A Madness for Identity: Psychiatric Labels, Consumer Autonomy, and the Perils of the Internet

ABSTRACT: Psychiatric labeling has been the subject of considerable ethical debate. Much of it has centered on issues associated with the application of psychiatric labels. In comparison, far less attention has been paid to issues associated with the removal of psychiatric labels. Ethical problems of this last sort tend to revolve around identity. Many sufferers are reticent to relinquish their iatrogenic identity in the face of official label change; some actively resist it. New forms of this resistance are taking place in the private chat rooms and virtual communities of the Internet, a domain where consumer autonomy reigns supreme. Medical sociology, psychiatry, and bioethics have paid little attention to these developments. Yet these new consumer-driven initiatives actually pose considerable risks to consumers. They also present complex ethical challenges for researchers. Clinically, there is even sufficient evidence to wonder whether the Internet may be the nesting ground for a new kind of identity disturbance. The purpose of the present discussion is to survey these developments and identify potential issues and problems for future research. Taken as a whole, the entire episode suggests that we may have reached a turning point in the history of psychiatry where consumer autonomy and the Internet are now powerful new forces in the manufacture of madness.

KEYWORDS: autonomy, bioethics, identity, Internet, mental illness, psychiatry

There appears to be a new psychiatric phenomenon emerging in the private chat rooms of the Internet, a novel syndrome that revolves around identity. At the same time, there are important ethical obstacles that prevent psychiatrists and bioethicists from studying that phenomenon. The two themes are inextricably linked. Psychiatry needs to study the phenomenon, but studying it poses complex ethical problems. The purpose of the present discussion is to describe the putative new syndrome and the ethical challenges involved in studying it.

The syndrome seems to be a sort of “madness for identity.” Its defining feature is a refusal by some psychiatric patients to relinquish the iatrogenic identity provided by their medical diagnostic labels. In one way, there is nothing new about the existence of refusals of this type; they probably go back to the dawn of psychiatry. But there...
is another way in which the refusals we are concerned with are novel. This is the medium in which they take place, namely, the Internet. That influences the form they take, which in turn determines the kind of phenomenon we are dealing with.

The phenomenon we are concerned with is largely, perhaps entirely, a product of the particular type of communities and social opportunities that Internet culture has made possible. In this mostly ungovernable social universe, the forces of consumer autonomy are running amok. Many psychiatric patients have decided to retain their psychiatric diagnostic labels no matter what. They are now “autonomous” consumers in a very real social and economic sense. Three examples illustrate this hypothesis. The labels in question are multiple personality disorder, borderline personality disorder, and anorexia. In each case, consumers have mobilized their forces on the Internet to defend their right to wear and live by their labels. On its side, establishment psychiatry seems powerless to stop or control this powerful new force in the social manufacture of madness.

The topic is urgent, because there are serious potential harms to consumers. What can be done about these new developments depends on what we can find out about them. This discussion is intended as a first step in that direction. To start, let us see how these developments fit in the context of psychiatric labeling and its associated ethical issues.

**Applying and Removing Psychiatric Labels**

Ethical issues associated with the application of psychiatric labels tend to focus on cases where someone is assigned a label they do not want and are helpless to remove it. Sometimes the label itself is said to be bad because of what it suggests. At other times, those who do the labeling are also held to be bad because they impose the label without the subject’s consent. One famous example that arguably touches on all these elements is hysteria. The victims in this case are the women who are labeled, the guilty are the male doctors who do the labeling, and the label is bad because it stereotypes and demeans women. This at least is one way of looking at the ethics of the application of this psychiatric label (Showalter 1986).

Homosexuality is another ethically controversial psychiatric label. The label itself is not always considered bad, because many homosexuals are proud to be called homosexual. Ethical problems occur when it is proposed as a psychiatric label that denotes a disease category. This is what happened when homosexuality was included as a mental disorder in the second edition of the *Diagnostic and Statistical Manual of Mental Disorders* of the American Psychiatric Association (American Psychiatric Association 1952). Its identification as a psychiatric disorder caused a vehement uproar and the label was eventually removed from the manual (American Psychiatric Association 1973, 44). There exist poignant testimonies of how the disease conception of homosexuality caused harm to homosexual patients (Duberman 2002). The victims in this case were homosexuals and the problem was the inappropriate medical use of the label homosexual.

Other ethical problems with psychiatric labeling occur when a legitimate label is imposed inappropriately and unjustly (Chodoff 1999). Such abuses are said to have occurred in the former Soviet Union and elsewhere. In these cases, the label schizophrenia was apparently inappropriately applied to people who did not medically warrant the diagnosis. Generally, these were political dissidents of some sort. The diagnosis of sluggish schizophrenia played a part in these abuses (Merskey and Shafran 1986). Although it was originally a legitimate medical diagnosis, it was eventually used for inappropriate political ends. These cases of abuse are examples where a medical label is inappropriately and unjustly applied.

These three examples illustrate one general kind of ethical problem with psychiatric labeling. The examples are all different but they share a common theme. In each case, the ethical problems arise from the fact that a psychiatric label is applied. The identity of those who are labeled is negatively compromised because a label is applied. Iatrogenic identity here is bad. There is
another general kind of ethical problem associated with psychiatric labeling. It occurs when a psychiatric label is removed. This can happen when a label is simply abolished. But it can also happen when a label is significantly changed and important aspects of its original meaning are lost. In this case, the identity of those who are labeled can be negatively compromised because a label is removed. These two dimensions of the ethics of psychiatric labels both implicate identity. But there is an important difference. In the first case, there is an unwillingness to accept a label. In the second, there is an unwillingness to relinquish it. When this unwillingness is extreme, it can lead to its own type of madness—a madness for identity. This in any case is the initial hypothesis adopted here.

