowel diseases (Janowitz 1992; Dixon-Woods and Critchley 2000).

Patients describe how shame and abjection "isolate" them from other people. The lack of control they have over their own elimination disrupts the routines of everyday life. The world, which was previously envisioned as a set of social and productive milieus, starts to look more like a set of agonizing paths between bathrooms.[29] One poster to cureibd said that this re-organization of the world extended into her dreams—"I just realized that in my dreams I make sure my dream self is always near a bathroom." (Several participants chimed in that they had had similar dreams.) Because of the secret and polluting character of elimination and the lack of understanding on the part of coworkers, friends, and other significant others, patients feel like they are constantly cleaning up or hiding their illness for the benefit of other people. This secretiveness is seen as a barrier to patient sociality and understanding, because sufferers overinternalize their sense of shame, hiding their disease both from antagonistic outsiders and potentially understanding biological peers.

Meeting or otherwise encountering similarly afflicted others is experienced as relief and a loosening of inhibitions. One of the most notable features of this loosening is the enjoyment of a simultaneously playful and serious scatological humour, whereby they can release their embarrassment without fear of judgment or "misunderstanding." Patients feel that they understand one another's experiences, which invokes a sense of empathy and a desire to help through sharing.

The things that sufferers do to "support" each other as ethical patients follow a variety of tracks—from textual expressions of understanding, to wearing or exchanging

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[29] Patients often dwelled on this psycho-geographic transformation in their discussions with one another about the problems of IBD. Indeed, as I discovered, the main German advocacy organization, Deutsches Morbus Crohn/Colitis ulcerosa Vereiningun, has as its logo a labyrinth, suggestive of both the human intestine and the tortuous routes patients are forced to follow to find respite.

bracelets and t-shirts, to creating quilt squares, to running or cycling on one another's behalf. Talking about the biking marathon she organized, Leah stated, "The empowering nature of events such as this one cannot be overstated," and this sentiment was widely shared in the patient communities I followed. Seeing biological peers enacting their health in athletic tournaments is described as inspiring and empowering for the ill individual. When I asked cureibd participants whether they thought that athletic fundraising events—which, after all, are common practice across many different disease categories, from AIDS to cancer to Parkinson's Disease—excluded disabled or seriously ill individuals, all of the eight people who responded to my question denied it. As one participant commented, speaking of her own involvement in an upcoming bike marathon, "I can only hope that seeing fellow sufferers participate would comfort one in knowing that hopefully someday when they are feeling better they would be able to do the same." The advancement of an idealized, athletic, participatory patient body is presented as a positive act because of the way in which it enables identification.

Identification is never abstract: it always occurs in the context of particular practices. Comparison is oriented toward action—in this case, empirical tinkering with and improvement of the body as well as political organizing on the part of a particular category of person. Hope emerges out of the way in which the *practice* of identification is linked to its predictive power.

The Disappearance of Value

Erin, a member of cureibd who also gave me permission to follow and quote from her personal weblog, wrote an interesting entry about the Got Guts bracelets in August of 2005.[30] At first, she wrote,

> I thought it was kinda neat: people could ask each other what each other's bracelets were for, therefore bringing awareness to other people. Of course, I was being totally optimistic (it happens sometimes) and shortsighted; I didn't even envision where the trend would go.
>
> Yes, it's a trend. And if it's not over yet, it should be.
>
> The problem was, things got way out of hand. Every cause had its own bracelet, causing colour overlap and market fracturing. Pretty soon, it was common to see teen girls with arms full of the things, like they were part of the 100 bracelets she got from the Pineapple Sticker Club. So, let me get this straight: you're about bringing support and awareness to the causes of Breast Cancer, Lung Cancer, Cancer in general, Children's hospitals, Liver Disease, World Hunger, MS, CF, Tsunami Relief, and Chronic Logorrhea—among other things? How very noble of you. Can you tell me anything about your pet causes? Besides "OMG, it sucks?" Wearing all your bracelets at once weakens the message of all the bracelets, if they even carried one for you at all. Not that you care beyond your bracelet.

The awareness bracelets had become meaningless because the symbolic properties of the items had been fractured and their use had become dissociated from personal and familial sentiment. In other words, they had become commodified. It was simply impossible, she speculated, for such people to care about as many causes as they symbolically affiliated themselves with. They were doing it to be fashionable: "Be a supporter—or just look like one! Collect 'em all!"

A commenter on her journal wrote that he and his family continued to wear the yellow bracelets because his father had survived pancreatic cancer—implying that this was made possible by increased awareness of early detection. Erin responded, "yay for

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[30] She did not provide answers to my interview questionnaire, and as such is not listed in the Appendix. I obtained informed consent to quote these excerpts. Erin is a pseudonym.

early detection! And yay for not having to bury a parent yet! If I had a bracelet for every disease me or one of my relatives had, I'd have an armful for sure."

