"We Are Here to Give You Emotional Support": Performing Emotions in an Online HIV/AIDS Support Group

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Since the advent of the Internet, social critics have debated its effects on intimacy and social relationships. I show how, by writing detailed descriptions of their illness experiences, participants in online support groups create emotionally vibrant, empathic communities in which emotional rhetoric frames various moral dilemmas. I illustrate my argument with a detailed analysis of "emotion talk" among members of an HIV/AIDS support group over a 2-year period. My findings add to current debates by encouraging sociologists to consider the emotional dynamics within the online support group as a moral, rather than just psychological or therapeutic, component of interaction.

Keywords: empathy; Internet; HIV/AIDS, support group; emotions; anger; narrative methods

If intimacy and emotion are grounded in the “fleshy predicaments of our moral human bodies” (Williams, 2001, p. 124), how does online sociality incorporate intimate emotions? The increased prevalence of long-distance relationships mediated by technology has made intimacy and care pressing sociological issues (Holmes, 2004; Kendall, 1998; Klaw, Huebsch, & Humphreys, 2000; Nettleton, Burrows, & O’Malley, 2005). As virtual relationships become more deeply woven into the fabric of modern life, traditional notions of intimacy based on physical proximity are seen to require reconceptualization (Smith & Kollock, 1999). Although empirical evidence now shows that intimacy can be lived out across the disembodied world of cyberspace, the Internet’s effects on intimacy, and its bodily, emotional, and social consequences, have yet to be ascertained.

How can participants in a variety of online interactions make emotional and social investments in others who might vanish, untraceably, at any moment, and whose identity claims are unverifiable (Slater, 1998, 2002)? Dystopian views of Internet sociality tend to view both the public nature of the online interaction, and its immateriality, as antithetical to true intimacy. Accordingly, cyberspace is dangerously narrowing down the rich plurality of emotionally embodied experience (Slouka, 1995; Watt, Lea, Spears, & Rogers, 2002; Williams, 2001). Heim (1992), for instance, raised the concern that the Internet promotes a moral indifference in people’s private relationships by putting individuals in contact with, but at a distance from, the concerns, anxieties, and vulnerabilities of others. In contrast, scholars, who hold a more positive view of online sociality, argue that the Internet enriches people’s social networks by fostering membership in multiple partial communities, providing companionship, social support, information, and a sense of belonging (Mesch, 2001; Wellman et al., 1996). Hardey (2002), for example, shows that the disembodied anonymity that characterizes the Internet provides a crucial foundation for building trust and establishing relationships.

Both dystopian and utopian views of online sociability focus, however, on the depth, sincerity, and authenticity of online emotional expression and on its role in fostering emotional attachments between users. Thus, they sidestep the question of the specific ways in which online emotional expression becomes a way of engaging in a public discussion about the problematic relations with self and others when facing a life-threatening illness (see Freeman, 1993; Gergen, 1991; Noy, 2004). The present inquiry addresses this lack in the literature by examining how participants in an online HIV/AIDS support group, HOPE, shaped specific...
emotional narratives or vocabularies to discuss various dilemmas arising from their illness experience (see Illouz, 2003; Lowe, 2002; Wiley, 1990).

By “emotional narratives or vocabularies,” I refer to the stories that accompany and shape the emotional directives and the common-sense perceptions participants have of how they or others must feel in a given situation and what must be done about it (Illouz, 2003; Moon, 2005; Young, 1995). The stories presented here exemplify an intense dramatization of emotions, as narrators discuss, for example, their embattled relations with their loved ones. I further suggest that this interactive emotional performance constitutes an online empathic community, where emotions are discussed as moral components of social relationships. In some narratives, emotions are explicitly discussed as moral issues and as indicators of the narrator’s moral fiber. In others, emotional talk is used to frame and discuss a variety of dilemmas. Thus, I am able to elucidate an important discursive pattern whereby questions such as “How should I feel?” and “How can I control my feelings?” are treated as moral dilemmas. In turn, the moral dilemma of a husband struggling to keep his marriage intact after infecting his wife with HIV instigates an emotional discussion on the meaning of love and devotion in the face of AIDS. My main argument therefore, is that the emotionally charged messages posted on the online support group forum constitute “textual acts” written primarily with the intent of implicating and involving the audience in “staged moral dramas,” thus giving rise to a discursive empathic community (Felman, 1982; cf. Noy, 2002).

I begin by highlighting the theoretical questions my study explores. A detailed discussion of cyber sociality and methods follows. I then introduce my findings, which are divided into two sections. The first illustrates how participants discussed the expression of anger as a moral dilemma. The second illustrates how participants discussed a moral dilemma in emotional terms. In both sections, I explore the emotional directives formulated in the group. Finally, I discuss the implications of my findings for the study of cyber sociality and its role in the constitution of empathic communities.

**Studying Emotions in Online Support Groups**

How are emotional scripts constructed in an imaginative (virtual) social setting, in which existing emotional repertoires can be safely contested and reinvented?