Ethical problems that spring from the removal of psychiatric labels have not been discussed as much as those that spring from their application. Consequently, in this discussion we focus on ethical problems with label removal. The first two examples of label removal we consider are multiple personality disorder and borderline personality disorder. The first case is real; it has already happened. The second is hypothetical; it may happen. Part of what makes these examples interesting is the role that identity plays in how the relevant ethical issues are framed. In each case, there is an unwillingness to relinquish the iatrogenic identity that a psychiatric label provides. Often, this appears to be because individuals with a diagnosis react to a change in labeling as if it somehow invalidates their experience under the label. This, incidentally, may offer one therapeutic strategy for addressing the problems we are considering. It is an area where the philosophy of psychiatry can make an important contribution to the clinical practice of psychiatry.

Our third example is an extreme and very ethically disturbing case where the unwillingness to relinquish a label turns into a desire to indulge in it. It is not a clear case of label removal, but exhibits many of the same dynamics, notably, the unwillingness to abandon a label. Together these examples provide a novel perspective on current debates in bioethics and psychiatric ethics where questions of identity are at stake (DeGrazia 2000; Edwards 2000; Elliott 2000a; Kramer 2000; Radden 1996). They illustrate a disturbing new madness for identity.

Speaking of a new “madness for identity” rings of hyperbole and rhetoric. Is this really a new phenomenon? The current edition of the Diagnostic and Statistical Manual of the American Psychiatric Association does have a diagnostic category that seems tailor made for our case, namely, Factitious Disorder, which involves the “intentional production or feigning of physical or psychological signs or symptoms” (American Psychiatric Association 1994, 474). It is also important that “the motivation for the behavior is to assume the sick role” (American Psychiatric Association 1994, 474; emphasis added). As we shall see, this is not what seems to be happening in the individuals we are concerned with. Typically, they genuinely are sick and already have a sick role, with all its associated signs and symptoms. The problem is that they do not want to give it up. The Internet does provide interesting and novel opportunities for factitious disorder (Chambers 2004; Feldman 2000). These might even coexist with our putative identity syndrome. However, on a first analysis, the two conditions do not appear to be the same.

Problems With Evidence

The Internet plays a major role in our discussion, especially its private chat rooms. Yet there is a surprising absence of data on how these consumer-driven forces affect the application and removal of psychiatric labels. There does exist interesting work on the influence of the Internet on our sense of community and the search for identity (Putnam 2000; Turkle 1995). But none of it deals with our topic explicitly. Psychiatry has also taken note of the Internet. However, these discussions tend to focus on issues of service delivery and education (Yellowlees 2000). Finally, in bioethics the Internet is just starting to receive ethical scrutiny. In a fascinating discussion, Tod Chambers describes how easy it is to pretend you are someone else on the Internet; how one can deceptively play and experiment
with various virtual roles and identities including the sick role (Chambers 2004). This scenario raises disconcerting possibilities for the subjects of this discussion. These are psychiatric patients and “survivors” who claim they are “no longer alone” now that they think they have found kindred spirits on the net.

Chambers identifies one serious ethical problem associated with the use of the Internet. There are other fascinating aspects of the role the Internet plays in our discussion. One is the fact that psychiatric labels may no longer be solely under the control of psychiatry. Label change is subject to powerful consumer influences mediated through the Internet. At the origin of these changes lies the ethical principle of autonomy, which guarantees the right to self-determination to mentally competent individuals (Beauchamp and Childress 2001, 57–103). The problem is that driven by the principle of autonomy and its self-determining individual, the pursuit of identity on the Internet can lead to very serious harms. However, proving this gives rise to additional ethical problems. These concern the acquisition and use of evidence derived from the Internet.

First, there are ethical problems. How is consent to be sought if individuals want to remain anonymous or be known only through pseudonyms? And what if some subjects are of dubious competence to consent? How could one determine competence in such a case? Note also that it might be possible to gain better evidence of what transpires in these chat rooms through impersonation than by joining as a declared researcher. But then that involves deception, which raises difficult ethical issues of its own, and usually requires special approval by ethics committees. Finally, there is the question of harm. It is possible that conducting research in these domains might cause harms that are not immediately obvious to researchers or even subjects. How are we to tell? What might they be? Without this information, it is hard to assess the relative harms and benefits of research for participants, which is an important consideration in gaining approval for research on human subjects.

All of this is new territory for bioethics. In the absence of any specific enough guidelines on the topic, the provisional strategy adopted here has been to err on the side of caution and strictly follow the injunction to do no harm. As a result, no direct evidence in the form of testimonies or Internet citations are provided. Hopefully, the indirect evidence referred to will be deemed sufficient to demonstrate that the problems identified require immediate attention.

Second, there are also practical problems involved in researching our topic. Many Internet sites come and go and chat rooms can be especially transitory. Even seasoned insiders can sometimes have problems finding the sites they want to. It can also be hard to keep up with changing security technology and shifting addresses. Indeed, virtually all of the sites initially consulted in the research leading to this paper have gone into the cyber underground. This is particularly true of the pro-anorexia sites, which are now forbidden by leading Internet providers (Reaves 2001; Udovitch 2002). Note that accessing some of these web sites may even be illegal and expose researchers to sanctions that range from legal prosecution to having one’s Internet service cut off.