Erin's mother had died of lung cancer, caused by heavy smoking, two years previously. In the two intervening years (and the agonizing period leading up to her mother's death), she had written extensively about her grief, how their illnesses intertwined—nicotine is frequently used as a treatment for ulcerative colitis (Loftus 2004; Birrenbach and Bocker 2004)—and how guilt and blame were unavoidable consequences of their relationship. Before her mother's death, she wrote about getting up first thing in the morning to buy her mother a pack of cigarettes. She was trying to be a good daughter, to take care of her mother's needs, but—"i've failed. how can i take care of my mom when she insists on making things worse and hastening her demise even more so? how can i take care of her when i enable her harmful behaviour? i feel like a tool."

In Erin's rant about the bracelets, the disappearance of value is linked to a lack of care. Because personal or familial ties do not exist to provide a moral context for the bracelets, they have become meaningless. Her post ended with the following sally, which gestured at her own familial history:

> Does this mean that next year, nobody's going to care about anything? Perhaps. But if you're looking for the next big disease, I'm willing to wager that it's gonna be Lung Cancer. It's due.

Other commentators on the bracelets declaimed against this seeming lack of intimate care, often citing personal or familial experience as the appropriate basis for identification and support. Karla Jay, writing in the *Chronicle of Higher Education*, argued,

> How, for instance, do some college students reconcile wearing a yellow bracelet while smoking? By now most people, including employees of the tobacco companies, are aware that smoking or using smokeless tobacco is a leading cause of cancer and that secondary smoke is almost as harmful. As a cancer survivor myself, I resent those who claim to support cancer education while causing the very illness they pretend to fight against. (Jay 2005:B5)

In Jay's words, the bracelets were "cheapening" the unassailable causes of awareness and support by reducing them to a wearable item. True commitment would be engaged and relational. She saw it as her duty as a cancer survivor to teach her students a more "meaningful" way of relating to illness. As part of their credit requirements for college courses, Jay said, she made her students engage in community volunteer work:

> [T]he experience of community outreach is life changing and almost addictive. They bond with and learn from survivors of all stripes instead of pitying or fearing them. In return, the students are empowered by their ability to cope with and manage difficult situations. (Jay 2005:B5)

The "bond" which people grow as a result of knowing and learning from survivors is not unlike the "bond" posited, in patient-targeted literature and patient talk, between IBD sufferers—a bond that is emotional and experiential rather than strictly biological. What we are seeing in this field of action, contra Rabinow, is not simply a division of social life through technological intervention into ever-smaller classificatory fragments—"the chromosome 17, locus 16,256, site 654,376 allele variant with a guanine substitution" (1992:58)—but rather a set of discourses and practices that link different categories of person together. IBD sufferers are "empowered" by coming "out of the closet"; they are "survivors" who "learn from one another's experiences." The language of ethical patienthood appears to vary little across disease categories. More to the point, it is mimetic: cancer and AIDS patienthoods are orienting referents for any attempt to cultivate patients.

The controversy over the bracelets illustrates both the appeal of and the tensions inherent in identification as a political performance—because they cannot guarantee an inner transformation on the part of the people who wear them, their value is compromised. "Awareness" and "support" are legitimate goals, but in order to be ethically accountable, they require the kind of commitment that requires a literalization of bonds.

From "Friends" to Family

Elizabeth and Wilf met through ColitisSucks. At the time, he lived in the Netherlands; she in Western Canada. Their long-distance romance, enacted first through semi-public flirtation on the forum, then through private email, and eventually in person, crystallized around mutual support during chaotic and painful periods of illness and surgery. Three weeks after their first "face" meeting they were engaged, and six months later they were married. Elizabeth packed up her life in Canada and moved to the Netherlands. At the time of my interview with them, they had been married seven years. The signature on their joint email appended the boast that they were the "*original* Sux couple".[31]

Though their diagnoses, understandings of etiology, and treatment regimes are different—Elizabeth has Crohn's disease, Wilf has ulcerative colitis—they emphasized that their shared experience of illness coloured their marriage with a particularly painful intimacy. After a lifetime of suffering in solitude, hiding their embarrassing and polluting

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[31] Tracy, another ColitisSucks member, also met her husband through the forum.

symptoms, seeing that pain reflected on the aspect of a loved one amplified its horror. Elizabeth wrote, “I was used to ME being sick and could deal with that. But seeing somebody that I love so much being in a pain that I knew so well, was really difficult.” The knowing of a specific type of pain produced registers of empathy and identification that bypassed the verbal. And this was where marriage to a fellow-sufferer began to pay off: “not having to explain when I have a bad day,” Elizabeth said, “because the other one knows and understands it so well, is really worth it.”