Williams (2001) suggested that the immateriality of the Internet creates a new variety of emotions, which are then sensationalized and serialized in digital and printed form, in effect becoming a spectacle. Thus, he warns that “these manufactured feelings” cause us to lose the depth of emotional experience, warmth, and understanding that come from embodied gestures. This view is problematic, because it neglects to take into account the emotional dynamics contained in and generated by the narratives staged in a variety of online interactions. As Illouz (2003) convincingly argues, popular culture is not only about entertainment or the alleged thirst for sensationalism; it is also about moral dilemmas. The emotional vocabularies that participants use in the online support group constitute a crucial symbolic tool for expressing, both to themselves and to their (imagined) audience, who they are, what their moral commitments are, and how they morally conduct themselves in situations fraught with uncertainties and risks. Consequently, the online support group draws both narrators and audience into a particular biographical story by activating particular kinds of emotions. These bind the audience to the storyteller through a set of assumptions about worthy or reprehensible behavior. Langellier and Peterson (2004) similarly suggest that online storytelling is not a retrospective reportage of events but actually a producer of emotional experiences; not by denying or reinventing them but by reflexively narrating them. Storytelling performance therefore conceptualizes narrative as an act, an event, and a discourse—a site for dissecting and reflecting on real-life dilemmas, embodied experiences, and identities. Thus, I maintain that the narrators’ choices to perform their stories in a disembodied medium demands an effective intensity that enables actors to experience and express a wide variety of emotions, as they critically evaluate the taken-for-granted emotional scripts available to them. I believe that in this way the Internet creates a new variety of emotions and experiences.

How can we account for the intensity of emotional expression observed in online support groups? Any attempt to answer this question must consider the role of the emotional narrative in constituting online sociality. The following extract is typical of HOPE posts:

Hi all, I just needed to let some feelings out. If this HIV doesn’t kill me first my feelings will. . . . I am so empty inside like someone ripped every piece of me out. So not only am I confused about all this HIV talk but I am very lonely…. Maybe I’m rambling on. I am sorry, I just needed to let out some hurting feelings. . . . [Mark, a participant]
Postings such as Mark’s are narrated with the intent of eliciting particular emotions and producing specific effects in other participants. Because the virtual presence is manifested in words and can be detached from the frame of the empirically verifiable, the vulnerability of the human body provides the starting point for communication in the online support group (Turner, 2002). I will even go as far as to suggest that human commonality is the basis for HOPE’s online ethic. Paradoxically, it is the omission of social identifiers, such as race, age, gender, and sociocultural status that facilitates this process of imagining and narrative reconstruction. Participants author their own posts, pass judgments, and evaluate others’ emotional narratives, imagining that those others are going through similar types of suffering as they are themselves. The text constructed online is hence a dialogical text that is endowed on its audience (Noy, 2002).

Because communication in online support groups is usually asynchronous, lacks regulatory feedback, and proceeds without the benefit of well-established conversational norms, the supportive, trusting, and helpful communication constructed online should not be taken for granted (Klaw et al., 2000). In many respects, the distant intimacy formed online epitomizes Giddens’s (1992) notion of “pure relationships,” in the sense that they demand voluntary ephemeral commitment that is based on emotional communication, with others and with the self, in a context of interpersonal equality (also see Hardey, 2002). Giddens’s idea of pure relationships is, however, founded on trust, which is achieved through self-disclosure (Lupton & Tulloch, 1998). Indeed, the stories posted on the forum tend to contain the strongest claims that can be asserted by narratives of personal experience (Noy, 2004). These claims remain, however, purely self-referential in that they exist solely by virtue of the enunciations participants make—confessions, confrontations, and disputes (Illouz, 2003). Not only are the assertions of the speakers unverifiable, but so is their identity. Hence, despite the boldness of participants’ disclosures, authenticity, reciprocity, turn-taking, and the dialogical establishment of intimacy are constantly challenged in the online support group.

Because the meaningful occurrences revealed online cannot be verified, participants must sufficiently anchor their narratives in culturally powerful and socially persuasive texts. Paradoxically, participants often rely on clichés or densely emotional utterances to convey some profound realm of meaning. In other words, participants correlate their unique experiences or dramatic occurrences with arch-narratives so as to authenticate them and render them credible and valid. For example, Danny writes:

So far my emotions are like a roller coaster. I am dealing with all the bad emotions. The reason for the emotions is that I made a promise to myself not to become infected. I have broken that promise. When I was infected, I didn’t care whether I got it or not. I was in a depression. Now I know that it was a mistake and that I have to live with HIV and fight it with everything I can, while being scared at the same time . . .

Linda responds:

I know exactly how you are feeling and I am sorry that you are going through so much heartache. . . . Keep writing here if it is helping you and say whatever you need to. Talking is therapeutic and can help!!! We are here for you. Try and stay with a positive frame of mind, even when things seem tough. They will lighten up, and there is light at the end of our journeys. Prayers to you, my friend. Keep the faith.

Although the asynchronous nature of the online support group allows for the creation of some kind of a collective memory—a record that persists beyond interactions in the present tense and projects a collective past into a normative future—the interaction remains one that exists among textual representations or traces of conversation that exist quite independently of the people that constructed them.

