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Health as moral failing: medication restriction among women with eating disorders

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Individuals with eating disorders often exhibit profound ambivalence towards taking prescribed medications. They may actively restrict their intake of medications, take them and then purge them, or hoard them and ‘binge’ on them. Such behaviors are often labeled clinically as ‘treatment resistance,’ and power struggles over medication adherence between clinicians and clients often ensue. This paper advances an alternative perspective. Based on extensive ethnographic and clinical engagements with women with eating disorders who restrict their medication intake, the analytical focus is pivoted to consider medication refusal not only as communicative in the interpersonal realm, but also as a powerful means of self-communication within the context of a larger ethical and moral project. This larger project makes visible the underside of what Lakoff (2008) calls the logic of pharmaceutical reason, which presumes that people naturally strive for optimal health. For these clients, by contrast, the optimal state is not health, but deprivation, which is experienced as a moral imperative extending well beyond issues related to body weight and shape. Within a broader cultural context where medication use is increasingly viewed as a legitimate and even superior means of self-management, medication restriction among people with eating disorders signals layers of meaning far beyond ‘treatment resistance.’ Refusing needed or useful medication can become a private and personally meaningful practice, largely independent of the material or interpersonal effects of the drugs. This suggests that the symbolic significance of medications must in some cases be discerned by their selective absence.

Keywords: psychiatry; medical anthropology; illness meaning; help seeking; ethnography

‘Can you tell me about your decision to stop taking your medications?’ I asked the young woman sitting across from me in the therapy room. In addition to being a full-time academic anthropologist, I work approximately ten hours a week on a non-profit basis as a psychotherapist specializing in the treatment of eating disorders. At the time of this conversation, Kelsey was a therapy client of mine. Her decision to abruptly stop taking her mood stabilizer (for bipolar disorder), potassium supplements (to prevent cardiac arrhythmias due to hypokalemia from purging) and anti-anxiety medication (for generalized anxiety disorder, panic disorder, and traits of obsessive-compulsive disorder) was concerning on a number of levels. Medically, I was concerned that Kelsey could have a cardiac or neurological event. Psychologically, I was concerned about a recurrence of her suicidal depression, panic attacks, and debilitating anxiety that were present when Kelsey was not on medication. I also wondered why Kelsey decided to stop all her medications now. She

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had been working hard in therapy and had recently made some important strides. Why would she choose now as the time to cut off what she had previously viewed as a necessary component of her recovery?

Kelsey is certainly not alone in her ambivalence towards psychiatric and other medications, nor is this ambivalence unique to people with eating disorders (Dumit 2012). Yet medications can take on particular significance for some eating disorder clients who develop practices of actively restricting their intake of prescribed medications, taking them and then purging them, or hoarding them and ‘bingeing’ on them. What I have learned from these clients resonates with cultural understandings of the body as flawed, but perfectible through pharmaceutical interventions (Dumit 2012), with moral responsibility for managing the body located firmly within the individual (Luhrmann 2000). Yet these clients’ experiences also point to an underside of this trend. The logic of ‘pharmaceutical reason’ (Lakoff 2007) presumes that people naturally strive for optimal health and use medications in order to improve their quality of life by alleviating pain (physical or emotional), optimizing performance, or otherwise enhancing their quality of life. But what about those for whom ‘health’ is as terrifying a prospect as ‘cancer’? How do these individuals experience medication use? What alternative motivations — besides the effects of the drugs themselves — might be at play? And what might the experiences of those for whom ‘health’ is not the governing logic tell us about biomedicine as cultural practice?

These questions highlight the importance of understanding medication use as a relational practice between the individual and the medicine (Geest and Whyte 1989; Carpenter-Song 2009). This concept of medication use as a relationship becomes more intelligible when we remember that pharmaceuticals exist expressly to do things to our bodies. They are meant to alter us. Medications, then, inherently contain a sort of agency in their capacity to transform, enhance, alleviate, or stabilize. People who use medications regularly, especially those that transform not only the body, but one’s sense of who one is, often develop intimate and highly complex relationships to these drugs and their transformative capacities (Cowley-Matoka and True 2012; Anderson-Fye and Floersch 2011). Viewed in this way, we can see that, beyond the effects of the substances themselves, people’s behavior in relation to their medications — especially psychiatric medications — can become powerfully significant avenues for shaping their understandings of themselves and their experiences of the world around them (Jenkins 2011). In other words, taking medications solicits a subjectivity of active self-care within logics of health that presumes a desire to ‘get better’.