In 2003 Elizabeth was encouraged by a counsellor to “write out” her fears about Wilf's impending surgery. To do this, she made a web page narrating the darkest points of their life together. The story began with Wilf's previous surgery in the summer of 1999. Following a seemingly routine first step of the three-step j-pouch procedure, Wilf's condition took a turn for the worse. He went into shock and was moved to intensive care, where he was sedated, defibrillated, transfused, and attached to an air-pressure machine to “knock the bad germs from his shocked lungs.” Elizabeth wrote,

> Here in Holland, the hospital staff make notes in your personal notebook which is left at the foot of your bed for the next staff member to read when they come in.... I read many entries in that period that said “the wife is here again, she sits and holds his hand, and cries, we don't know what to say to her....” What can you say to somebody who has been married for less than a year and has only just moved to a totally foreign country, doesn't understand the language completely and is confronted with a severely ill husband who is attached to so many drains, monitors, IV's and tubes that she can't even kiss her man without fear of disrupting the very things keeping him alive?

The new round of surgeries had its own complications and setbacks. Wilf was on a waiting list and his surgery kept being postponed. In the meantime, he was unable to eat and was being fed through a tube. An internet friend and fellow-sufferer flew in from Manchester to help them through the stressful waiting period. All the while, Elizabeth continued to write and to engage with the text-world of the online support group. “I was blessed in my friends from Sux – I had offers of support from all quarters.... I cannot begin to thank Sally enough for caring and being able to be here with me. It took a lot of stress of both my mind and Wilf's."

Elizabeth and Wilf's relationship is both visceral and literary; mediated and immediate. Her account of their physical separation by the machines keeping him alive incites reflection on the roots of their connection: because they are naturally united through marriage, community membership and experience, the technological boundary is framed as an unthinkable rupture.

Visible and Virtual Bonds

IBD patienthood is in many ways determined by a discourse on the relationship between the visible and the evident. The invisibility of the illness exists on several different levels—it is not well-known; its symptoms are embarrassing; it involves private bodily functions; it is isolating. Efforts by activists to create a patient polity that is "engaged" and "empowered" are oriented toward making the illness visible. The creation and circulation of items that signal an ethical commitment to overcoming IBD acts as a bridge between the "virtual" world of online talk and support, and the visible world of flesh, blood, and intimate relationships.

As the preceding cases show, many patients articulate discomfort with "going public" about IBD. Though they know that it is ultimately in their best interests, they worry about the immediate consequences—particularly "having to explain"—of revealing their disease status to outsiders. Community with fellow-sufferers, in some sense, provides them with a context in which certain things are already evident and do not have to be said. Oddly enough, however, they are said again and again. Understanding, experience, and knowledge, as the appropriate bases for ethical relationships, have to keep being reiterated in order to maintain their force. Otherwise, like the bracelets, they become "meaningless"—visible, exterior, and evident, but also shallow and empty.

This formulation of the relationship between a thing's visibility and its "out-there-ness" complicates the argument, made by many medical anthropologists and sociologists, that visualizations of *cause* are especially desirable among patients with "invisible" or "hidden" chronic illness. With IBD, the acts which render the disease visible (colonoscopy; loss of bowel control; weight gain due to prednisone use) are often horrible, painful, and abject. Keeping symptoms under control means keeping things inside. "Experience," as a way of knowing that is not entirely visual in its frame of reference, suggests a sensory holism that does not rely upon seeing for understanding. Tracked on to the virtual relationships between patients, this discourse asserts and reasserts their predictive, ethical likeness—without mandating a single, identifiable marker of similarity.

CONCLUSION

When IBD sufferers talk about the similarity of their bodies, they often do so while referring to the source of their knowledge of that similarity: a news story, a doctor, a friend's anecdote, an informative website, an advocacy pamphlet, a support group meeting, a book on naturopathy. Their most intimate likeness is a fact supported by a massive knowledge apparatus distributed through their worlds and made available because of particular medical interventions in their bodies and an increasingly dense mass of information available through the internet. Having been scoped, prodded, diagnosed, misdiagnosed, rediagnosed, excised, and drugged, each patient is already bound up in these networks, reliant on their interventions to ease their suffering. When a patient being tested for Crohn's disease goes to the gastroenterological clinic at Vancouver General Hospital, they are greeted by a wall of pamphlets produced by the Canadian Society for Intestinal Research (underwritten by Schering Canada, makers of Remicade) explaining the condition they might have and giving advice on how, as a person with Crohn's disease, they might appropriately relate to others. "I share my problems, but do not dwell on them," reads one of 15 Guidelines on one such pamphlet. "I am in a group of people with a common bond," reads another. Surgeons, x-ray technicians, nurses, and specialists, seeing them through painful and abject crises, sometimes give them words of advice and consolation: as Erin wrote in her online journal, "hey, even my normal GI doc came to see me, a move which broke down my facade and made me weep. 'you've got some guts,' he reminded me." Perhaps they receive in the mail, as Megan did, a bracelet from an internet friend, to wear as a symbol of their resilience—linking them back to the CCFA, to one another, and to an acceptable "survivor" identity. All of these are examples of the ways in which experiences of suffering understood as fundamentally *private* are scaffolded by specific institutions of knowledge and expertise. They are alike because they are caught in the same nets, and because the facts with which they order their worlds come from the same sources.