Because participation in the online support group is often erratic and intermittent, the emotional discourse constructed in the group is primarily designed to produce intimacy between accidental strangers. Hence, the use of emotional vocabulary is not oriented to allow for a lengthy therapeutic process or for the creation of long-standing relationships but rather to enable the staging of one’s story (Moon, 2005; Wiley, 1990; Wolkomir, 2001). Because participants must elicit empathy from a sympathetic yet fleeting audience, they carve out their experiences into an intimate personal story that is easy to identify with and relate to emotionally (Lomsky-Feder, 2004; Zhao, 2005).

Finally, embedded in a cultural context that views both the self and the body as “projects” or “endeavors” to be worked on reflexively and continually (Beck & Beck-Gernsheim, 2002; Giddens, 1991; Lupton, 1998), HOPE allows for the fashioning of an unsolicited and unfinished narrative that is subject to continuous reconstruction (see Hardey, 2002; Shilling, 1993). Hence, the online support group serves as a locus of moral drama, as the sickbed is metaphorically
transformed into a stage and the patients, their family, friends, and even doctors become performers, revealing their secrets and opening them up to public scrutiny.

Research Strategy and Method

Narratives are not pre-existing abstract concepts but rather are developed and articulated in specific performative and interactional communicative events, such as the one offered by the online self-help group (Noy, 2002). This inquiry focuses on instances of narration, fleeting moments in which narratives are uttered and articulated online. The interrelationship between the dramatic event of narrative performance and the narrated events depicted therein renders the narrative expression a social action in and of itself (Noy, 2002, 2004). Such an online support group is, therefore, an excellent site for studying how the narrating individual converses with multiple socially constructed interpretive schemes and through them creates his or her own personal version of the lived experience (Goodman, 2001).

HOPE is a public forum that acts as a virtual community center for those affected by HIV/AIDS, providing medical information, job postings, links to community services, and a public discussion group. Studies dealing with AIDS-related coping and bereavement draw attention to factors such as social stigma, “victim blaming,” and multiple losses, which render the management of AIDS qualitatively different from the management of other terminal illnesses (Clare & Coyle, 1996; Crossley, 1997). Two other factors render AIDS-related coping unique. One is the negative symbolism surrounding AIDS, and the other is its contagious nature. Hence, it is not unusual for caregivers to be HIV positive or to have AIDS themselves. Participants often describe feelings of anger, shock, guilt, sadness, and regret. Despite these distinctions, participants’ emotional reactions seem to conform to the reactions commonly described in the literature in relation to other terminal illnesses (Charmaz, 1999; Pitts, 2004; Seale, Ziebland, & Charteris-Black, 2006).

Participation in the online support group is voluntary and open to anyone who wishes to read or join in the discussion, provided that they respect the etiquette of the group. The bulletin board is designed for educational purposes and therefore does not restrict participation to specific subgroups; nor does it restrict access to its archive. No registration is required to participate in the discussion group or view the archived posts. The Web site uses an asynchronous bulletin board service, whereby individuals post messages in forums that are accessible by anyone with an Internet connection and a browser. Participants can interact with one another by clicking on threads within each forum. Threads are textual conversations that are organized chronologically on the forum’s Web pages and constitute its “conversational life” (Denzin, 1998; Williams & Copes, 2005). Once participants choose a thread, they can read the available posts and add their own voices to the conversation, if they want. Participants who wish to personalize their communication with others often continue to communicate via their personal e-mail addresses.

To avoid interfering with the group’s discursive dynamic, I kept my presence unknown to the group. Thus, my research method involved reading, downloading, and interpreting archived messages posted on a large American public forum dedicated to those diagnosed with HIV/AIDS. Most of the data came from the period 2003-2005, although some posts date from as early as 2000. At the conclusion of the study, the number of posts on the board exceeded 11,300. Discussion threads were stored in two stages. First, I downloaded all available discussion threads under the heading “Living with AIDS” (N = 450). I then proceeded to identify and code the prevailing topics and concerns posters discussed in relation to their living with HIV/AIDS. This process highlighted the centrality of emotions in the discussion of moral dilemmas. Then I refined my search to elicit threads whose titles explicitly denote feelings or emotions. For example, threads titled “Feeling Empty Inside,” “My soul Mate,” “Dad has AIDS—Conflicted Emotions,” “Love,” or “Dealing with a Great Loss” were downloaded and coded for explicit and implicit mention of emotions (N = 105). This subsequent coding resulted in a coding list comprising specific emotions addressed in the posts. Next, I used the search engine installed in the qualitative analysis software to elucidate any mention of specific feelings or emotions such as anger, betrayal, fear, rejection, humiliation, pride, hatred, compassion, pity, and love in the remaining 345 posts. Finally, I organized the discussion threads according to the moral dilemmas they addressed.

Discussion threads were downloaded in their entirety to preserve the context in which they were written and to maintain a sense of continuity. ATLASit (©2002-2007, ATLAS.ti Scientific Software Development), a qualitative analysis software, was used to systematically classify the findings into themes (categories) and subcategories. Reading and rereading the texts revealed
sets of categories related to care, emotional expression, and suffering. Choosing to focus on anger as a main code, I used three subcategories: expressions of anger, legitimacy (group responses to expressions of anger), and rationalization of anger. These were used to identify specific aspects of the emotional and moral narratives constructed in the group. As suggested by Perlow (1999), observations were assigned to categories while alternating between the written texts and the theory. During this reflexive process, particular categories or category sets were retained, revised, and discarded.