All of these problems surrounding the acquisition and use of evidence derived from the Internet pose great difficulties. Nevertheless, it is still possible to make some headway and that is our purpose here. At the very least, it should become evident that the developments identified here require urgent attention.

**Identity and the Harms of Label Removal**

It is important to recognize that not all cases of label application and removal involve harms. Label application can lead to positive benefits because it leads to successful treatment. Successful treatment, in turn, can lead to label removal because an individual has been cured, another positive benefit. The examples discussed here are different. In each case, we are concerned with how label removal can lead to harms. Resistance to label removal is one of the main harms discussed. It is noteworthy that even label removal in the context of successful therapy can lead to
harm. The pivotal factor in all these cases is the fact that individuals sometimes identify very strongly with their labels. A good example of the harm that can ensue when a psychiatric label is removed is provided in the autobiography of New Zealand author Janet Frame.

Frame vividly recounts her distress at finding out that, after years of being diagnosed as a schizophrenic, the diagnosis was incorrect. She writes that, “the loss was great . . . the truth seemed to me more terrifying than the lie” (Frame 1985, 103). Her diagnosis was gone, “officially banished by the experts” (p. 103). In the course of her testimony, Frame describes being “stripped of a garment I had worn for twelve or thirteen years” (p. 103). She also explains what her diagnosis came to mean for her: “how in the midst of the agony and terror of the acceptance, I found the unexpected warmth, comfort, and protection: how I had longed to be rid of the opinion, but was unwilling to part with it, and even when I did not wear it openly I always had it for emergency, to put on quickly, for shelter from the cruel world” (p. 103).

Although she resisted it at first, Frame eventually “surrendered” and accepted her label. When she was invited to relinquish it, she suffered an identity crisis of a serious sort: “the official plunder of my self-esteem (p. 103). Happily, she finally managed to come to terms with giving up her label. Frame’s experience is a good example of how closely people can identify with their psychiatric labels and how they can suffer when those labels are removed. It is a fitting opening for the more sinister problems with identity examined here.

THE MANUFACTURE OF IATROGENIC IDENTITY

Psychiatric diagnostic labels can provide an iatrogenic identity for the persons they label. It is important to understand how this iatrogenic identity is socially manufactured and sustained to appreciate how identity figures in the ethical problems associated with the removal of such labels. The role of the Internet has become increasingly prominent in psychiatric label formation and dissemination. It is now a powerful reinforcing factor in the manufacture of iatrogenic identity and the ethics of labeling. In part, this is because the Internet provides a medium where iatrogenic labels can be kept alive by consumers even though they have been psychiatrically abolished by the medical establishment. But first let us look more closely at how identity figures in the ethical issues we are concerned with.

Many psychiatric patients suffer from disorders that directly implicate questions of identity. Some psychiatric conditions are actually called disorders of identity. In these cases, the disorder a person is said to have can shape their conception of who they think they are. Initially, many patients resist the application of psychiatric labels. This certainly appears to be the case with borderline personality disorder, a label associated with the most “difficult” psychiatric patients (Antai-Otong 2003; Gross et al. 2002; Loughrey Jackson, and Wobbleton 1997). However, as we shall see, in some cases even a diagnosis of borderline personality disorder can eventually provide a welcome sense of identity: iatrogenic identity. You are, at least, a person with that disorder. So the borderline diagnosis can provide a minimal sense of identity for some people; it provides them with an iatrogenic identity. The fact that this can happen with borderline diagnosis is especially interesting, because the label is so often actively resented by those who are labeled that way. Other psychiatric diagnoses can also provide a welcome sense of identity for psychiatric patients. In general, the initial sense of identity provided by iatrogenic identity often gets amplified when sufferers discover self-help organizations and Internet sites devoted to their condition. Not surprisingly, people identify with the topics and other participants of these sites. Once they actively get involved and enter the private chat rooms, they are finally no longer alone. Iatrogenic identity is the key to this need to identify. The simple fact of stigma is probably a powerful motivating factor. This is because stigma is often tied to an increased need for acceptance (Goffman 1963, 8). When you join these sites, your label is no longer a stigma; it is a
shared and accepted feature of who you are. You have found people of your own kind and can bask in the solace that there are others like you (Goffman 1963, 21–22). In this way, the Internet has come to play an increasingly important role in the social manufacture of psychiatric labels. No doubt, this is an important new addition to what some cynics have called the “manufacture of madness” (Szasz 1970). The expanding role of the Internet in the manufacture and promotion of psychiatric disease has not been adequately addressed in contemporary psychiatric histories. In most the word does not even figure in the index (Healy 2002; Shorter 1997). Recently, however, it has attracted the attention of bioethicist Carl Elliott.