Before going further, a brief explanation of my professional training and orientation is in order. First and foremost, I am an anthropologist. In the context of broader interests in the cultural mediation of existential distress, I have studied eating disorders and eating disorders treatment ethnographically for over two decades. During my early years as a faculty member in the department of anthropology at Washington University in St. Louis, I decided to pursue clinical training and spent over 5000 hours working at a local eating disorders clinic as part of my education and licensure. After completing her training and an additional year of research at the clinic, I began a small private psychotherapy practice specializing in eating disorders. My clients know of my academic research career and I obtain additional informed consent from them to draw on their psychotherapy sessions (in completely de-identified ways) in my teaching, speaking, and writing about eating disorders. My ethnographic and clinical interests dovetail, then, and I come at these issues from both of these perspectives simultaneously.
‘Food is Medicine’

One of the standard mantras of contemporary eating disorders treatment in the United States is ‘food is medicine.’ Eating food, patients are told, is like taking a pill, something presumed to be symbolically neutral. Framing food as medicine is meant to help patients view food through a utilitarian lens, stripped of its hefty symbolic and cultural meanings.

This reframing of food as medicine does, indeed, seem to help many patients, at least to some extent. It seems to help them separate out the nutritive purposes of food from the desires and pleasures associated with eating. And if food is medicine — and it is good and important to take your medicine as prescribed — the enjoyment of food becomes slightly less guilt-laden, as pleasure becomes viewed as simply a side effect of the food/medication rather than the driving reason for their ‘indulgence.’ This approach fits well with many analyses of eating disorders that view them as centered on issues of sexuality and bodily pleasures, with restricting food or binging and purging seen as ways of controlling those desires or denying them all together (e.g., Bordo 2004).

Over the years, however — both at the eating disorders clinic and in my private practice — I have observed a parallel phenomenon that is openly acknowledged among clinicians yet is entirely absent from the clinical or social science literature, aside from its inclusion as a form of ‘treatment resistance.’ Many eating disorder patients have extremely ambivalent and complex relationships with their medications, often beginning long before they encounter the ‘food is medicine’ discourse in treatment. They may take their medications as prescribed for some time, but then begin restricting them, taking a smaller dosage than prescribed or skipping them all together. Some take their medications but then purge them. Some hoard their medications, finding comfort in having stockpiles of drugs and using them in what they plan to be a final, terminal medication ‘binge.’ Notably, it is not only psychiatric medications that become enlisted in the restriction and binge/purge dynamics for these clients. Other supplements, such as multivitamins, potassium, calcium or even insulin are also sometimes used in this way. While clinicians may promote the view that ‘food is medicine,’ these clients seem to suggest that, at least for some people with eating disorders, ‘medicine is food.’

How might we understand this phenomenon? What might it tell us not only about eating disorders, but also about how cultural understandings of the body as a biomedical object rather than organic subject become entangled with our understandings of healthy selfhood? And, always forefront in my mind, what does this mean in terms of actually helping people? In approaching these questions, I will introduce two women, both of whom I first met when they were clients at the eating disorders clinic at different times. Both subsequently sought psychotherapy with me in my outpatient practice, separated by some years. While very different in many ways, both of these women — and several others I have known over the years — developed methods of idiosyncratic medication ‘management’ that was often dismissed as ‘acting out’ or ‘manipulation,’ but which in fact emerged from deep and troubling issues at the heart of their eating disorders.

Sarah

Sarah was nineteen years old when I met her at the eating disorders clinic in St. Louis, MO where I was completing my clinical training. Short, very pretty, with shoulder-length dark brown hair and brown eyes, Sarah would not immediately be identifiable by the
average person as ‘sick.’ She seemed, at first glance, to be a very together, very self-assured young woman. But she was not.