HOPE is an open-access public forum, and therefore postings were considered to be in the public domain for ethical purposes. In general, posters refrained from disclosing their e-mail addresses and chose to converse in the public domain of the support group. However, several “veteran” posters, who regarded themselves as pillars of this online community, encouraged participants to e-mail them whenever in need of a more personalized form of emotional support. To avoid distorting the posters’ intentions and detracting from the narrative flow and depth, the posts are presented almost in their entirety. For maximum clarity, however, most spelling mistakes were corrected. Objectionable language was omitted if it did not alter the nature of the narrative. Because participants in HOPE discuss highly sensitive and personal matters, I concealed prominent biographical details in any quotations used in this report (Flicker, Haans, & Skinner, 2004; Morton-Robinson, 2001; Seale et al., 2006; Sixsmith & Murray, 2001). Although each of the stories presented here is distinctively situated within the specificity of the protagonist’s individual biography, the stories are not exceptional. Together, they richly illustrate how participants talk about their emotions. Nevertheless, I regard each post or thread as an instance of a phenomenon, “an occurrence which evidences the operation of a set of cultural understandings currently available for use by cultural members” (Denzin, 1998, p. 99). Following Goodman’s (2001) suggestion, I compare and contrast diverse narratives of the same illness experiences, arguing that similarities and differences between versions may be explained on both the individual and collective levels.

Because participants posting on the board constructed almost biographic accounts of their illness experience, I based my analysis on Lieblich, Tuval-Mashiach, and Zilber’s (1998) narrative-analysis model. I applied the holistic-content mode of reading to elucidate how participants made sense of their illness experience by embedding it in a broader biographical context. I then used the categorical-form mode of analysis to focus on discrete stylistic characteristics of the narrative, such as the use of metaphors, repetition of phrases, and use of active versus passive speech. Combining the two methods allowed for a sensitive analysis of individual accounts as well as the interactive construction of care discourse.

**Anger: The Legitimate Expression of a Paradoxical Emotion**

In this section, I show how HOPE participants talked about their anger, often to point out an injustice or a breach of ethical norms that led to almost unbearable suffering. I chose to focus on anger for three reasons. First, when analyzing the narratives constructed on the HOPE forum, anger emerged repeatedly in many of the posts as a particularly significant emotion. Second, although Western discourse on anger constitutes it as a paradoxical emotion, often described as endangering both the social order and the possibility of constructive political or therapeutic dialogue (Lyman, 2004; Young, 1995), it is also acknowledged for its power to gear constructive change processes. Third, anger is, par excellence, a moral emotion. Anger not only indicates the elusiveness of the norms that should ground social relations but also emphasizes the problematic relation between the self and others (Illouz, 1999).

I now present two narratives, Karen’s and Dave’s, both of which detail the violation of a moral code caused by a disrupted relationship, or an injustice that had to be acknowledged and rectified in some way for the self to restore its autonomy, self-determination, and self-control. Although Karen’s is a story of endurance, Dave’s is one of victimhood and loss. Both accounts center on the problematic expression of anger and its consequences, and in both instances, the conversation digresses from the subject of “how one ought to feel” or “how one ought to express one’s anger” to a problematization of the relationship between selfhood and emotions.

**Karen: A narrative of becoming.** Karen, a loving spouse, speaks of her difficulties in coming to terms with her husband’s illness. Throughout her post, she battles with the question of “how to blow off steam,” or in other words, “What are acceptable ways to feel and express anger?”

I am so angry at this disease sometimes. I could just give up, but I am not a quitter and if I gave up I would only be letting AIDS beat me in more than one way. My husband is HIV pos and for some unknown reason I have been spared becoming infected. It just breaks my
heart to think that I might have to go on without him in the future. Not only do I love my husband, but I actually enjoy him as a person. I never wanted to be rich or live in any spectacular manner but I just wanted a relationship with someone who I could be myself around and we finally found each other. God I feel so cheated!

Karen feels angry and cheated because a basic premise of her Western moral universe—that virtue and merit are rewarded appropriately—is undermined. She begins her post by referring to what Illouz (2003) calls the “eruption of moral chaos”—a state of affairs in which one’s fate and one’s moral worth fail to correspond. Although Karen draws attention to the arbitrariness of her tragic fate and to the lack of control that good, decent people have over their destiny, her story is not simply one of victimhood but of overcoming and endurance, as the rest of her post reveals:

I do my best to help him in any way I can and try not to let him see how badly this whole mess upsets me and I know through all this we are better people for it, but it still makes me mad as Hell. And when I hear people talking about AIDS and they don’t have the facts and still think you can get it by shaking hands or some other way that isn’t possible I just want to scream. People that get AIDS are just people not some group of social misfits. They are doctors, bankers, children, next-door neighbors, wives and from my point of view one of the best husbands any woman could hope for. So thanks for listening and if you have any good ideas about blowing off steam please post them —— I have already maxed out the credit cards so shopping won’t do it!!! ha-ha-ha-ha!...........................................

