Self- and Other-Diagnosis in User-Led Mental Health Online Communities

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David C. Giles[1] and Julie Newbold[1]

Abstract

This article consists of a qualitative analysis of discussion forums in online mental health communities whose members routinely write about diagnosis. The analysis concerns the function of diagnosis from the perspective of personal identity, with particular focus on the status of official diagnosis, as well as community members' discussions of symptoms and psychiatric syndromes that amount to informal diagnosis or consultation. Self-diagnosis sometimes takes the form of recommended "quizzes" and other online quasi-diagnostic tools. Other-diagnosis, in which a third party is discussed by community members, is also considered. We discuss the implications of such online discourse for Internet users themselves as well the challenges for the health and medical professions.

Keywords

communication; discourse analysis; group interaction; Internet; mental health and illness

Among the many predictions made in the early years of the Internet was the idea that the World Wide Web would become an "identity laboratory" where people would be able to "try out" different selves online (Wallace, 1999). Initially, it was felt that experimentation would take the form of marginalized individuals hiding behind a conventional or normalized disguise to overcome stigma, and that this would essentially be an empowering feature of the technology (Turkle, 1995). Then arose the fear that devious individuals (such as middle-aged male pedophiles) might conceal their real identity to gain access to vulnerable users such as children, a potentially problematic feature of the Internet (Quayle & Taylor, 2003).

To what extent either of these predictions has come true it is hard to say. Isolated cases of identity disguise have come to light, chiefly in relation to dating Web sites, and the use of the Internet by pedophiles for "grooming" purposes is well documented. But the most fascinating instances of identity experimentation have emerged in ad hoc online communities, clusters of Web sites that have evolved simply through recognition by like-minded individuals suddenly finding that there are others out there in cyberspace who share their own unconventional worldview. Most notorious of all, perhaps, are the communities of suicidal individuals, which are regarded by many medical professionals as potentially dangerous in encouraging suicide (Rajagopal, 2004; Tam, Tang, & Fernando, 2007), although they might be better characterized as support networks (Horne & Wiggins, 2009).

Online self-help networks ("user groups") for mental-health-related issues have a surprisingly long history (Salem, Bogar, & Reid, 1997). Over the last decade, however, these have blossomed into communities of related, interlinked Web sites dealing with borderline personality (Charland, 2004), pedophilia (Durkin, Forsyth, & Quinn, 2006), pro-amputation (Bell, 2007), self-harm (Whitlock, Powers, & Eckenrode, 2006), and bipolar disorder (Vayreda & Antaki, 2009).

One online mental health community that has already attracted a good deal of controversy is the "pro-ana" community of individuals with eating disorders (Giles, 2006; Hammersley & Treseder, 2007; Williams & Reid, 2009). These Web sites emerged by way of resistance to clinical psychological and psychiatric services, with their focus on treatment and "recovery," and instead promoted anorexia (in particular) as a lifestyle, and even a state of physical perfection, providing much "thinspiration" for community members by way of photographs, anecdotes, and artwork. The pro-ana community has posed something of a dilemma for mental health professionals and researchers. It has been roundly castigated, accused of glorifying anorexia

[1]University of Winchester, Winchester, United Kingdom

Corresponding Author:
David Giles, Department of Psychology, Faculty of Humanities and Social Sciences, University of Winchester, West Hill, Winchester SO22 4NR, United Kingdom
Email: David.Giles@winchester.ac.uk

and endangering the lives of vulnerable young people who unwittingly stumble across its sites (Nagourney, 2005; Paquette, 2002). Meanwhile, some social scientists have argued that the sites are empowering in the very act of resistance, giving an important voice to individuals with eating disorders, and counterbalancing the conventional wisdom of health and medicine (Day & Keys, 2008; Dias, 2004; Fox, Ward & O'Rourke, 2005a; Miah & Rich, 2008). It would be a mistake, however, to portray the pro-ana community as anything more than a body of resistance (to any kind of formal or informal offline support or professional intervention). There is no coherent pro-ana philosophy, belief system, or political standpoint. There is no agreed definition of anorexia across or within individual Web sites, and there is a diverse range of accounts of its origins, causes, and meanings (Csipke & Horene, 2007; Giles, 2006).