Sarah had been in treatment the year before at a clinic in another part of the country – eight weeks of residential care – and had since relapsed badly. Her parents had spent all of their savings on her previous treatment, so Sarah – at age nineteen – obtained a personal loan from a bank to pay for the $1000/day stay at the clinic. Technically, Sarah fit the diagnosis of EDNOS – Eating Disorder Not Otherwise Specified – a catch-all category used for patients who do not neatly fit into the strict criteria of either Anorexia Nervosa (AN), Bulimia Nervosa (BN), or Binge Eating Disorder (BED) alone. Since health insurance plans often exclude treatment for EDNOS, however, Sarah was admitted under the diagnosis of BN, which was, indeed, perfectly apt. Before coming to the clinic, Sarah binged and purged several times a day, some weeks only leaving her apartment to buy more food. She had left college – she excelled in academia and this was devastating for her – stopped seeing friends, and was isolated from her family. At age nineteen, Sarah had been struggling with her eating disorder and a grinding, debilitating depression and frantic anxiety for 5 long years. Sarah also engaged in regular self-harm, slicing her arms and thighs with razors and burning words into her skin. Across her abdomen were scars in the shape of three of her own personal Scarlet Letters: F – A – T.

Sarah had tried various medications while in her previous treatment and in the intervening year before arriving at the St. Louis clinic. The standard antidepressants did not work for her. The physical activation associated with these medications made her mind and body race, rendering focus very difficult and triggering panic attacks. Anxiolytics helped with her anxiety but tended to make her depression worse. She had been on various mood stabilizers, but developed horrible side effects that were both dangerous and intolerable. Finally, after many weeks of trying different combinations of things in different dosages, they found one that worked: Sarah started on a regimen of Neurontin (an anti-epileptic that has been shown to have mood-stabilizing effects), Lexapro (an anti-depressant) and Paxil (an anxiolytic).

Sarah made some strides in the clinic, but she quickly gained a reputation among the staff as a ‘difficult client.’ She certainly did not make their jobs easier. She argued with the dietician about her meal plan. She pushed against rules about computer use, bedtimes, and access to bathrooms. She sometimes refused to go to groups or to therapy. For a period of time, she refused to eat at all, necessitating the placement of an NG (nasogastric) tube to deliver liquid nutrition directly into her stomach. And she periodically refused all medications. This latter issue posed a real problem for the staff. Legally, they could not force her to take medicines against her will. Yet without them, her moods became increasingly unstable and her panic attacks returned, both of which impeded her ability to engage in treatment.

The staff interpreted all of these behaviors, especially the medication refusal, as indicative of Sarah’s underlying personality disorder – Borderline – and as evidence of her ‘immature’ mode of relating that used defiance of authority figures as a means of asserting independence. Certainly, they understood that Sarah’s issues were complex and not easily reducible to a single dynamic. Nevertheless, the issue of Sarah’s refusal to take her medicine came to assume center stage in her treatment at the clinic, indexing for the staff her willingness to commit (or not) to recovery. Power struggles flared up frequently between Sarah and the staff, neither she nor they were willing to budge an inch. It was overall a very unpleasant and unproductive situation.

When I first met Sarah, I was at the clinic solely in the role of ethnographer. As such, I occupied an interstitial space; I was neither ‘staff’ nor ‘client,’ but participated in
activities sometimes considered proprietary to each. In this sense, I was positioned outside the power structure of staff and client, which is likely what enabled me to develop a rapport with the otherwise guarded and sullen Sarah.

As I watched the evolving tensions between Sarah and the staff I sensed there was something more going on for her than simply ‘treatment interfering behavior’ or adolescent stubbornness. On those occasions when Sarah refused to go to group and was sitting in the common area, I began to sit with her and chat. Since Sarah knew I was an anthropologist, she was not surprised by my questions about her experiences of treatment so far, what she was finding helpful, or unhelpful, and why. This naturally included discussions about medications.