Toward the end of her post, Karen describes a second betrayal, only now the betraying party is not God or blind fate, but society. Karen refers to the breaking of the moral code that regulates the relationship between the healthy and the ill in contemporary society. In her attempt to make sense of the turmoil and disturbance bestowed on her family, Karen narrates a story that names both the injustice and its rectification. It is Karen’s love, self-sacrifice, and emotional restraint that reorders the disrupted experience and restores the audience’s faith in the benevolence of others.

To be worthy of compassion, Karen must convince her audience that she is a victim rather than a perpetrator. Karen fights her husband’s symbolic annihilation by rejecting his depiction as an embodiment of HIV (Lekas, Siegel, & Schrimshaw, 2006). She does so not only by protesting against the persisting acts of stigmatization against AIDS sufferers but by diligently constructing her moral biography and her husband’s. Her devotion and dignified expression of anger allows her to call attention to the meritorious lives of herself and of her husband, thus enabling her to recover their “spoiled” identities and to reclaim a sense of dignity. And so, it is in these horrible circumstances that her moral identity as an active and dedicated caregiver is constituted. Gradually, the solicitation of indignation turns to an invocation of compassion for Karen and her husband. Unlike indignation, compassion is a moral sentiment provoked not by the violation of norms but rather by attending to particular people and to their plight (Illouz, 2003).

By discursively contrasting the protective nature of the home with the cruelty of the outside world, Karen highlights the irrelevancy of the public sphere in grounding the moral foundations of individuals’ claims of justice and compassion. Thus, she singles out both the home and the online support group not only as safe havens in which a communion of painful experiences can exist but also as potent arenas for the formulation of abiding moral codes. In effect, Karen’s vote of faith in the benevolence of the group constitutes HOPE as an empathic community.

What moral positions did participants in the group assume as they responded to Karen’s story? Karen’s post received four responses, all similar in their content. Here, I consider two representative posts. Ruth wrote:

I do not want you to get hurt that is why it is so important to have support groups so you can go somewhere and let off steam . . . I know something that might be helpful to you or your husband, just do not get yourself down. Think positive there are people living now with the virus for 15 to 20 years so just keep smiling and if you need someone to talk to e-mail me and I will answer you as soon as possible. Hang in there and do not ever give up. Your husband needs you and you need him.

Loren, another participant, wrote:

I’m HIV+ and my boyfriend left me, so I must say your husband has a special person right there beside him. And to give you some advice on letting off steam, I just cry and cry and I go to a family member to have his shoulder to cry on. That’s the only way I know how to let out my steam. It may not be a lot of help, but there are people out there to help you through this.

The respondents acknowledged Karen’s and her husband’s moral fiber and reified her assumption that the virtual support group is indeed a safe and supportive place in which she can freely express her thoughts and feelings. At the same time, the responses to Karen’s...
post contain explicit and precise emotional directives. First, the group created a fine distinction between positive emotions that must be encouraged and negative ones that are to be suppressed or controlled. Anger was generally viewed as a wild and dangerous emotion, which at best should be avoided, or at least controlled. Accordingly, anger should be talked about or released through crying in a controlled and perhaps even supervised manner.

It is therefore possible that by skillfully framing her painful experience and affects into a publicly accepted set of meanings, Karen was able to not only recover her spoiled identity and evoke the group’s sympathy but also to voice her criticism. Karen’s story adheres to a legitimate illness idiom: the tale of the hero who emerges victorious against all odds (Kleinman, 1988). Despite her terrible misfortune and anger, she remains in control, and so she is able, despite her suffering, to preserve a sense of normalcy, at least in the home. She is, therefore, not only able to recover her and her husband’s spoiled identities, but also to claim moral superiority for remaining in control and not caving in to suffering (Charmaz, 1999). And so, what starts out as an uncontrollable scream, ends up as an eloquent and powerful statement that transforms Karen’s private suffering into a social critic indicating social rupture and injustice. Let us deepen our understanding of the emotional directives constructed in HOPE by considering the conversation spurred by Dave’s story.

Dave: A narrative of effacement. Dave’s post echoes some of the issues already discussed; however, contrary to Karen’s story, his centers on loss of control. The post begins with the violation of a normative code specifying the obligations binding a child and his parents. The violation of such a fundamental moral code develops into a story of the injured self that becomes a problem for itself (Illouz, 2003). So although Karen’s story brings to life an active caregiver who is also a victim of circumstance, Dave’s autobiographical story presents a victim and details the process of his effacement—the becoming of a “nothing”:

My post deals with my extreme anger of not ever once having control in my life…the I am currently a [male bodybuilder, in very good shape, but not employed since I’ve been on disability for years. My ultimate dream/goal is to go do culinary school and become a chef. Years ago, at the age of 18, I received my HIV positive diagnosis. This was after coming from a physically abusive father who I was very afraid of. My mother, on the other hand, got into drugs and told me to lie to people and tell them I fell off my bike, or tripped down stairs, if anyone asked about why I looked so beat up from my father’s abuse. . . . What I cannot let go of, and what has me so angry, that it is ruling my existence, is the fact that once I got away from the fear and control of my father, the next year, HIV came into my life to pick up where he left off. I WANT TO BE LEFT ALONE AND LIVE LIFE HOW I WANT TO!!!!! I don’t want a virus telling me what I can and cannot do and threatening me, similar to how my dad threatened me. I’m so angry that I’m afraid of how far it is going to escalate!!! Everything makes me mad, everyday!!!! I have thoughts of revenge and getting back at bad people. I rarely, if ever, sleep. I can only sleep with sleeping pills of some sort.