In an earlier participant observation study, the researchers elicited very different responses to the same user profile from different Web sites within the pro-ana community (Brotsky & Giles, 2007). Indeed, the most important functions of the pro-ana community appear to be peer support—notably the recognition of shared experiences—and the construction of authentic identities from the various membership categories available (Giles, 2006; Hammersley & Treseder, 2007). One can be a true "ana," or alternatively a "mia," a mere "wannabe," or, worse still, a "normal" or a "dieter." This phenomenon was described by Charland (2004) as a "madness for identity," whereby, in complete contrast to classic labeling theory, groups of Internet users are demanding to be labeled and to play out a sick role of sorts. The celebration of previously stigmatized *DSM-IV* (American Psychiatric Association [APA], 1994) categories extends far beyond the pro-ana community itself, to numerous other mental-health-oriented communities. The discussion forums of these communities are characterized by the rigorous policing of boundaries to shut out "wannabes" and fakers; celebration, even glorification, of the condition or category; intense, often highly technical discussion of psychological, psychiatric, and behavioral characteristics of the syndrome; and identification of (quasi-clinical) subgroups and subtypes of the syndrome (Giles, 2007). The whole constitutes a vast tapestry of identity work in which, far from hiding behind conventional disguises, community members are fiercely defending their right to be identified as depressed, schizophrenic, autistic, or bipolar.

Central to the formation and validation of online mental health identities is the status of having been diagnosed with the particular syndrome that characterizes the community. For example, in previous research on the pro-ana community (Giles, 2006), the first author identified group membership as a frequent topic of message boards and discussion forums, in particular members' status as "ana" (anorexic) or "mia" (bulimic). More generally, he was able to draw a distinction between individuals with an eating disorder (ED) and "normals" (the remaining population, composed of various outgroups, some positive, others negative).

Increasingly, researchers have applied the techniques and theories of conversation analysis to the study of online forums (Horne & Wiggins, 2009; Lamerich & te Molder, 2003; Vayreda & Antaki, 2009). Here, asynchronous exchanges in forum "threads" are treated as conversations in which features of interaction are studied, such as turn taking and narrative. For example, one of the features of Internet communication—identified early on by Wallace (1999), Turkle (1995), and others—is that users have no reliable visual information that enables them to make person judgments about fellow users. Credibility rests, as in the conversational openings of telephone calls analyzed by Sacks (1992), on the rhetorical work done through claims to first-hand experience, expert knowledge, and authenticity. A similar phenomenon has been observed through research on talk radio (Thornborrow, 2001), where callers to phone-in radio shows need to establish their credentials very early in the call to warrant voice, and establish for themselves an identity that gives them the right to make certain claims (to expert knowledge, and so forth). This right is accorded only if their "credentials" are convincing.

Likewise, the way in which identities are constructed can be treated as a local practice: an identity becomes a rhetorical tool for managing the interactional activity (Horne & Wiggins, 2009). In the pro-ana community, a member is accepted as "ana" solely on the basis of convincing interaction. In the absence of other certifiable information, the claim that one has a particular diagnosis ("I have been diagnosed as anorexic") or a particular group identity ("I have been anorexic/ana for two years") is sufficient to be credited with that particular status. Nevertheless, claims are far from untested in the pro-ana community. A covert participant observation study (Brotsky & Giles, 2007) found that, on some pro-ana sites, new Web site members undergo a rigorous initiation process in which established members can become extremely hostile when claims fail to be warranted.

The warranting effect of diagnosis has been observed in other online mental health communities. For instance, Brownlow and O'Dell (2006) observed subtle labeling effects of diagnostic categories in their study of autistic spectrum online discussion groups. As with the pro-ana community, a fundamental ingroup/outgroup distinction was made between individuals with an autistic spectrum (AS) diagnosis and those without (NT = neurotypical). Within the AS community, ingroups appear according to

DSM-IV (APA, 1994) criteria: autism, high-functioning autism, Asperger's syndrome, and so on. Such is the value of clinical diagnosis in this community that a new ingroup has emerged—ACs (autistic cousins)—to contain nondiagnosed members who nevertheless wish to participate in the community and be identified as AS, yet lack the credentials. The power of group identity construction in this community can be witnessed on sites such as wrongplanet.com, alone boasting more than 28,000 members, specifically devoted to autism and AS. Wrong Planet has become a small industry, with an online store offering a considerable range of T-shirts, caps, and school bags, and links to amazon.com for numerous books on autism and AS.