In his book, Better Than Well: American Medicine Meets the American Dream, Carl Elliott examines how the notions of personal fulfillment, self-realization, and enhancement have shaped and influenced American medicine and what Americans expect from it (Elliott 2003). Much of his research is drawn from Internet web sites sponsored by self-help organizations. One notorious example is a group of individuals who advocate for the right to have their limbs amputated (Elliott 2003, 208–238; see also Elliott 2000b). Some members of this group are lobbying for the medical recognition of their disorder. Variously referred to as Apotemnophilia and Amputee Disorder, this condition is sometimes confused with Gender Identity Disorder and Body Dysmorphic Disorder. Evidently, it is a condition still in search of a label. Many sufferers hope this will be a psychiatric medical label, largely because of what this implies for treatment: medically sanctioned and supervised amputations. Elliott’s analysis strongly suggests that this social mobilization of amputee seekers—“Wannabees”—would probably not exist without the Internet. He notes that, “by all accounts, the Internet has been revolutionary for Wannabees” (Elliott 2003, 217). This could be the first psychiatric disease “manufactured” in cyberspace.

The Internet appears to be a new addition to the ecological niche philosopher Ian Hacking says is required for the social birth and growth of some psychiatric illnesses. He shows how the dissociative fugues of the nineteenth century were made possible by the development of tourism (Hacking 1998). Of course, they were not created by tourism alone. But the social, institutional, and industrial circumstances that accompanied the emergence of tourism opened a new ecological niche in which travel became a lot easier. Individuals suffering from amnesia or dissociative episodes could travel relatively easily if they found the means. It was now possible to suffer from “fugue.”

In another related study, Hacking shows how the epidemic of multiple personality in recent times emerged out of a new understanding of trauma and child abuse and a peculiar American obsession with the family (Hacking 1995). His hypothesis is that a certain set of social circumstances—a particular ecological niche—was required before the multiple personality epidemic could take its hold on popular consciousness.

Likewise, Carl Elliott’s research capitalizes on the fact that most psychiatric disorders now have supporting organizations and web sites for sufferers. Each disorder has its own “virtual community” on the Internet. Some of these web sites are partially or entirely created and supported by industry. Others are entirely consumer driven. In both cases the Internet is the common denominator. Because of its accessibility and limitless geographical range of action, the Internet has played a pivotal role in the creation of these virtual communities. In the words of Robert Putnam, “computer mediated communication can support large, dense, yet fluid groups that cut across existing organizational boundaries, increasing the involvement of otherwise peripheral participants” (2000, 172). This is an excellent example of what Hacking refers to as a “vector” in an ecological niche.

Apparently, then, the Internet is a new addition to the ecological niche in which mental disorders rise and fall. It permits new forms of community association; a sort of “cyberbalkinization” where like-minded individuals can join and share in a special inner circle (Putnam 2000, 178). These are not typical self-help groups like those where members sit in a circle talking. Private chat rooms, in particular, provide a particu-
larly paradoxical form of “community” involvement. They are solipsistic communities. Unlike traditional sit-down self-help groups, participants in chat rooms are strangely isolated in their own personal protective cyber bubbles. At the same time, they are sometimes immensely open and vulnerable. Normal rituals and procedures of social interaction are different or inapplicable in these chat rooms. Many participants never actually meet in person and some probably would never want to. Intimacy is both heightened, but also more artificial, because it is often artificially restricted to a few key topics. It is also more fragile, because people can come and go, are accepted or banished, with little accountability or recourse. Indeed, cyber friends seem to be more interchangeable and replaceable than “real” ones. Finally, there is no proverbial coffee and everyday chit chat after the meeting, because “meetings” usually never really start or end; they are eternally ongoing, always there, at the click of a mouse.

Some of these virtual disease communities are openly funded by the medical and pharmaceutical establishment. Indeed, the suggestion has been made that pharmaceutical companies sometimes engage in the creation of such virtual communities to market the existence of a new disease concept to prepare the way for the medication, which is still in development (Moynihan 2003). However, other virtual disease communities are genuinely self-help projects run by real psychiatric “survivors.” Most of these web sites provide information about the disorder in question, as well as links and referrals for consultation about the disorder. Especially significant is the fact that they almost always provide chat rooms where sufferers can share their experiences of what it is like to live and cope with their disorder. These chat rooms offer solace and solidarity for the pain and alienation sufferers usually experience as the result of the stigma associated with their disorder (Elliott 2003, 218; see also Goffman 1963, 22). Finally, many sites engage in advocacy of some sort. Typical advocacy themes include fighting the stigma associated with a particular disorder, challenging or promoting various treatments, and even sometimes arguing for the application or removal of labels for psychiatric disorders. There is now a web site advocating for the psychiatric baptism of the label Body Integrity Identity Disorder, the latest proto-psychiatric label for amputation seekers.

Participation in these psychiatric virtual communities probably strongly reinforces the iatrogenic identity of their members. Validation is both sought and found. As Elliott notes, “on the Internet you can find a community to which you can listen and reveal yourself, and instant validation for your condition, whatever it may be” (Elliott 2003, 217). For many sufferers, shared Internet chat rooms are the only route to the relief of knowing that they are no longer alone, a mantra that resonates across this virtual world. For many of these geographically isolated and socially alienated identity seekers, “all they have is the Internet, their own troubled lives, and the place where those two things intersect” (Elliott 2000b, 84). The solidarity made possible by the Internet thus provides solace through shared experience and companionship. Because these are all positive benefits, they reinforce the sense of identity provided by the original diagnosis. As a result, people probably become more attached to their diagnosis and iatrogenic identity. In effect, their identity becomes increasingly defined by, and inextricably intertwined with, their diagnosis. Philosopher Ian Hacking calls this process the “looping effect of kinds”.