The peer networks described in this study present for us an interesting question: are relationships initiated and conducted between people sharing a diagnosis of IBD exemplary of a new, or at the very least interesting, model of affinity? Moving outside of the traditional boundaries of the analysis of chronic illness—the individual body, the medical case history, the illness narrative—how does experience-talk, through its arrangements and deployments of symptoms, states, and organs, draw old relationships out of new materials?

Attempts to make biosociality into an anthropologically engaging concept have generally focused on how metaphors of genetic descent and reproduction interact with scientific and lay descriptions of similarity (Helmreich 2003; Ley n.d.). Other writers use the term as a proxy for a particular type of novel polity—the patient organization (Rabinow 1992; Nguyen 2005a, 2005b; Dumit 2004)—which is presumed to be the "social" manifestation of biopolitics. The sense that "kinship" has something to do with these phenomena is not ungrounded, although there is a lack of consensus on how to treat kinship as a phenomenon. Is the existence of biosocial organizations evidence for the fact that social life—into which I'd subsume concepts of the person and of relatedness—is undergoing a transformation towards the biological, or are there registers to the type of social interactions taking place in such contexts that suggest alternative explanations?

Untangling these questions is difficult precisely because of how "kinship" appears in everyday life: as a powerful interactional and representational resource with significant political effects. Rapp, Heath, and Taussig (2002) point to some of these problems in their discussion of advocacy groups for people with dwarfism:

> In the 1950s and 1960s, before the widespread availability of growth hormone... LPAers [Little People of America] described an organizational hierarchy based on proportion. Pituitary dwarfs (whose short stature was caused by a growth hormone deficiency) were widely viewed as the elite of the organization. Normally proportioned, they dominated social functions and held all the important offices, at least in the memory of several older activists. Achondroplasts ("achons"), with their alternative proportions (longer trunks, shorter limbs, and larger heads), were considered the plebes of the population. (2002:396)

A metaphor drawn from a pre-existing model of society—plebes and elites—is used to describe relationships between members of a biological category and to illustrate the differences between them. In an American context, this depiction of sociality is explicitly critical: it foregrounds exploitation and hierarchy by citing the Roman polity. (One wonders whether pituitary dwarfs or achondroplastic dwarfs were responsible for crafting this metaphor.) In formulations of ethical patienthood crafted by IBD sufferers, the metaphors more frequently used are familial or "friendly." However, these metaphors are remarkably plastic, attributing to families (and friends) a variety of different qualities. Nancy, describing the members of ColitisSucks, wrote, "we're like a big internet family. Not everyone gets along all the time." She followed this "realist" assessment of familiality with the following comments:

> People are always willing to help. And you can always count on support, and sharing of knowledge (and that knowledge and experience level has increased greatly the bigger Sux gets. Now there's always someone that seems to have 'been there, done that'.) And there's still a sense of camaraderie, or something. It's hard to describe. I 'know' lots of Suxters better than I know my 'real' friends. The subjects that IBD leads to discussing (like how many times a day you go the bathroom) lead to a greater level of intimacy than you would get with most real life friends/acquaintances.

"It's weird," she wrote, "you know all about these people and the minute details of their lives, but you have no idea what they look like." Intimacy is not reliant on proximity or shared substance—it is, rather, a product of the day-to-day iteration of similarity through conversational practices of comparison. "Experience" sediments and becomes distributed through the informatic structure of online forums: the bodies of others, although virtual and distant, become embedded through narrative practices.

The "realness" of similarly-afflicted others—versus the abstract, standardized sameness of medical information—delivers what Karin Knorr Cetina calls "the embeddedness experience" (Knorr Cetina 2001:532). In her meditations on "post-social relations," she argues that "object worlds"—among which I'd include cyber-environments, where others are frequently invisible or unknown—embed individuals through the way in which they encourage position-taking. Looking back at George Herbert Mead's theorizations of social interaction, she writes:

> Mead devised his famous role-taking formula for an interpersonal sociality, which he thought comes about when a person sees the world from the perspective of the other, includes in his or her perspective-taking the other's attitude toward him/herself, and when the process is mutual, involves both parties in an interaction.... The process of position-taking involves the subject's 'becoming the object', a sort of crossover through which the subject attempts to see the object world from the inside, to 'think' as it does, and to feel its reactions (Knorr Cetina 2001:531).

The "structural affinity between subject and object" in online social relations—a structural affinity enabled by particular practices of comparison, extrapolation, and testing—"provides a sort of backbone for the idea of a reciprocity" (Knorr Cetina 2001:530). It is this reciprocity, literalized through the giving and receiving of "information" and "support," which allows claims of identification and duty to become a crucial part of the work of patienthood. This is perhaps what Joyce Lamerichs had in mind when she puzzled over why support seemed to be "an accountable matter"—why it seemed "so troublesome to ask for support in a straightforward fashion" (Lamerichs 2002:62-3). Support is one transactable in a moral economy which has as its goal the production of a certain type of person: one that is aware, rational, and self-determining, yet also empathetic, open, and giving. "Personal experience" is a form of currency that everyone has, albeit in different measures; the value of biological peers emerges out of their ability to partake in morally accountable and collectively beneficial exchanges.