On one level, Sarah readily admitted that she refused to take her medications simply because the staff wanted her to take them, and she was feeling angry and defiant. But there was also much more to it than that. Sarah hated the panic attacks, and the depression was deeply frightening to her. Yet she still refused her medications. On one occasion, after I helped talk her through a panic attack, I asked her why she was still reluctant to take her medications. As she caught her breath and tried to calm herself in the aftermath of the panic attack, she told me that she had actually wanted to start her medications again the previous day, but that she found that she could not. She literally could not get herself to do it. She had actually asked the nurse for her morning medications, sat down with them and a glass of water, telling herself over and over to take them, and yet sitting there completely paralyzed by anxiety and fear. She sat there for 30 minutes before giving up and returning the pills to the nurse. ‘Why couldn’t you take them?’ the author asked her. ‘I don’t know,’ she said, in a voice full of frustration and bewilderment. ‘I have no idea. I wanted to take them. I had them in my hand. I kept willing myself to just put them in my mouth and swallow them, but I just couldn’t do it. I couldn’t. I have no idea why.’

Days went by and Sarah continued to struggle with taking her medications. She still maintained that she wanted to take them, but could not. I asked her what would happen — what would feel different to her emotionally — if she were able to take her medications that evening. After a long pause she said quietly, ‘I would feel like I failed.’ ‘Failed at what?’ I asked. ‘Would it feel like you were giving in and letting them [the staff] win?’ ‘In part,’ she answered, ‘but that’s not what I meant. It would feel like I was letting my body win.’ When I asked her to clarify, Sarah explained that taking her medication was an acknowledgment that her body needed something and she was providing it willingly. This she could not tolerate. The anxiety and overwhelming guilt and shame of participating in the enhancement or even the prevention of further decline — of her physical functioning completely paralyzed her. And the longer she was off her medications the more intense these feelings became.

Once Sarah was able to articulate that the core struggle for her was less about defying the staff and more about her own crushing shame about willingly attending to her body’s needs, she and the staff were able to come up with a solution. Sarah found she could tolerate accepting the medications if they were ground up and fed through her feeding tube rather than her actively taking them. In this way, she could rationalize to herself that the agency at play was not her own, but the staff’s; they were ‘making her’ take them. Even so, allowing herself to accept these feedings was very difficult for her and she felt an enormous amount of guilt about it at first. After about a week, and with a great deal of struggle, Sarah finally became able to take her medications by herself again.

After leaving the clinic, and after I had completed my clinical education and training, Sarah began to see me for individual therapy in my outpatient practice. We met twice a
week for almost three years until Sarah graduated from college and moved to another state. In outpatient therapy, Sarah often struggled with medication restriction, or taking her medications and then purging them. Usually, she would purposefully skip a dose here and there, or stop taking one medication or the other for a few days, but nothing that significantly altered her welfare. On these occasions Sarah and I were able to talk about her medications in the terms she herself first identified — as a form of bodily nourishment about which she was extremely ambivalent.

On more than one occasion, however, Sarah’s medication restriction was much more extensive. Periodically, Sarah would come into session and tell me that she had stopped taking all of her medications. Just stopped taking them, even her multivitamins and calcium. When I would ask Sarah why she had stopped, her initial answer would always be something like, ‘I don’t know, I just didn’t want to take them anymore,’ or ‘I’m tired of taking pills every day’ or ‘I don’t think they’re working so why should I bother taking them?’ While there was undoubtedly truth to these statements, they seemed rather flimsy justification for risking the kinds of emotional and physical suffering Sarah faced when the depression and anxiety hit. But each time, no degree of my reminding her about how horrible things got for her when she was off her medications, or how vital it was for her to take care of her basic functioning, did any good. She knew all of that. In fact, she had enough insight to know that’s why she was doing it, as form of self-harm, self-sabotage, and punishment for doing better. Each time she had to descend to rock bottom, to the point of acute suicidal misery, before she would finally begin taking her medications again.