The looping effect of kinds occurs when “people classified in a certain way tend to conform to or grow into the ways they are described” (Hacking 1995, 21; see also Elliott 2003, 227–234). Classification of this sort is an interactive phenomenon. This is because the classifications that do the classifying “interact with the people classified by them” (Hacking 1999, 123). This gives rise to the looping effect that connects what is classified with what does the classifying (Hacking 1999, 105, 121). In this spiraling dialectical process, each element—the classification and the classified—mutually reinforce and sustain each other as they evolve jointly. There is considerable evidence that the Hacking looping effect is a genuine sociological phenomenon. In his work on psychiatric labeling, Thomas Scheff refers to
something very similar, which he calls “feedback in deviance amplifying systems” (1966, 97–101). Edwin Lemert describes a related phenomenon called “secondary deviance” (1972, 63). In all of these cases, the focus is on how labels become integral organizing factors in the lives of the individuals who are labeled, as they search for validation and acceptance by bonding with others of their own kind.

Elliott and Hacking fail to mention one central aspect of the manufacture of iatrogenic identity, namely the role of autonomy. Compared to previous ages where paternalism was the dominant ethical and political ideology, we now live in an age of autonomy where the right to self-determination of the individual is paramount. Autonomy is enshrined in both law and ethics in the doctrine of informed consent (Beauchamp and Childress 2001, 57–103). It is also manifest in the openness to pluralism and diversity so prevalent today. Autonomy also has economic dimensions and is reflected in the important place of customer choice and satisfaction in our consumer culture. These combined social manifestations of autonomy have had dramatic consequences for the practice of psychiatry and the “manufacture” of psychiatric labels.

At no time in the history of psychiatry have members of the public exercised so much power over the psychiatric establishment that serves them. Things were not always so. Before psychiatry, there were quite simply no “psychiatric” labels. For example, speaking of the historical situation in England prior to the development of psychiatry as a profession, historian Roy Porter states that “particular specifications of madness were, of course, ‘socially constructed’” (1987, 33). However, he points out that “they were constructed out of grassroots experiences and community tensions rather than being essentially medical codifications serving the interests of a ‘psy profession’ or a ‘therapeutic state’, as arguably they eventually became” (Porter 1987, 33). Things changed with the development of psychiatry as a distinct clinical profession. Labeling then entered an age of psychiatric paternalism and the definition and deployment of psychiatric labels was the exclusive prerogative of the psychiatric profession (Goldstein 2001; Scull 1993). Neither patients nor patient groups were consulted when psychiatric labels were applied and removed. Today, psychiatric labeling is a much more complex process, subject to numerous social, political, and economic interests (Healy 2002, 129–178). The examples below also testify to this. They are meant to illustrate the thesis that the removal of psychiatric labels can lead to difficult ethical problems that are different from those normally associated with the application of labels.

**Multiple Personality Disorder**

Multiple Personality Disorder has “gone out of existence” (Hacking 1995, 17). The official name for what used to be called “Multiple Personality Disorder” is now “Dissociative Identity Disorder” (American Psychiatric Association 1994). The old label is now only mentioned as a reminder of the new label’s origins. In the relevant DSM section, it is stated in brackets: “(formerly Multiple Personality Disorder).” This change in the psychiatric labeling might look like a simple case of exchange but it is not. It involves the replacement of a label that denotes one thing by a new label that denotes another. The change is therefore not merely cosmetic; it is materially significant. According to the scientific authorities responsible for initiating and implementing the change, the reason for the amendment was to focus on the real pathology involved in the original Multiple Personality label. The point is that integral multiple personalities are not the focus of the pathology in question. Rather, the fundamental problem is a disintegration of identity in one personality. The real problem then is one of integration. It affects identity, consciousness, and memory. In the words of Robert Spitzer, the architect of the change, “the problem is not having too many personalities, it is having less than one personality” (Hacking 1995, 18). In effect, a theoretical commitment to the existence of multiple personalities thought to be real has been replaced by a commitment to the presence of “two or more identities or personalities or personality states.”
ence in this case means present to consciousness. So although “two or more identities or personalities or personality states” may be said to be present by subjects, and although they may be experienced as “real,” like delusions, they are not real. Multiple personalities during the reign of DSM-III were real, but after DSM-IV they were not. That surely is a big difference; from real entity to delusional figment.

The change did not go unchallenged. Support groups and other interested parties protested (Hacking 1995, 269 nt. 8, 270 nt. 20, 271 nt. 31). Still, the change went ahead. Physicians could no longer write “MPD” as a diagnosis. The International Society for the Study of Multiple Personality and Dissociation had to change its name, and did. It became The International Society for the Study of Dissociation. The case of Multiple Personality Disorder is therefore a clear example of label removal. What were the ethical issues involved?

Any analysis of the ethical issues involved in the change from Multiple Personality to Dissociative Disorders will probably vary depending on whose interests are involved. Because of the many interests involved, the situation is complicated. In his famous study on the topic, philosopher Ian Hacking traces the political, social, medical, and moral factors in the rise and fall of Multiple Personality Disorder (Hacking 1995). One of the lessons of his account is that none of these factors can really be studied in isolation. Nonetheless, it should be possible to say a few things about the clinical circumstances of patients during these developments. Consider, for example, the possible harm to patients implied by the sort of diagnostic change in question. There are important considerations here.