I'd like to return for a moment to Bruce's description of interpersonal "flare ups" cited in Chapter One.

> These fights would blow up and then die down, and blow up again, sometimes simmering for a year or more between flare-ups. And then someone would say something that someone else would take offence at and the whole thing would ignite again.

Here, Bruce describes social discord in terms that are metonymic with how patients describe the course of inflammatory disorders, including IBD. In earlier drafts of this thesis, I avoided drawing attention to his wording because I believed that extending this interpretation would be apophenic reasoning on my part. However, after rereading Emily Martin's seminal ethnography *Flexible Bodies*, I decided that Bruce's account was worth further discussion. Martin writes, "(immune) system thinking has permeated our culture" and worries about "the propensity to extol harmony within the system and reliance on the group while paradoxically (and distractingly) allotting individuals a dynamic, ever-changing, flexible role" (Martin 1994:247). I recalled the title of Elaine Gottschall's SCD self-help book—*Breaking the Vicious Cycle*—and looked back into my field notes on pop patient literature. W. Grant Thompson, author of *The Angry Gut: Coping with Colitis and Crohn's Disease,* writes,

> The gut is the body's principal port of entry, and its tortuous anatomy constitutes a vast frontier. If the body is to restrict entry, it must have a customs and immigration service; otherwise, the gut would be subject to invasion not only by nutrients but also by all the microbes, toxins, inert substances, and other flotsam that pass its way. Many protective mechanisms are in place.... Those items denied entry are carried away by peristalsis. Despite this, invasive bacteria or damaging toxins can breach the epithelial barrier, permitting entrance of unwanted aliens. It thus falls to the body's immune system to police the frontier and destroy or deport the invaders. (Thompson 1993:9-10)

In Thompson's description and in Gottschall's theory of intestinal harmony, we see different envisionings of autoimmunity which nevertheless generate an isomorphism between a model of society and an understanding of the body. The notion that the body (via the immune system) can be a "knowing," "aware," "community" is engaged by Martin, and reflected in the following excerpt from Jini Patel Thompson's self-help book *The IBD Remission Diet.* Patel Thompson divides the body from the mind in a way that transposes their usual positions within Cartesian frameworks: the body knows, the mind acts. She writes,

> Accessing your body's wisdom is very simple. Lie or sit somewhere quietly, wherever you feel most relaxed—it may be in your bed, your living room, at the beach or in the forest, or in the bathtub with some candles lit. Do some deep breathing for a while to relax your body and your mind. When your limbs feel heavy and you maybe feel a little sleepy, place your hands on your belly and ask your colon/digestive system how

> long it needs you to stay on the elemental diet. If you're not used to using your intuition, or asking your body for guidance, the feeling you get may be quite vague or faint. Don't worry about that, no matter how 'iffy' the first answer or impression feels, act on it and stick to it.... You asked your body and your body told you what it needed and it's best that you honor your body by following through. (Patel Thompson 2003:29-30)

In this description, needs and knowledge are attributed to an objectified but agental body, not to the self or to the mind, and practices of care become directed toward an other that is conjured through a practice of dialogue. The patient invites herself to "become the object" and to empathize with it. Listening to the body and acting towards it as though it were another person is morally reasonable in part because the body is not the self. Self-care becomes an ethical *act of listening*.

Amy Shuman (2005), writing on the politics of experiential discourse in practices of storytelling, critiques the naturalization of empathy and the way in which empathetic identification is seen to inevitably result in social solidarity. Describing the textual and speech modalities of illness-based activism as rhetorically not unlike "political junk mail," Shuman writes, "appeals for money in junk mail letters are based on the idea that by helping the cause, you, the reader, help the person. The premise in such appropriations is a metonymic fit between the person and the cause, or an allegorical relationship between the personal and the universal.... an uncontested fit gives the appearance of an essential, 'natural' reference, in which the cause is to the personal situation as the whole to its parts" (Shuman 2005:124). If all of the isomorphisms described above are "allegorical conflations" linking the individual body to (particular models of) society and to an idealized community typified by reciprocal dialogue, what kinds of social action, interpretations, or experiences might these conflations foreclose?

Let me give an example from cureibd to explain how accounting for participation normatively requires resort to naturalizing metaphors. One day, a young woman posted a fairly routine question about medication which she prefaced with the offhand statement, "I'm new to the Crohn's scene." Angry reactions from other participants zeroed in on her use of the word "scene": it implied things they did not think reflected their reasons for using online support groups. For these young people, "scene" was associated with trendy music, fashion, and other practices marked as consumerist and inauthentic. The word "scene" implied choice rather than needs, self-enrichment rather than ethical relationality. Likewise, Erin's concern, described in Chapter Three, that the "awareness bracelets" had become "a trend" were countered by a commentator's insistence that he had an ethical, *familial* reason for wearing them. Thinking about "kinship", then, requires reflection on how families are idealized and how those idealizations make kinship an especially flexible resource in fashioning communities as responsible. Because of how family relationships are assumed to be accompanied by an "enduring, diffuse solidarity" (Schneider 1980), they are easily transferred metonymically to other, desired forms of affiliation.