I have a very loving, kind, caring partner (HIV negative) who accepts me being HIV positive . . . and yet I feel like I’m not good enough for him. I don’t know what it’s like to go through a day of not feeling sad and very, very angry. I just want to live without hurting everyday and especially, THIS DAMN VIRUS CONTROLLING ME WITH FEAR LIKE MY DAD USED TO!!!!! What should I do? How can I be happy??? I’m afraid to go to therapy because I will have to relive the painful events that happened to me, which in turn, will get me even angrier!!! I’m so tired and worn out from this all. Thank you for reading this. I know it was so long. I’m just desperate and feel very alone.

Dave’s story is framed as a story of violation. First, the basic trust of a child in his parents is undermined, then HIV violates the intactness of his body. In Dave’s mind his father and the disease conspired to bring about his demise. In perhaps the most powerful sentence in Dave’s post, he equates the horrors of his childhood with the deleterious effects of the disease when he says, “Once I got away from the fear and control of my father, the next year, HIV came into my life to pick up where he left off. I WANT TO BE LEFT ALONE AND LIVE LIFE HOW I WANT TO!!!!!” Once again, anger is employed to signal the breaking of fundamental social and moral codes. And so, the rhetoric of control is used to articulate a concern with the disintegration of boundaries, on both the personal and social levels (Lupton, 1999; Lutz, 1990; Scheper-Hughes & Lock, 1987).

In this story, however, the violation of a moral code causes severe injuries to the self, rendering it unpredictable, unreliable, and dangerous to both itself and to others. Presenting a violated body that is ruled by its chaotic impulses, Dave emerges as a “walking wounded,”...
whose self is constituted by its lacking or negation (Fournier, 2002). He has no control over his life, no vocation, and no capacity for love or forgiveness. His body, hence, becomes at the same time both “empty of meaning, and an excess of flesh, nothing but a mass of hurting flesh” (Fournier, 2002, p. 62). Dave defines himself in terms of his disease, which surprisingly is not AIDS, but his uncontrollable rage. In this current state of turmoil, stress, and grief, he presents a “failed self” who is unable to achieve self-mastery, happiness, and well-being, and is therefore ineffectual in the public realm as well as in the private sphere of domesticity.

Finally, the moral dilemma Dave battles with is not how to constructively let off steam but how to be happy. The subtle differences in the way Karen and Dave articulate their plea to the group spark an interesting discussion on the merits of anger and how it should be resolved. Stephanie, a group member, replies to Dave’s post:

I am going to call you POWERFUL because that’s what you are... You may not realize it but your feelings are most powerful and I do as well as others understand exactly what you are feeling... Getting your life in control, being happy and knowing what to do all comes from within. I too came from a dysfunctional family... I have been raped two times in my life and had an uncle do things to me that family just does not do... I have been searching for peace all of my life. I just turned 35, married... and found out that my husband gave me HIV. I was not even married two full months and I was given this as a wedding gift!!!! You can say that it has been all down hill since then, or you can look at it as an eye opener to what I have been missing out of in my life... I spent many years being angry about being raped and about my family. I missed the beauty of each day and the good and kindness of my heart and soul that God had given me to help others.

I am not saying that you have no right to be angry... Dammit, you do!!!! BUT you also need to get some help... You took the first BIG step by telling your story to us-strangers... loving people, but strangers none the less. We don’t think any less of you... In fact we want to help you but you do need to get yourself into some sort of therapy so you can begin to heal... Not so much because of the HIV but because of your anger from your childhood. In order to move forward you need to conquer each little step slowly along the way and then my friend you will be free of your anger and be able to live out your dreams...” writes Stephanie, as she encourages Dave to take an active stance vis-à-vis his feelings of anger, desperation, and fear. This sentence and others, such as “hang in there,” “keep smiling,” and “try and stay with a positive frame of mind” articulate the essence of the emotional narrative constructed in HOPE; namely, that the fatalistic acceptance of destiny, renunciation of the world, and misanthropy are not moral or narrative options. Accordingly, anger is only comprehensible or meaningful within an understanding of the self and the body as “endeavors to be worked upon continually” (Lupton, 1999, p. 89). Participants are consequently morally obligated to engage in emotional work as a way of remedying the “diseased self” and improving the character of the emotional self.

Brian’s post clearly demonstrates the perceived imperative of the “failed self” to transform itself to restore its moral standing:

The other day, though I had a really good day, and I will tell you what happened, I met someone who is NOT HIV+ but by God, he is in such a sorry state of repair. Financial[ly] he is ruined, emotionally he is a wreck, physically he looks like death, and he has lost all spirituality. He is an alcoholic and has recently started using drugs as well. When I looked at the sadness of him I asked myself if I would like to swap places with him if I could... and the answer was a definite no! Sometimes I forget how lucky I am in so
many ways. Sometimes I forget to be grateful. And then I remember and life just gets so much better . . . For me . . . I am thinking that perhaps I should start volunteering with some or other organization where I work with those less fortunate than I am. Perhaps this may remind me to remember.