Suppose you are a patient diagnosed with Multiple Personality Disorder during the DSM-III era. Imagine that after being encouraged to first accept the existence of your multiples, you have spent the following two years talking and negotiating with them under the guidance of your therapist. One day your therapist informs you of a decision by the American Psychiatric Association that your multiples are no longer thought to be real personalities. They are merely delusional figments of your disorder. Your problem is not that you have too many personalities, but rather that you do not even have one. It is hard not to think that this would result in serious iatrogenic trauma. This is especially true given that the patients in question already suffer from severe problems with identity. The sudden change in diagnosis simply compounds these original problems. From a clinical perspective, then, there are good reasons to believe that as a matter of principle the proposed change constitutes a plausible potential harm to patients; quite likely, a very serious harm. Without access to actual clinical records or personal testimony, it is hard to validate this claim empirically. But as an argument based on principle, the worry is still worth taking seriously.

There is some indirect evidence that the change in diagnosis from Multiple Personality to Dissociative Disorder may have caused actual harm to patients. It can be found on the numerous web sites sponsored by interested individuals and supporting organizations. But the evidence is not uniform. One reaction is denial that any significant change has occurred. The two diagnoses are treated as equivalent or the change is regarded as irrelevant. In one case, the sponsoring organization officially states that they simply disagree with the change. Indeed, in a large number of cases, individuals and organizations have simply retained the old language of multiples and its association with real alternate personalities.

Evidently, the medical death of a psychiatric label is not always final; there can be consumer label survival and immortality after death. This is a consequence of the power shifts that have occurred in this new age of autonomy. Patient autonomy now includes the ability of patients to contest and defy the nosological edicts of medical authority. You can remain a multiple if you want to. One way to interpret these reactions is denial in the face of real harm. Giving up the multiple label is simply too confusing and distressing, and so many patients have organized themselves to keep it. Together with the plausible imaginary clinical scenario painted, these observations should constitute sufficient evidence that in some cases, the removal of a psychiatric label
is likely to lead to harm. This is an issue in psychiatric ethics that deserves careful attention as psychiatric labels continue to appear and disappear.

**Borderline Personality Disorder**

The example of Multiple Personality Disorder we have just discussed has actually taken place. There is some evidence for believing that it represents a case where label change can lead to serious harm for patients. Another more speculative but timely example is Borderline Personality Disorder. In this case, there are good grounds to believe that label change may happen. This could cause serious harm to patients currently diagnosed with that disorder who have finally found an identity—an iatrogenic identity—through their disorder. Again, these are patients who already have problems with identity. This compounds the possible harms of label removal.

*Borderline Personality Disorder* is currently defined as “a pervasive pattern of instability of interpersonal relationships, self-image, and affects, . . . marked by impulsivity beginning by early adulthood and present in a variety of contexts” (American Psychiatric Association 2000, 710). Typical manifestations include emotionally unstable behavior, suicidal threats, manipulation, inappropriate and intense anger, a chronic sense of emptiness, as well as other signs and symptoms. A central feature of the disorder is a “persistently unstable self-image and sense of self” (American Psychiatric Association 2000, 710). In the current DSM, Borderline Personality Disorder is grouped with three other personality disorders in a cluster. It is part of the Cluster B disorders, the “dramatic” ones. The Cluster B disorders are the Antisocial, Borderline, Histrionic, and Narcissistic Personality Disorders (American Psychiatric Association 2000, 685). The remaining six personality disorders are grouped in Clusters A and C.

At present, all the DSM personality disorders are classified categorically. This is in keeping with the DSM general categorical orientation. However, there is an alternative way of viewing disorders of personality, namely the dimensional approach. On a dimensional view, “personality disorders represent maladaptive variants of personality traits that merge imperceptibly into normality and into one another” (American Psychiatric Association 2000, 689). This is in stark contrast to the categorical model, where personality disorders represent “qualitatively different clinical syndromes” (American Psychiatric Association 2000, 689). There are good reasons to believe that the current categorical scheme for personality disorders may be replaced by a dimensional one in the next edition of the DSM, namely, DSM-V (Charland 2004). The arguments are complex. The main reason cited in defense of the change is that the current categories for personality disorders have not been sufficiently empirically validated. To put it bluntly, there is not enough evidence to believe that the existing DSM classifications actually capture real pathologies of personality. In effect, the “current classifications are arbitrary collections of diagnoses drawn from diverse sources without a clear rationale or explicit structure supported by empirical research” (Livesely and Lang 2000, 34; see also Livesely 2003).

There is therefore a very good chance that the current DSM personality disorders may be radically revised in the next edition of the DSM. The adoption of a dimensional model would represent a drastic change, a significant paradigm shift (Kuhn 1962). It is not clear whether or how much of the original classifications and their labels would be retained. In some dimensional proposals, probably most current terms for these disorders would be abandoned. What if this happened?

There are now many consumer web sites devoted entirely to Borderline Personality Disorder. Many of these are for persons who care for persons with the diagnosis. In these sites, caregivers can find information about the disorder and current treatment alternatives. Other sites are more exclusively targeted to borderline individuals themselves. These usually offer chat rooms to share experiences with fellow borderlines. Because borderline individuals tend to generate and experience a lot of friction in their dealings with
professional and family caregivers, these chat rooms offer a sort of “sanctuary” away from the normal reprimands borderlines encounter in their dealings with the “outside” world. The chat rooms evidently provide welcome relief for the exasperated borderline individual. However, at the same time, they also reinforce and validate the borderline diagnosis. They are a strand in Ian Hacking’s “looping effect of kinds,” as mentioned.