Knorr Cetina sees self-help phenomena as manifesting "subjectivity thinking and subjectivity imagination" (Knorr Cetina 2001:524)—an "emptying out of a social imagination" (525) in which the individual's internal needs are posited as the nexus of sociality. Critics of "health consumerism" make a similar claim when they argue that the "disappearance of the clinic" has left patients to fend for themselves in a sea of contradictory and often unreliable knowledge about illness. I would propose that the expansion of patient identification is perhaps better understood as an expansion of patient *context.* Internet communications—with which many of my research subjects would likely have been involved despite their illness—have a unique set of rhetorical modalities, interactional stylings, and currency demands. In patient settings, one identifies as a patient in order to meet to those demands and to perform an adequate self-presentation. Modes of speech—"ranting," "meds talk," pleas for help (Hall et al. 2004)—are imbued with conversational cues that require or incite particular types of response. That which appears, to the outside observer, to be a desperate cry for help in dealing with an uncaring doctor *may* be indexed to an unmanageable health care system—but it may also be a way of conversing with others that is narratively coherent. That which appears to be a form of biological identification based on genetic resemblance may be a legitimating cue in a friendly discussion, an offhand mention of a curious news item, or a teasing joke.

It is possible that for many people, talking about illness in cyberspace begins as just something to talk about, and that community with fellow-sufferers does not become needed or desired until after it has already been instantiated. Because of the way in which hypertext perseveres and amasses, it is always ready-to-hand, providing the appearance of a distinct "community" of patients; and because of the way in which declarations of needs confront a moral economy of personhood, people have to account for their behaviour in ways that suggest the existence of an ethical relationship. Real ethical relationships are often drawn out of these communicative practices, but their priority to community is ultimately unknowable. The expansion of a literate context in which patienthood is a membership entitlement creates recursive loops—bodily being, mental state avowals, and management practices all need to account to a diagnosis in establishing an appropriate and moral ground for conversation.

This thesis has described how resemblance and empathy are flexibly deployed by IBD patients in accounting for their participation in online peer support, and how their likeness is always a matter of social and moral import. Biosociality, theorized as an institutional technology of likeness affecting intersubjective discursive strategies, operates most effectively as a critique of the cognitivist and needs-oriented models of affiliation that pervade health psychology. It can help provide a framework through which to investigate how (and why) illness-based organizations discursively produce "the material and semiotic effect of [a] natural relationship" (Haraway 1997:52) in their attempts to cultivate patients.

Directions for Future Research

Patient advocacy organizations and support groups, on- and off-line, are now an integral part of how medicine operates. The rapid growth of medical informatics and telemedicine, as well as the "virtualization" of the human body through technologies of visualization and modelling (Sandelowski 2002; Dumit 2004), means that diagnosis and treatment are increasingly removed from clinical settings. The rationalization of health care in many countries requires an increasing amount of research and labour by patients and their families. Moving medicine from the hospital to the home presumes, and requires, a particular type of home occupied by people with particular resources, skills, and understandings of responsibility.

The "ethical patients" and "good subjects" in this study are, as mentioned in the Introduction, relatively privileged. Though I felt it would be inappropriate to collect detailed information on household income and socioeconomic status, most indicated that they had privately-owned computers and health insurance, which in most cases are reliable indicators of membership in the middle class (though prolonged chronic illness can have a significant detrimental effect on real income). As stated by Mathews (2000), support groups are usually ethnically homogenous; and "the class-inflected etiquette of voluntary organizations may feel more comfortable for middle-class families who are used to assuming "new" professional identities and seeking help from specialized sources" (Rapp, Heath, and Taussig 2001:397). Considering that participation in patient groups is promoted as a responsible way of taking control of one's health, research is needed on the ways in which social class, mobility, and ethnicity determine participation.

There is almost no research in any field on class and computer-mediated communication, except as it relates to access (or to "race" and ethnicity as proxies for class) (but see Kendall 1998). The discursive modalities and language ideologies of ethical patienthood are likely middle-class ones; and the subjectivities that emerge from participation in patient groups may be closed off to those who do not have the time, money, or education to pursue them. Though cybersupport settings can be inclusive and socially meaningful spaces for patients, they may in fact enable, through their homogeneity, the reproduction of an acceptable form of biological citizenship based on an "unmarked" white, middle-class identity.