Several authors have noted the apparent irony here. Many online mental health communities set up independently from, or even in direct defiance of, the health profession nevertheless demonstrate an apparent reverence for *DSM-IV* (APA, 1994) diagnostic criteria that form the basis for group identity. The diagnostic practice of applying discrete category labels for psychological disturbance has its roots in medical science (notably the classification system devised by Kraepelin, 1893), although the American Psychiatric Association's *Diagnostic and Statistical Manual* (*DSM*) system itself is relatively recent, with its first edition appearing in 1952. The *DSM*'s categories have come under frequent criticism from both inside and outside psychiatry: until *DSM-III* in 1980 (APA, 1980), homosexuality constituted one category. At this time there was a shift from a clinical biopsychosocial approach to diagnosis to a more scientific, symptom-based approach (Pilgrim, 2007). Charland (2004) warned that relying on diagnostic criteria for identity can have a potentially damaging effect should those criteria ever change, pointing out the risk posed to the online community by a potential change in the category *borderline personality disorder* (at the time of this writing, *DSM-V* is targeted for publication in 2013).

Nevertheless, the allure of psychiatric diagnosis for identity purposes remains seductive. Vayreda and Antaki (2009), for example, presented a not untypical instance of a bipolar online community member celebrating the confirmation of her diagnosis ("I'm really excited"). To some extent, the appeal of rigid diagnostic categories might be explained by their reductive nature: as Pilgrim (2007, p. 536) has argued, the media and policy makers find it simpler to refer to diagnostic-related groups than deal with the "complex variability of madness and misery in unique contexts." However, part of the *DSM*-category appeal lies in its apparent explanatory power for behaviors that otherwise leave individuals open to blame and personal accountability. In a discourse analytic study of individuals with depression, LaFrance (2007) described how diagnosis plays an important role in their biomedical framing of the condition. One participant even stated following diagnosis, "I had a name." Another saw diagnosis as validation and, ironically, evidence that she "wasn't crazy" (p. 130). So great is the sanitizing power of mental illness discourse over many decades, that it seems "crazy" is no longer compatible with the receipt of a psychiatric diagnosis.

In the present study, we chose to focus on diagnosis as an organizing structure for identity within the discussion forums of various online mental health communities. What is the rhetorical function of claiming to be "officially diagnosed"? How does the discourse of diagnosis operate in the local context of forums? What is the relationship between diagnosis and group identity? No specific technique was used to answer these questions other than a broad rhetorical analysis, drawing on insights from conversation and discourse analysis where relevant.

Method

Data Collection

The data described in this article consist of three extracts taken from a large corpus of data collected from online mental health communities visited during the month of November, 2008. These sites were identified following an open search using various *DSM-IV*-related terms such as *bipolar*, *Asperger's*, and *schizophrenia* (APA, 1994), links from more general health and medical Web sites, and additional links from previously visited sites. The main purpose of the search was to identify sites that qualified as "user led"—in other words, sites that were not owned or constructed by mental health professionals. These could be identified, for example, if the front page did not include links, advertisements, or any other material placed by professional health or medical services. Nevertheless, a few treatment-oriented sites were included in the analysis, specifically if the discussion forum was accessed through a link on another forum (although the Web site itself turned out to have a strong treatment or recovery focus).

Ethical Considerations

Ethical issues around the analysis of Internet data have generated considerable debate over the last decade (Flicker, Haans, & Skinner, 2004). Of particular concern is the threat of intruding on "private" exchanges in which users are ostensibly unaware that their contributions can be accessed publicly, or through search engines (Eysenbach & Till, 2001). Some guidelines for Internet research even preclude behaviors such as "lurking"—scrutinizing the content of open-access discussion forums without the permission of a Web site moderator (Fox et al., 2005a). However, as

Hammersley and Treseder (2007) argued, ethical concerns should be balanced against the perspective and the goals of the researchers. The above constraints should apply only if the researchers are particularly concerned about protecting a specific community. In this study we were interested in observing very broad trends in Internet use, so ethical concerns were less prominent. Nevertheless, steps were taken to protect users' anonymity as far as possible.