Many of the borderline individuals who use and visit the borderline chat rooms are “survivors” trying to learn to live with their diagnosis. Apparently many do not question the diagnosis. They assume it is valid. In this context of solidarity and sharing, the borderline diagnosis probably provides a sense of identity—iatrogenic identity—for persons who are clearly plagued by serious identity problems and disturbances. It therefore seems plausible that the abolition of that diagnostic label could cause serious harm and confusion to affected individuals. This conclusion, however, is only tentative and somewhat speculative. The evidence alluded to here is based on what can be gathered from borderline chat rooms from the outside by an outsider. Evidence from borderline insiders has also been consulted, but those persons have chosen to remain anonymous.

**PRO-ANOREXIA**

The search for identity can also take a dark turn in the unregulated virtual communities of the Internet. Some identity seekers attempt to reinforce their sense of iatrogenic identity by indulging in their disease. This is a telling illustration of Lemert’s “self-defeating deviance” (Lemert 1972, 85). Certainly, these individuals would surely resist label removal of the official sort. But they even appear to resist label removal of a therapeutic kind. They do no want to get well and instead indulge in how to be sick—more effectively. In this third example, the search for identity has degenerated into a full-fledged madness for identity.

Consider the fact that there are “pro-anorexia,” “pro-bulimia,” and even “pro-cutting” sites and chat rooms on the Internet. In these virtual communities sufferers laud each others’ efforts to starve and cut themselves. Some of these sites post pictures that may put researchers at risk of being charged with pedophilia and other pornography-related offences. In this case, ethical problems in research are compounded by legal ones.

Because these ethically questionable practices so obviously cause harm to vulnerable psychiatric patients, is it not imperative that psychiatrists and bioethicists figure out how to study them? Yet this is a domain where exact references and citations might be very harmful. In effect, they could function as advertisement for these dangerous sites and very likely put vulnerable and lonely identity seekers at risk. Some “survivors” speak of the risk of being “triggered” by accidental visits to these “pro” disease sites.

Psychiatrist David Healy traces the origins of the modern syndrome of anorexia nervosa to the 1870s. He describes successive theories and descriptions of the condition, starting with the work of Charles Laségue and William Gull, through Paul Janet, to more recent accounts like the one provided by David Garner and Paul Garfinkel (Healy 2002, 359). On the whole, Healy appears to consider anorexia a “transient mental illness” of the sort Ian Hacking describes in his book, *Mad Travelers* (Hacking 1998). That is, he views it as a kind of mental illness that is inextricably tied to specific social and historical circumstances, including, notably, the development of the weighting scale (Healy 2002, 361). Note that for Healy, calling an illness *transient* in this sense does not exclude chronic, life-long, mental illnesses of great severity. In this, perhaps, his use of the term departs slightly from Hacking, for whom transient illnesses are perhaps slightly less severe. However, what seems sure enough is that for both of them anorexia and its pro-anorexia manifestations constitute severe mental illnesses that at the same time can be called transient in an important sense. In Hacking’s terms, the pro-anorexia syndrome we have just described suggests that the “ecological niche” of anorexia now includes a new “vector” (Hacking 1998, 51–81), namely the Internet. Slang and colloquial terms
mark the arrival of this new form of anorexia. We now live in an age where there are “weborexics” (Schmitt 2004).

**How Novel This Madness?**

We have considered three examples of what appears to be a disturbing new madness for identity taking place on the Internet. Based on the evidence consulted for the present article, it is impossible to say conclusively whether the three examples of label retention discussed here form a unified syndrome. They do appear to form a family, with shared resemblances and overlapping themes. Further research is required before anything more concrete can be said. Nevertheless, despite the poverty of the available evidence, it is helpful to try to distinguish the phenomenon we have been discussing from other related psychiatric conditions with which it might be confused.

At the start of our discussion, we dismissed the possibility that the syndrome we are concerned with is simply Factitious Disorder. The reason for this claim should now be clear. In each of our three examples, the individuals in question already are sick and have a sick role. They are not healthy individuals who feign signs and symptoms in order to assume a sick role. The problem is that they do not want to relinquish the sick role they have. As we saw, in some cases, they even want to retain and reinforce their “sick role” with a vengeance, by indulging in it. Nevertheless, the suggestion that our syndrome may ultimately be a new variant of Factitious Disorder is worth keeping in mind. Settling that question would require clinical data, which as we have seen, is practically and ethically hard to acquire. For the time being, the wisest course seems to be to consider the syndrome described here to be a distinct from Factitious Disorder.

Our discussion is obviously heavily indebted to Carl Elliott’s fascinating account of amputee “wannabees” and his description of their special Internet culture; the “ecological niche” in which their disorder thrives. However, it is important to appreciate that the phenomenon described here is quite different. Elliott’s “wannabees” do have problems with identity. In part, they are striving for medical recognition of their condition as a genuine medical disorder; they seek iatrogenic identity. This is very different from the cases we have considered, where the concern is to retain an iatrogenic identity that already exists. Note that Elliott’s wannabees do not appear to be cases of Factitious Disorder either. The main reason is that their signs and symptoms appear to be mostly genuine. They do not intentionally produce or feign their signs and symptoms in the manner required for a diagnosis of Factitious Disorder.