Is Anger a Legitimate Emotion?

All of the respondents used moral vocabularies to rationalize their anger. Anchoring their emotions in a particular mode of moral reasoning created a hierarchy of moral vocabularies but at the same time formed a shared emotion: empathy. And so, although both Karen’s and Dave’s narratives elicit the empathic responses of their audience, it is obvious that Karen’s story more easily assimilates into the group’s cultural idiom of heroism, endurance, and control. Sentences like “try and stay with a positive frame of mind, even when things seem tough,” “Hang in there and do not ever give up,” and “You can say that it has been all down hill since then, or you can look at it as an eye opener to what I have been missing out of my life,” in effect reaffirm Karen’s “becoming” narrative. So whereas the dominant voice normalizes suffering, the less common “other voice” frames suffering as traumatic and irreparable; together they compose the group’s cultural text.

Another important aspect of the emotional directives formulated in the group had to do with designating appropriate sites for the expression of anger, sadness, passion, and despair. Participants repeatedly encouraged caregivers to seek sympathy and emotional outlets outside of the home. Participants often considered the counselor’s office and the public arena of the support group (both online and face-to-face) as appropriate venues for revealing the true self and solving conflicts through communication. By constructing the home as a site of constrained expression, participants reified the notion of the home as a regulated emotional sphere that imposes strict emotional obligations shaped by the responsibilities that accompany caring work (see Hochschild & Machung, 1990; James, 1989).

What remains to be explored is how HOPE participants constructed an empathic community by using a shared emotional narrative. In the next section, I show how the expression of feelings constitutes the foundation for empathic online sociality.

The Emotional Discussion of a Moral Dilemma

Although a fleeting audience, participants in the group serve as more than an aggregate of (imagined) people; rather, they constitute a moral community constituted through a shared vocabulary of sentiment, centering on their illness experiences. As Young (1995) suggests, it is within this community that participants’ confessions and stories are valorized and exchanged as gifts, each gift creating a moral debt. Consider the conversation spurred by Brad’s post:

Brad: I was the one that contracted this disease and passed it on . . . I just don’t know what to do. I love my wife very much and can’t imagine my life without her. I have told her this many times but it just doesn’t seem to make a difference. I feel like our marriage is hanging on by a thin string. Does anyone have any suggestions? Sorry to put my heart on the table but without the fight it is not worth it. [emphasis added]

Yelena: If you had not put your heart on the table I would have bypassed your post and not replied. Always put your heart on the table man, that’s what makes us human . . . Cleave to each other as one. That’s what husband and wife do. With you both being HIV+, it’s even more important that you support each other . . . You say you were the one who contracted the dis-ease. Have you forgiven yourself?? Work on that. Let that go. Move on . . . [emphasis added]

Carol: To love is a wonderful gift BUT it really needs to come from the heart, not because you both are HIV+ or because one feels guilty or badly for leaving or staying. I understand your problem, very much so, almost too close to home (so to speak) BUT what you have to do is try really, really, REALLY hard to understand YOUR feelings first and then deal with the feeling[s] of your wife . . . Remember that we are all here for you always.

Sharon: All I can say to you is it must be a heavy burden on you to see someone you love suffer so much with the struggle of knowing that you have given someone you love HIV. I realize that you did not know of your status but in your wife’s mind that is not of importance at the moment. You may have to come to terms with the fact that the marriage is over . . . It is important that she knows she can trust you and that you will be patient, loving, kind and caring while she learns to deal with the illness . . .

Toni: I can understand where she would be upset and sad hearing the news that she was HIV+ and got the disease from you. You ARE her husband and there is a TRUST factor that does come into play here . . . more so than with a stranger or drugs. Your wife seems like she is just going through the typical steps in which is to be expected in a situation like this one. I realize that you may love your wife BUT at the
same time I also understand how she must be feeling knowing that she got this disease from you and now has to learn how to accept the life altering changes that comes along with it. Thank you for being honest and telling us all your story. I am sure it was not easy but you really do need to give your wife space and time to heal, think, learn and accept. If you are to stay together than [sic] it is placed in Gods hands and he will provide ... We are all here for you and you need to remember mostly that if you love her as much as you say you do then you will give her the understanding, compassion and time she needs to heal and move forward with you in life ... [emphasis added]

This sequence displays many of the traits for which online sociality is famous: abundant focus on emotion—especially on pain, guilt, and anger—proclivity for victimization; staging of conflict; quick-fix recipes to resolve intricate problems. Nevertheless, it is noteworthy that the “emotion-ethic” cultivated and celebrated by this emotion talk is not centered on the narcissistic needs and wants of the individual but rather is a talk about the simultaneous importance of intimate relations and the elusiveness of the norms that should ground such relations (Ilouz, 1999). Again, emotions become the only sure way to talk about broken commitments.

Brad’s public confession of the shameful act of infecting his wife and imperiling her life is moral in the additional sense that its staging presumably repairs the broken solidarity. In Yelena’s view, for example, Brad’s willingness to be vulnerable before both the group and his wife is what makes him worthy of forgiveness and compassion. What such rituals of confession carry is the belief that by publicly confessing our faults and pain, we will restore our membership in the moral group. Hence, participation in the group constitutes a kind of “sentimental education,” as participants learn what the culture’s ethos is and how certain aspects of their own private sensibilities look when spelled out externally in a collective text.