To begin with, sites were only selected for analysis if they had an open link to a discussion forum or message board, ensuring that the data were in the public domain. Sites were excluded if access to such material was password protected. In terms of the data reported here, any real names or identifying information have been removed, as well as community members' usernames (a subsequent search using contributors' usernames elicited a large amount of information, including much personal disclosure, and even photographs). Although some sources guard against the revelation of URL addresses and Web site names, these have been retained in our analysis because we believe that it is essential to understand the contexts in which the data have been collected.

Results

Message threads were searched for themes that corresponded broadly to those arising from previous pro-ana research (Brotsky & Giles, 2007; Giles, 2006), such as social identity (ingroup/outgroup distinctions), attitudes toward health professionals, discussion of significant others (friends, family), treatment of "newbies" (new Web site members), and medicalized descriptions of experience (discussion of symptoms, syndromes, subtypes of a condition). However, as mentioned previously, the focus of this article is on talk about diagnosis per se.

Three extracts were selected and are presented here for their focus on diagnosis-related talk. The first deals with the explicit relationship between identity and official diagnosis. The second deals with informal diagnoses carried out online, often for local purposes. The third explores the phenomenon of "other-diagnosis," in which community members speculate about diagnostic criteria relating to an external party.

The extracts, set in table format, are reproduced in as much detail as possible, including all spelling and punctuation errors, and emoticons (both textual and graphic; see Tables 1, 2, and 3). The only alterations made include codes for usernames (A1, A2), and the inclusion of a sequential numeric reference for each post in the thread (P1, P2, and so forth; N.B. Extract 2 omits several intermediate posts). Some of the abbreviations and terminology used in the discussions might appear rather esoteric to readers not fully conversant with online orthography. We have attempted, where appropriate, to decipher emoticons in footnotes, although there is no formal lexicon, and a wide variety of interpretations can be applied to any given symbol.

"Ur Just Not Diagnosed Yet": Establishing Identity

Extract 1 consists of the first nine posts in a thread in the depression community forum accessed through www.facetheissue.com, a Web site devoted to "health issues and life challenges." The significance of this extract lies in the role that diagnosis plays in a discussion about bipolar disorder. Although it is A1 who initiates the thread, the extract is dominated by an exchange between A2 and A3 over their relative status as bipolar (written as "bp" or "BP").

In terms of format, A1's first contribution is fairly typical of initial posts in a thread (Horne & Wiggins, 2009), with a brief narrative, a time reference ("about 5 years"), and extreme case formulations ("consumes your whole life," "never free from it"). It is notably apologetic, however, which seems to reflect A1's uncertain status within the community. A2's response is also typical, at least of the threads studied by Vayreda and Antaki (2009), in that it offers empathy and advice, ranging from "don't let it take over your life" and "accept what's what," to "get professional help." However, it is an interesting response because it opens with a personal declaration and closes with a belated welcome-to-the-forum gesture ("Erm. Hiya") that seems to acknowledge the fact that she or he has been guilty of self-indulgence and overelaboration, whereas A1 simply requires support.

Additional questioning elicits the information that A1 has already been diagnosed (Post 5), but after this point the thread switches in emphasis toward A2's own diagnostic status, triggered by the entry of A3. A3 ignores A1 until the end of her post, focusing on A2's earlier declaration, "I don't have BP, just bad moodswings xDD" [1] (P2). The "jokey" emoticon indicates the arch nature of A2's statement, but A3 responds to it as a form of denial, inconsistent with earlier postings, presumably on other threads in the same forum ("u've said urself b4 that u've got bp"). However, A3 then goes on herself to deny having BP, despite claiming that "a few peoples" have diagnosed her. A2's response to A3 (P8) seems to complete the shift of attention away from A1's initial post. In a series of increasingly cryptic statements, she repeats her earlier denial while seemingly upholding the comments of A3's "few peoples" by saying, "I see where those people are coming from." A3 then responds with a rather noncommittal "maybe." (After P9, incidentally, the thread gradually reorients to A1's initial concerns.)