Kelsey

Kelsey, like Sarah, was also a patient at the eating disorders clinic when I first met her. She was 27 at the time and had struggled with anorexia and bulimia since she was 12 years old. She had been in treatment four times before at different treatment centers before coming to the St. Louis clinic, but had never reached a level of functioning that could be considered ‘recovery.’ At admission, she was 70% of her ideal body weight.

By this point I had completed my clinical training and I was assigned as Kelsey’s therapist while she was in residential care at the clinic. However, Kelsey and I barely had time to get started on our work together when her insurance ran out and she had to be discharged. I did not hear from her or about her for many years, until I had a chance meeting with her father at a conference. He told Kelsey he had seen me and she emailed me, asking if I would consider taking her on as an outpatient therapy client. Kelsey had not been in treatment for her eating disorder since discharging from the clinic, but she had been hospitalized several times for dangerously low potassium levels (caused by purging), which can produce heart arrhythmias and cardiac arrest — the primary cause of death in bulimia. She was hovering at around 78% of her ideal body weight, restricting her food intake during the day, bingeing and purging several hours each evening, and getting up in the middle of the night to exercise for three to four hours.

Residential treatment was not an option for Kelsey, despite the fact that she desperately needed it. Financially, it was untenable. She is supported by federal disability insurance and few treatment centers (and none closer than 600 miles away) accept Medicare. After five different treatment centers, her parents had made it crystal clear that they were not paying for any more of her care, and there was no way she could otherwise afford the $1000+ per day cost. Even if finances had not been an issue, though, Kelsey was extremely ambivalent about getting rid of her eating disorder.
To be clear, Kelsey loathed bingeing and purging — she found it disgusting and burdensome. She detested restricting as well — she, like most people with eating disorders, got hungry and it was a mighty struggle of will not to ‘give in’ and eat. But she was terrified of gaining weight. Not only because she didn’t want to become ‘fat’ — it was much more than that. Whenever Kelsey gained weight past about 80% of her ideal body weight, she began to have her sexual feelings return (these are often suppressed at low body weights), accompanied by paralyzing nightmares of abuse, and both were absolutely intolerable for her. She was not consciously aware of any abuse in her childhood, and she had no idea of the nightmares were of actual events, but they were utterly debilitating nonetheless. She was, however, consciously aware that she was gay, a realization that had emerged the last time she was closer to a healthy weight, and she was not yet able to accept this aspect of herself fully. In both domains — the nightmares and her sexual orientation — the awakening of sexual feelings was completely overwhelming for her and at that point she would resolve to lose weight until the feelings went away.

I knew from working with Kelsey at the clinic, and what she had told me of her intervening years, that she often restricted her medications. She was on a mood stabilizer for bipolar disorder, anxiety medication to help with her panic attacks and OCD tendencies, and potassium supplements to protect her from cardiac damage, as well as something to help her sleep. It was her potassium she mostly restricted. Not usually to the level of acute danger (although on two occasions she misjudged how much she needed to take and wound up in the ER), but enough that she knew she was not giving her body what it needed. In fact, Kelsey became obsessed with her potassium values, managing it as carefully as she did her weight. Anything below a potassium level of five is considered dangerous, warranting hospital admission. Kelsey liked to keep hers between 3.5 and 4, but was hypersensitive to any physical signs that her potassium has become dangerously low (heart palpitations, pain in her feet) and would quickly take enough supplements to bring it back up.

At the clinic, Kelsey was viewed by the staff as manipulative, attention seeking, and resistant to treatment, which she quite readily admitted she was. However, like Sarah, there seemed to be much more going on with Kelsey’s medication refusal than simply an intent to infuriate others or to get attention. In fact, Kelsey felt most gratified when no one but her knew about the potassium restriction and she found it annoying and inconvenient in the extreme when she had to go to the hospital.