The forms of disease fundraising described in Chapter Three—especially those involving athletic events like marathons—have become ubiquitous in urban North

America. My surprise at participants' reactions to my critique of these events as potentially exclusionary to those with different levels of ability forced me to contemplate the connection between idealized "muscular" citizenships (Mol 2005) and idealized "rational" personhoods. Being bodily in certain ways appears connected to an ability to be rational in certain ways—marathon running, after all, is a highly rationalized and technically-managed process. I would very much like to see research in the anthropological tradition on how the practices of training for marathons are discursively associated with rationalized practices of disease management. In the figures of Lance Armstrong and Terry Fox, we also see formulations of national identity brought into stagings of survivorship, charity, and "support". The fact that national, familial, and experiential discourses are co-present with incitements to rational athleticism suggests important linkages between ethical citizenship, rational self-management, and intimate practices of love and care.

APPENDIX: STUDY PARTICIPANTS

Name	Stated Location	Stated Diagnosis	Age	Community Membership	Interview Method
"Noah"	Sunnyvale, CA	"Crohn's"	26	Cureibd	IM
"Dan"	Sydney, Australia	"UC"	24	Cureibd	IM
"Marianne"	Newark, DE	"Crohn's"	20	Cureibd	IM
"Sadie"	Wayne, NJ	"first diagnosed with ulcerative colitis when I was 15… rediagnosed with crohn's disease last year."	24	Cureibd	IM
"Megan"	Abbotsford, BC	"UC"	24	Cureibd	IM
"Alix"	Northern Virginia	"I had the final step of 3-step j-pouch surgery on October 13th of this year and so for the most part, I'm rid of UC"	-	J-pouchweb	IM
"Kim"	Kentucky	"ulcerative colitis"	18	J-pouchweb	IM
"Brandy"	Cornwall, ON	UC "I've had the j-pouch operation in 1998"	21	J-pouchweb	IM
"Valerie"	San Diego, CA	"I had UC, had my colon and rectum removed 9/24 and now have an illeostomy.."	-	J-pouchweb	IM
"Candace"	Dallas, TX	"I have just been re-diagnosed with Ulcerative Colitis. I am currently very anemic, severe sinus infection, chronic insomnia."	35	J-pouchweb	Email

Name	Stated Location	Stated Diagnosis	Age	Community Membership	Interview Method
"Pat"	New York	"colon cancer 3 ½ years clean"	43	J-pouchweb	Email
"Lucy"	-	"Pregnant I'm in good health"	-	J-pouchweb	Email
"Tanith"	Calgary, AB	"Indeterminate colitis."	38	J-pouchweb	Email
"Wynne"	Richmond, BC	"Juvenile Myclonic Epilepsy; Ulcerative Colitis; Type II diabetes, most likely as a result of the drugs I was on for the UC. I also have oseteopenia… as a result of the drugs for UC"	25	J-pouchweb	Email
"Todd"	Provo, UT/ Vacaville, CA	"post-op for a 2-step total colectomy with j-pouch ileoanal anastomosis with temporary diverting loop ileostomy (now reversed). This surgery was for ulcerative colitis"	21	J-pouchweb	Email
"Mike"	Idaho	"I have a J-Pouch as a result of a total colectomy resulting from severe ulcerative colitis."	33	J-pouchweb	Email
"Sally"	St. Paul, MN	"Moderate to severe Ulcerative Colitis, active, total colectomy / J-pouch construction recommended."	36	J-pouchweb	Email
"Kasia"	Krakow, Poland	"I was diagnosed with ulcerative colitis in 1996… In 2000 I had emergency surgery - colectomy. Then in 2002 I had j-pouch created."	37	J-pouchweb	Email
"Tom"	Toronto, ON	"Over all, very good, however, I do suffer from chronic pouchitis and have Migraine headaches, I also have osteoporosis, an unexpected surprise thanks to the years of Prednisone therapy!"	36	J-pouchweb	Email
"Michel"	Edmonton, AB	"UC diagnostic at 17yo, total colectomy and J-pouch January 2004. Currently I have chronic pouchitis"	32	J-pouchweb	Email
"Michael"	Thorton, CO	"1996 dx psc (primary sclerosing cholangitis- liver) 1999 dx uc, 2002-3 3-step j-pouch procedure (cured of uc). 2003/4 dx with soy allergy and nut allergy (may have been related to my illnesses)"	24	J-pouchweb	Email
"Patricia"	Port Coquitlam, BC	"Currently have a j-pouch and I am in excellent health."	31	J-pouchweb	Email

Name	**Stated Location**	**Stated Diagnosis**	**Age**	**Community Membership**	**Interview Method**
"Geoffrey"	Wilberfoss, UK	"Since my final surgery in May 2002 I've not really considered myself ill. Other than annual checkups at the hospital I no longer think about my previous illness (ulcerative colitis for about 20 years)."	43	J-pouchweb	Email
"Gerda"	Toronto, ON	"Was diagnosed with UC in 1998… I had 3 step j-pouch surgeries in 1999"	36	J-pouchweb	Email
"Katherine"	Vancouver, WA	"Severe crohn's disease. Dilated bile ducts and rectal abscess from fistula formation."	39	J-pouchweb	Email
"Eva"	Scottsdale, AZ	"Ulcerative Colitis. I flared/remission for many years. … I had my j-pouch surgery at 8 weeks post partnum"	36	J-pouchweb	Email
"Katrien"	Netherlands	"Currently I have a j-pouch and I am doing great…I am infertile due to adhesions from the operations which are located around my tubes. We have just started IVF treatment"	25	J-pouchweb	Email
"Deborah"	New York, NY	"Crohn's disease (previously Ulcerative Colitis) moderate state of health"	18	J-pouchweb	Email
"Victor"	Rural Nebraska (central area)	"Post J-Pouch doing well, learning how to deal with the new system"	49	J-pouchweb	Email
"Jon"	70 miles north of NYC	"Ulerative colitis. Colon removed because of colon cancer. No spread of cancer. Good prognosis."	54	J-pouchweb	Email