Table 1. From the Thread "Bipolar" (Extract 1)

Author	Post
A1	I'm sorry for chucking this on here but I'd like there to be a thread dedicated to this. I suffer from BiPolar disorder, I have for about 5 years. I know how it comsumes your whole life and you are never, never free from it. If there are any more on here whole suffer from BiPolar Disorder, I'd like this to be the place where we can talk about it's effects, personal problems, share advice etc. Any chance this could be made a sticky?
A2	I don't have BP, just bad moodswings. xDD It sucks, aye. But what can you do? =) Don't let it take over your life... just accept whats what, and cope as best you can. I don't think anyone can live with BP with no support or help, because either you'll make a huge dick of yourself, and make life hard or you'll find yourself in such a pit of despair there seems to be no way out but suicide. Make things easier for yourself, and get help. Professional help. =] Erm. Hiya. xx
A1	I'm too scared to persue professional help. Every time I go to the docs they make me feel like I'm making it up
A2	But you know yourself if you were making it up or not. =/ Maybe you have BP maybe you don't, just be honest with yourself and the doctor and they'll diagnose you with whatever and give you the help you need. However, if your current doc isn't a help then it's important you change docs. =/ Or get a good psych. xx
A1	Oh, I've been diagnosed! I had to see a Psych a few months ago and she diagnosed me with BP. I just can't bring myself to take it inot my own hands and carry on treatment
A2	Ooooh. Well well done you for taking the first steps! x Why not? You know you have BP, you know you need help... what's stopping you? =/
A3	[A2], theres no way u can just have bad mood swings, u've said urself b4 that u've got bp .. ur just not diagnosed yet, i've been told by a few peoples that they think i've got bp but **** them, i don't i'm sound. nice thread btw [*A1's real name*] i hope it gets stickied
A2	[*A3's real name*], Yes there is. =] If someone all serious knows things about me, and decides to probe into my business I can just turn around and say, "Moodswings, dahling, deal with it". It beez normal and natural and everything. Yeah [*A3's real name*]. I see where those people are coming from. Except if you did have BP... it's be like :| Rapid cycling. =) xx
A3	hmm, i don't see it myself i never thought i changed moods that easily lol maybe i do i dnt realise idk, hmm i spposee

Following Horne and Wiggins' (2009) "doing being suicidal," Extract 1 offers an illustration of the way community members use diagnosis as a way of doing "being bp." For A2 and A3, "being bp" is inextricably linked to being diagnosed by, in A2's words (P8), "someone all serious." Without the diagnosis, A2 disclaims the bp identity; for A3, all A2 needs is the official confirmation ("ur just not diagnosed yet"). A2's comment (P8), complete with startled emoticon, that "if you did have BP…it's be like :\|"[2] seems to indicate the troubling implications of being diagnosed. A1 is not oriented to in this exchange because her status is unambiguous (A2 in P6: "you know you have BP"). Her tentative opening steps (in P1) might also serve as a sign that she is not yet fully integrated in the community.

Extract 1 is typical of other mental health community forums in that there is an ambivalence regarding the role of the health professions. A2 repeatedly advises A1 to seek help through "docs" and "psychs," although she herself displays a somewhat cavalier attitude toward them

Table 2. From the Thread "Just Curious" (Extract 2)

Author	Post
B1	Does anyone else on here go see a psychologist/therapist for their issues? And has anyone on here been diagnosed with a specific mental illness? I have: Major Depression, Bipolar Disorder Body Dysmorphic Disorder Social Anxiety Disorder and of course eating disorder
B2	Yes I'm seeing a therapist and a psychiatrist, but my psychiatrist is being changed to someone that I won't even be able to understand. I've been diagnosed with depression so far and I know that I have a lot more disorders but I just don't want people to know some of the embarassing things I have to go through. I havent seen my therapist in a few months but I'm going to see her in a week or so. ugh.
...	...
B2	Seeing my therapist doesn't help me at all. At least I think it doesnt... Oh, by embarrasing things I mean stuff like having to do things a certain way, or I'll do them until I do it right. Like, if I stick a thumb tack into the wall, I have to take it out and do it over again until it feels right.. its weird. And then I do stupid things on purpose, like saying bad things to teachers, just to see their reactions. I don't see why I find pleasure in doing stuff like that, but I do. I also do things like see how far i can stick a pencil into my arm until I can't stand it anymore, just because I'm curious. I'm just stupid like that
B1	I do weird things like that all the time!! Now that you tell me that it makes me feel not so much like a complete weirdo I don't tell my therapist everything anyways Oh and the thing with the thumbtack maybe thats OCD
B2	Yeah, I suspected OCD for that but I'm not completely sure yet

("I can just turn around and say, 'Moodswings, dahling"'; P8), as does A3 ("**** them"; P7). Ultimately, however, it is the professionals who have the power to diagnose, and for this power, at least, they are respected.