One other possible diagnosis for our three cases comes to mind. This is hysteria. As a medical diagnostic label or category, the term *hysteria* has fallen out of favor in modern psychiatric circles. At the same time, the term keeps on resurfacing outside psychiatry. In the words of one commentator, “no term so vilified is yet so popular; none so near extinction appears in better health” (Slavney 1990, 3).

Despite the fact that the label *hysteria* has fallen into medical disfavor, some clinicians insist it is still useful (Healy 1993; Slavney 1990). But generally it is outside medical circles that *hysteria* is popular. One immensely fashionable account has recently been articulated by historian and cultural critic Elaine Showalter. The syndrome she describes bears some resemblance to the problems of identity described here. It is therefore worth asking whether our putative new syndrome may be a form of hysteria of the sort described by Elaine Showalter. So, could the examples we have considered simply be manifestations of the hysterical epidemics discussed in Showalter’s provocative book, Hystories (Showalter 1997)? She does list anorexia and multiple personality among the “hysterical epidemics” she describes. Is this maybe the correct interpretation of our putative new syndrome? Again, to really answer this question conclusively we need better clinical evidence. But even on a very general level the diagnosis of hysteria seems off the mark, at least as it is formulated by Showalter.

In her book, Showalter “redefines” *hysteria* as “a universal human response to emotional conflict” (Showalter 1997, 17). She claims it is a “mimetic disorder; it mimics culturally permissi-
ble expressions of distress” (Showalter 1997, 15). The key to hysteria is the “interdependence between mind and body” (Showalter 1997, 12). Initially, hysteria was thought to be an illness of the body that affected the mind. Later it became an illness of the mind that affected the body (Showalter 1997, 14). As indicated, it is a culture-bound syndrome. And so, signs and symptoms of distress are taken from a local pool of socially accepted manifestations of distress. Various types of hysteria thrive and succeed each other as one culturally accepted set of signs and symptoms is replaced by another. According to Showalter, the most recent manifestations of hysteria in the West are chronic fatigue syndrome, Gulf war syndrome, recovered memory, multiple personality disorder, satanic ritual abuse, and alien abduction.

Showalter’s expanded concept of hysteria is interesting and suggestive in many ways, especially her attention to the role of modern media in the rise and fall of the various epidemics she describes. But her account of hysteria can also be criticized for being too wide and encompassing. A more conservative analysis would retain what is special about hysteria and at the same demarcate it from the putative identity syndrome I have described (Merskey 1992, 1995). On the question of the media, it is notable that Showalter never seems to single out the Internet. This makes her account and the syndromes she discusses heavily dependent on public media. This is quite different from the more private, intimate, personal, and social nature of the identity syndrome described here. In sum, although Showalter’s account of modern “hystories” is relevant to our topic, the two subjects seem initially quite different and should be kept separate until there is evidence to show otherwise.

**Psychiatry, Autonomy, and Identity**

The evidence reviewed here suggests that psychiatric labels can survive and even flourish without psychiatry. The examples we have examined show that where there exists sufficient consumer interest and solidarity, psychiatric labels and their virtual communities can be kept alive online through the technologies of the Internet. These both validate and reinforce psychiatric diagnoses that may no longer be considered scientifically valid. Thus psychiatric labels may survive among consumers although they have been abolished by professionals.

The relative independence and persistence of psychiatric diagnostic labels despite their abolishment by institutional psychiatry raises several novel ethical problems. First, because persons often identify with their label, to remove a label is to threaten a person’s identity. Saying the label is no longer legitimate, or was a mistake in the first place, can therefore cause serious harm, particularly to persons already suffering from disorders that implicate identity. Second, the retention of psychiatric labels by consumer forces that operate independently of the psychiatric establishment can possibly cause further harm to patients if the labels are truly empirically invalid. New, more scientifically appropriate labels may not be adopted and more effective treatments may not be sought.

Some of the ethical issues identified in this discussion arguably existed before the Internet. But undoubtedly they have acquired a new scope and dynamic as a result of it. This is new territory for both psychiatry and bioethics. Despite their good intentions, web sites that offer consumer label survival after official label death may prevent sufferers from getting better help and treatment. There is also the worrisome possibility that sufferers in search of solidarity and a validated identity may be lured by “pro” disease sites quite contrary to the ideals of health and recovery. In both cases, the potential harms are considerable. Not to be forgotten is the possibility that in a context like this the Internet may itself constitute a harm. Some critics have likened life on the Internet to a “Hobbesian state of nature” (Putnam 2000, 173). Doubts have also been raised about whether the Internet might hinder rather than enhance communication because of its intellectual and verbal orientation (Putnam 2000, 176).

The hypothesis advanced here is that participation in these Internet activities is driven by a
normal need for identity that has turned into an obsessional craving for identity. Bioethicists and the relevant health professions need to start paying more attention to these disturbing developments. However, there are important obstacles. One is securing evidence and doing so according to acceptable ethical standards of research. The other problem is autonomy. Unleashed by the Internet, the prospects for autonomy continue to expand as the boundaries of self-determination expand. The examples I have discussed show that in such a context the search for identity may slip into a dangerous madness of its own. Most disturbing is that we may be ethically powerless to stop this, because it is under the banner of autonomy that identity is sought. Ironically, and tragically, autonomy may now be poised to devour its young; a new generation of vulnerable, self-determining, psychiatric “survivors” mad for identity, sometimes at any price.

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