Name	Stated Location	Stated Diagnosis	Age	Community Membership	Interview Method
"Maria" (parent)	California	"She has a jpouch now for a little over 5 years and has now just started to develop a reoccuring abscess. Two years ago, diagnosed with cuffitis but under control with pentasa."	Daughter is 22	J-pouchweb	Email
"Bruce"	Boston, MA	"I was diagnosed with CD in 1969...I narrowly survived a close encounter of the dead kind at the age of 28 and had a resection of the terminal ileum. Following that I remained in remission through my 30s and went on with my life."	55	ColitisSucks (moderator)	Email
"Pita"	Hamilton, New Zealand	"I have crohn's disease ... I have also been (since my crohn's dx, and partially as a result of time away from exercise) diagnosed with hypermobility syndrome. Last week chronic fatigue syndrome was added to my list, probably as a result of crohn's, a year on prednisone, and surgery."	26	ColitisSucks	Email
"Veronica"	Fayetteville, NC	"DX- Fistulizing Crohn's colitis, HEALTH - joint pain associated with Crohn's Disease (CD), reproductive problems due to CD and previous meds, skin deterioration due to failing ileostomy, general fatigue, daily fevers, rashes associated with current meds (remicade)"	24	ColitisSucks	Email
"Liz" (parent)	Indianapolis, IN	"At this time, my daughter is technically "cured" of her pancolitis due to the total colectomy she had in 1998 at the age of 10... the following "issues" remain: chronic pouchitis... joint pain"	Daughter is 16	ColitisSucks	Email
"Brooke"	Brooklyn, NY (Villanova, PA for school)	"I have ulcerative colitis, currently in remission."	20	ColitisSucks	Email
"Grant"	California	"In and out of remission"	49	ColitisSucks	Email

Name	Stated Location	Stated Diagnosis	Age	Community Membership	Interview Method
“Bree”	Ottawa, ON	“UC – moderate; chronic fissure; close to remission.”	23	ColitisSucks	Email
“Elizabeth”	Alkmaar, Netherlands	“CD with underlying IBS – health is stable with maintainance drugs”	36	ColitisSucks	Email
“Wilf”	Alkmaar, Netherlands	“re-occuring pouchitis/proctitis; permanent ileostomy after colectomy due to UC”	36	ColitisSucks	Email
“Jason”	Boston, MA	“Crohn’s. Health is stable; disease is primarily in remission.”	27	ColitisSucks	Email
“Nancy”	Boston, MA	“Crohn’s Disease. Currently in remission. (Also have Type 1 Diabetes)”	41	ColitisSucks	Email
“Leah”	Brooklyn, NY	“Crohn’s disease, onset approximately summer 1998; diagnosed December 1999. Current state of health: pretty good. Occasional, somewhat unpredictable, but manageable flare-ups.”	34	ColitisSucks	Email
“Frances”	Columbus, OH	“Currently I have an end illeostomy as a result of a proctocolectomy (removal of colon).”	28	J-pouchweb	Email

Name	Stated Location	Stated Diagnosis	Age	Community Membership	Interview Method
"Simon"	Long Island, NY	"Celiac Disease, Lymphocytic colitis, hypothyroid, osteopenia, allergies, asthma, right side neuropathy."	43	SCD	Email
"Esther"	Indianapolis, IN	"No symptoms of CD. Feel wonderful. Living as I never did before in my whole life."	75	SCD	Email
"Alicia"	Burnsville, MN	"I have ulcerative colitis and was diagnosed in December 1998. Currently I have no diarrhea, no blood, no cramping, no urgency and generally feel great. I also have discontinued my Asacol as of this last month"	46	SCD	Email
"Gordon"	San Diego, CA	"I was diagnosed with ulcerative colitis 11/94. Current state of health is excellent with no UC flare-ups since first diagnosed."	42	SCD	Email
"Felicia"	Kelowna, BC	"I have had no active Crohn's Disease for over twelve years. I am in excellent health."	53	SCD	Email
"Patty"	Ottawa, ON	"I was diagnosed with Ulcerative Colitis in September of 1999 but had experienced symptoms for about a year before the official diagnosis. I have a possible diagnosis of PSC [primary sclerosing cholangitis] but have not proceeded on an official diagnosis."	36	J-pouchweb	Email

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