"The Thing With the Thumbtack": Informal Diagnoses

In the next extract we can see how, irrespective of professional diagnostic power, community members offer possible identities for one another on the basis of disclosed information, and informal diagnoses can be worked up, at least in the local context of the forum. Extract 2 also comes from the "Face the Issue" Web site and a discussion thread entitled "Just curious." The initial post is an open invitation to share "issues" (taking the term, presumably, from the Web site title), containing also personal disclosure of diagnostic information. B1 proudly presents a list of his diagnoses; it has the feel of a collection. The first response comes from B2 (P2), who takes up the collecting theme by claiming that his diagnostic quest has only just gotten underway ("I've been diagnosed with depression so far and I know that I have a lot more disorders"). This sets the tone for the subsequent exchange (the intervening posts have been edited here) on what other diagnoses B2 might be able to accumulate.

In an earlier post (sandwiched between contributions from other members), B1 had asked B2 for clarification of his remark in P2 about "embarrasing [sic] things." B2 obliges with a series of unusual behaviors that elicits a delighted cry of recognition on behalf of B1 in P7: "I do weird things like that all the time!!" This type of exchange is very common in online mental health forums, where the first post consists of a narrative or string of behaviors, and the second post is an excited "me-too" response. (On another forum one member exclaimed, "I'm exactly the same…It's like you're me!")

These exchanges tell us much about the value of online forums for community members as support mechanisms, but they also reveal how important identification is for users. Face the Issue's slogan, "You are not alone," is brought to life vividly by "me-too" responses, and their importance for users is demonstrated by B1's subsequent comment (P7): "Now that you tell me that it makes me feel not so much like a complete weirdo." This comment has much in common with LaFrance's (2007, p.130) interviewee, who claimed that receiving a diagnosis of depression reassured her that she "wasn't going crazy." In both cases, the realization that their experience is shared by others acts as validation. Under these conditions, doing crazy or weird things becomes legitimated. Just to complete this legitimization process, B1 (P7) suggests that

Table 3. From the Thread "How Can I Tell the Difference Between Just Odd Behavior and Mental Illness?" (Extract 3)

Author	Post
C1	Hi all. I have a really difficult situation at home - I have a relative who has always had anger-management and self-esteem issues, as well as a penchant for odd behavior. For instance, a few weeks ago she came over for dinner and, because we were watching the end of a movie on a DVD, she went off to the living room and sulked rather than (a) join us or (b) choose another movie we could have enjoyed together. She also does horrible things to others, then denies she ever did them and will insist that she's never in the wrong, while everyone else is. Thing is, I'm convinced my relative is mentally ill, but the rest of the family insists that it's just odd behavior and that she's mentally fit. Are there any tried-and-true methods to test this?
C2	I'm not a psychologist, but if she goes from being happy to being sad all of a sudden, she might be bi-polar. I wouldn't really consider it odd behavior though, sulking I mean, some people are just like that, but it's also a sign of depression. As for treating people like crap, and denying it, or genuinely not remembering it, it might be Munchensens Syndrome by Proxy, a mental illness in which people bring harm to others to direct attention towards themselves. It's not up to you to define someone as mentally ill, that's up to a psychologist. If she's really mean to people in your house, then kick her out the door and tell her not to come back until she's seen a shrink. Because nobody deserves to be treated like crap for no reason.
C3	Yes, it DOES sound a bit like bipolar disorder, but of course we are only guessing on these boards being most of us are not doctors, and also only have what you typed here to go by. But people with mood swings from highs to lows with denial have been known to be bipolar. Is she up for seeing a health professional to get diagnosed?
C4	Even though I'm no expert on the subject, the relative the first poster is writing about does, at the very least, have some serious anger-management issues. Both E2 and E3 are dead-on in suggesting that E1's relative should at least seek professional help.
C5	The only tried and true method is to get her to seek professional help and get diagnosed. The problem with this though is that most people with disorders do not feel that they need any help, so it can be a bit tricky. Short of having her commited, there is not much you can do unless she admits to herself that she indeed may have a problem and seek help or at least a diganosis.
C1	Getting her to seek professional help is the sticking point, me thinks. We have tried to get her to see a psychologist or therapist, but, as you say, she insists there's not a thing wrong with her.
C5	Unfortunately many people are like that. Good luck though, and keep us posted as to what she decides and/or what happens.