**Discussion**

For many of the participants, being a “moral patient” means living an emotional story of endurance, overcoming, and personal growth. In this respect, my findings confirm Radley’s (1999) contention that, in Western cultures, the only legitimate account of suffering is that of patients fighting bravely, wisely, and successfully against the ravages of disease. However, although Radley notes the transmutation of expressive reactions to suffering, my findings are slightly more complex. Participants did allow both narratives to be voiced, but although they empathized with Dave’s pain, they were unwilling to accept his feelings of resignation and urged him to seek therapy. Only those who had epitomized the “becoming” ethos and who had proved control over their bodies and emotions in the face of suffering were thought of as being entitled to express their crisis and criticism. Karen exemplifies the “becoming” ethos, because she is willing to make the ultimate sacrifice (in the face of possible threats both to her health and to her identity), as well as have control over her body and emotions. Thus, she is granted the right to express her indignation. On the other hand, Dave’s feelings of frustration and anger are denied. Even so, his narrative of effacement is heard, probably because it did not, in effect, undermine the essence of the “becoming” narrative; if anything, it reaffirmed it.

Participants’ online experiences rest on a deeply theatrical appreciation of the public space in which the interaction takes place. By competently using discursive resources relating to their illness experience, participants conversationally position themselves and their audience in a unique role, as witnesses to their pain, coping efforts, and entitlement to sympathy. Thus, their performances amount to constitutive occasions in which a symbolic space is constructed to allow emotional work and resonate with the participants’ unique illness experience (Noy, 2004). Formulated as heartfelt advice and using heavily suggestive language, the online text engages the readers and encourages a lively dialogue. Faced with these dense and moving emotional texts, participants have little choice but to take a stand, pass judgment, and evaluate others’ emotional narratives as they imagine themselves going through similar types of suffering.

In spite of the virtual realm’s dynamism and temporality, participants treated the online support group as an enduring community that rests on a solid collective memory, as apparent from sentences such as “Remember that we are all here for you always” and “You took the first big step by telling your story to us... strangers... loving people, but strangers none the less. We don’t think any less of you...”

Hence, the online feeling community is constituted as it brings to focus assorted mundane experiences, while being set aside from everyday life as “merely a game” or “a leisure activity.” The public staging of conflicts and confessions creates an emotionally saturated text that articulates the moral dilemmas associated with
in which participants “do” emotions online in their support groups largely overlooked by existing studies.

In this respect, the online support group is a unique cultural forum, because it problematizes emotions as a moral component of interaction. As such, it places the wounds and pain of ordinary private actors on the agenda for discussion. Why do I suffer, and how should I best cope with my pain? These seem to be the questions that haunt HOPE participants. And so, participants interactively formulate an emotional ethic, as they discuss their problematic relations with the self and others. Consequently, they participate in an emotional discussion of moral dilemmas as well as in a moral discussion of emotional dilemmas.

The centrality of emotional talk in HOPE must be understood as embedded in a larger sociocultural context. Alasdair MacIntyre (1984) called this growing tendency to use emotional terms to adjudicate between conflicting points of views and morality, emotivism. He ascribed this tendency to the increasing fragility of normative prescriptions grounding behavior. Drawing on ideas of late modernity (Beck & Beck-Gernsheim, 2002; Giddens, 1992), Illouz (2003) similarly suggests that because social relations can no longer be discussed by leaning on solid and consensual moral prescriptions, emotional vocabulary becomes the only cultural category through which moral dilemmas can be discussed. Consequently, the public sharing of emotional narratives renders the support group an empathic community that is transient and has a purely linguistic existence.

Drawing on these theoretical vantage points, this article makes several contributions. First, it encourages sociologists to consider the emotional dynamics within the online support group as a moral rather than just psychological or therapeutic component of interaction. Thus, it identifies and describes a function of Internet support groups largely overlooked by existing studies.

Second, the article details with the particular ways in which participants “do” emotions online in their attempt to intrigue and involve their audience in their drama. These communicative actions make up the emotional dynamics of the empathic community. Moreover, many of the posts contain explicit and implicit emotional directives written with the intention of shaping others’ moral outlook and emotional experiences.

HOPE presents its participants with a moral proposal, one that can be either accepted or rejected, but hardly ignored. Because such online groups act as moral agents, it is plausible that the mere performance of these emotional narratives can transform participants’ experiences and outlooks. The limits of this article prevent me from concluding whether these emotional directives actually change participants’ moral and emotional perspectives. However, the conceptualization of effective performance I introduce here can offer a promising interpretation of the ways in which the Internet’s materiality creates a new variety of emotions or emotional experiences. This lead should, of course, be pursued in future studies.

Finally, the studied online support group exemplifies how individuals competently manipulate the technology at hand as they negotiate, redefine, and reinvent existing cultural codes to make sense of their illness experience. The article thus stresses the significance of the online support group as a mechanism for collectively deliberating on real-life moral dilemmas.

References


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