B2's "thing with the thumbtack"—a stereotypical repeated behavior—"might be OCD" (obsessive-compulsive behavior). At this point, the behavior ceases to be "weird," and instead becomes another symptom in the *DSM-IV* (APA, 1994)—medicalized, and therefore legitimate. B2 offers cautious agreement (P8).

"I'm Convinced My Relative is Mentally Ill": Other-Diagnosis Online

The third extract presented here was not necessarily selected because it is a typical or representative example of online discourse around diagnosis, but because it illustrates the potential for online dialogue to move away from self-diagnosis toward working up informal diagnoses of other individuals. The thread appeared on a Web site devoted primarily to treating addictions of various sorts (www.addicted.com), which was included in the dataset because it has an extensive range of discussion forums, including one devoted to "mental health support and recovery."

Although the nature of this forum (and the Web site in general) is somewhat different from those of other Web sites in this study (indeed, it is more like the bipolar Web site studied by Vayreda and Antaki, 2009), the discussion shares some characteristics of those discussed earlier. To begin with, respondents to the original post adopt the same kind of paradoxical position seen in previous extracts, whereby disclaimers are issued ("I'm not a psychologist," "I'm no expert," and so forth) before the contributor goes on to deliver an informal diagnosis of some kind, or at least a recommendation that the "relative" engage professional services. These recommendations should not be surprising given that the forum itself, unlike others considered in the study, is devoted to "recovery." What is of interest is the process by which the informal medical consultation is built up following C1's claim that his "relative" is "mentally ill." C2 (P2) diagnoses several potential candidate disorders. C3 (P3) then picks up on bipolar disorder as a promising diagnosis. The fourth post is more cautious but still recommends treating "anger

management" (which was explicitly mentioned in the initial post).

The later posts steer clear of specific matching of symptoms to syndromes, with contributors expressing increasing caution ("seek professional help" is repeated by several). Again, this preference for leaving diagnoses to professionals could simply reflect the nature of the Web site, with its emphasis on recovery and reverence toward therapists (several addiction therapists' photos and profiles are linked to the homepage). To reiterate, this final extract is included simply as an example of the kind of online dialogue that is potentially problematic: Whereas online self-diagnosis can be seen as simply an extension of "cyberchondria," other-diagnosis has harmful implications for the rights of the individuals whose "symptoms" are under discussion.

Discussion

The purpose of this study was to explore the way that diagnosis functions in the context of online mental health community forums. We have examined how community members construct local identities around their status as formally diagnosed, and how, for the undiagnosed, the forums operate like informal medical consultancy, with members offering various diagnostic suggestions in response to other members' described behaviors. Up to a point, what online mental health community members are doing here is not unlike the information seeking that might be expected of contemporary health consumers—"expert patients" (Fox et al., 2005b; Shaw & Baker, 2004), who are utilizing available technology to make themselves better informed before (if at all) presenting to medical services. Some researchers (e.g., Nettleton, Burrows, & O'Malley, 2005) argued that, contrary to health and medical professionals' fears, most health information seekers tend to be quite discerning, and rely largely on trusted "official" sites.

However, the purpose of the current study was to explore the interaction that takes place within online communities that are outside of the health and medical mainstream, that are mostly "user led," and offer advice and information that can deviate from standard medical opinion. The very high number of "me-too" responses on these forums indicates the significance of shared recognition in attracting users to online communities. This reinforces the idea that online communities offer largely peer support rather than trusted advice and information (Fox et al., 2005a; Gavin, Rodham, & Poyer, 2008; Horne & Wiggins, 2009). Unlike the broad condemnation of health professionals found in pro-ana communities, frequent recommendations to "seek (professional) help," and disclaimers ("I'm not a psychologist") suggest that even on some of the more explicitly antirecovery forums, there remains a degree of reverence for professional expertise. This is to an extent countered by a willingness to recommend online diagnostic or quasi-diagnostic instruments such as "quizzes." Nevertheless, even these are often recommended with qualifying statements about their lack of official status.

It is worth considering that pro-ana sites, which have attracted the vast majority of research on this topic to date, are a special case, a community with a range of positions quite unlike those elsewhere on the Web. It could be that the broad sweep of online mental health communities considered in the present study is too heterogeneous, and that the more radical pro-ana stance is not representative of online mental health communities in general. Nevertheless, there are certain characteristics of pro-ana sites that resurface in other communities, most notably the importance of diagnoses, particularly official ones, for personal identity.

The reverence for official, or formal, diagnoses sits uncomfortably with online communities' counter-cultural resistance to the medical establishment, with health professionals often characterized negatively (as "dumb" in one thread, or simply as reliable or untrustworthy). As with pro-ana sites, medical professionals are respected for their authority rather than their expertise, and there is likewise a resistance to "treatment" of any kind. Community members talk of hiding things from their therapists, of being afraid to use services, and of actively resisting diagnoses. Most importantly, within the local (online mental health) context, to be formally diagnosed means to belong to a specific community.

What implications do these interactions have for the future provision of mental health services? To begin with, it is not yet clear to what extent mental health professionals trust or mistrust the role of the Internet. With regard to general health, a range of views have been expressed by practitioners, from those who regard the Internet as a threat, filling patients' heads with nonsense, to those who regard it as a useful adjunct to professional consultation (Fox et al., 2005b; Nettleton et al., 2005). In the mental health field, though, the long-term implications are different; the most likely outcome is that online communities offer potential alternatives to seeking treatment of any kind (whereas many of the issues in general health online surround the advertising of, and access to, pharmaceutical products). A 20-year-old "Aspie" (a person with Asperger's syndrome) could present to mental health services for the first time after 5 years of online interaction with fellow Aspies and be deeply offended by not receiving a satisfactory diagnosis. Indeed, this is a highly plausible scenario given a *DSM*'s working party's recommendation to remove the Asperger category altogether from the

forthcoming fifth edition (American Psychiatric Association, 2010).

As Duchan and Kovarsky (2005) argued, diagnosis is a cultural practice that can be performed by lay individuals as well as professionals. We can all pick up a copy of *DSM-IV* (APA, 1994) and match a set of behaviors to a syndrome identified in the manual. Through continual consultation of diagnostic criteria and the reading of multiple personal accounts of disturbed behaviors, online forums are a breeding ground for "cyberchondria" (White & Horvitz, 2008), with all manner of bizarre or quirky behaviors being identified with psychiatric syndromes.

Many criticisms of diagnosis in both the antipsychiatry and phenomenology traditions (see, for example, Bradfield, 2007) are based on the idea that psychiatric diagnosis within the medical model imposes behaviors and experiences on individuals and is therefore inauthentic, not to say disempowering. However, it seems that the reverse is happening: Diagnosis empowers individuals in a market-driven health system because it gives them rights (to certain treatments) or credibility as part of a "proto-professional" discourse (de Swaan, 1990). An alternative possibility is that online mental health communities are somewhat remote from the offline psychiatric syndromes they appear to deal with. The conclusion that pro-ana sites offer support rather than providing lethal "advice" seems to reflect a certain lack of seriousness on behalf of community members. The playfulness in Extract 1 is indicative of this. Perhaps, ultimately, online communities are sites for identity exploration as much they are "powerful new forces in the manufacture of madness," as Charland (2004, p. 335) argued. However, their reliance on *DSM* categorization could yet prove to be highly problematic, as mental health categories themselves fluctuate from one edition of the manual to the next.

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Notes

1. xDD = smiling face with two mouths for emphasis.
2. :| = a bewildered and startled expression (in this instance).

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Bios

David C. Giles, PhD, is a reader in media psychology in the Department of Psychology at the University of Winchester, Winchester, United Kingdom.

Julie Newbold, BSc Psychology, of Winchester, UK, graduate of psychology at the University of Winchester, Winchester, United Kingdom, worked as a research assistant on this project.