Kelsey’s relationship with her medication became a focus for us in the early part of her outpatient therapy. Kelsey knew that my foundational ethical obligation was to intervene if I felt Kelsey was an imminent danger to herself or others. She also knew that my therapeutic philosophy is intensely collaborative and focused on helping clients develop their own sense of presence and power in their lives, and that I would not move to usurp that except in the gravest and most immediate of circumstances. Such a stance of radical respect of the client’s personal and emotional boundaries is essential when working with eating disorder patients, who frequently struggle with accepting their own right to exist. By identifying and explicitly honoring the client’s right to control her own body and to make her own decisions, even if they are ones the therapist does not necessarily support, the therapist affirms the client’s right to “take up space” physically as well as relationally. This, in turn, can help alleviate a client’s sense that she must fight for space to exist by pushing back against therapeutic interventions.

As Kelsey’s periodic stopping of medications was explored, it became clear that medication restriction held a particular significance for her beyond just a desire to be obstreperous. Neither was her medication restriction a roundabout means of suicide — despite the danger of restricting her potassium supplements, she was very careful to take just
enough to prevent a full-blown medical crisis. As Kelsey and I focused more on her relationship to her medications, Kelsey began to see how she restricted her supplements to keep her potassium at deprivation level in the same way she restricted her food to keep her body at starvation levels. Following this line of discovery, Kelsey came to see that the core issue at stake for her was that she wanted to punish herself for continuing to be alive. She experienced herself as a worthless, loathsome, utterly repulsive human being. She hated herself with such vehemence that the idea that she might do something — like eat, or take medications — to continue her existence felt morally wrong and intensely shameful to her. Yet she could not quite bring herself to commit suicide. She had overdosed on medications on two separate instances, but in neither case was it enough to kill her or produce lasting damage. So she had settled for what, in her mind, was the next best thing — subsistence in a state of constant deprivation.

Discussion

Looking at these two cases it is clear that much more is going on for Sarah and Kelsey than simple ‘acting out’ or ‘non-compliance,’ as medication refusal is often characterized in clinical settings, and in fact we see that the main motivations for medication restriction have much more to do with their own internal processes of fear, shame, and guilt than manipulating others. In other words, medication refusal for them was about cultivating and maintaining a moral subjective stance that structured their entire philosophy of being. Their ambivalent relationships with medication indexed intense existential struggles about how to survive in a world where one’s very existence feels irredeemably wrong.

Creatively idiosyncraticizing psychiatric medication use as a means of regulating inner experience is by no means uncommon or unique to people with eating disorders. Jenkins (2011) and Carpenter-Song (2009) have discussed this at length in their work on ‘pharmaceutical selves.’ And, as Anderson-Fye and Floersch (2011) found in their study of psychiatric medication use among college students, altering one’s moods and focus to achieve an idealized state — a simulacrum of the ‘normal’ — can be a primary motivator for students’ experimentation with dosage and timing, often devising their own personalized regimens.

What is notable about Sarah and Kelsey, however, is that the ‘idealized state’ they sought was quite different than the elevated mood, reduced anxiety, or enhanced capacity to focus that Anderson-Fye and Floersch found to be goals for students in their study. In fact, Sarah and Kelsey were willing to risk descending into horrific depression or becoming wracked with anxiety and panic in order to restrict their medications. So why were they doing it?

One might suspect that restricting medications could be an effective way to get attention, or to generate crises wherein others felt obligated to come to the rescue. These motivations were certainly part of the picture for both Sarah and Kelsey, but were not the most compelling for them. In fact, both Sarah and Kelsey were highly secretive about their medication restriction and went to great lengths to hide their emotional struggles from others so that their behaviors would not be discovered. Furthermore, their restriction extended to multivitamins, calcium supplements, and potassium supplements as well, clearly suggesting that the focus of this behavior was something other than direct mood alteration through the substance of the medicines themselves.

Rather, the ‘idealized state’ sought by both Kelsey and Sarah was the awareness of depriving the body of what it needs to function optimally. For both of these women — and several others I have worked with over the years — restricting medications became a way of maintaining a state of constant deprivation, of not allowing oneself to thrive.
Medication restriction is about cultivating a subjective stance that is acutely morally charged (Gooldin 2008; Warin 2010). What can be seen with both Sarah and Kelsey is enormous ambivalence and shame about taking proactive measures for their bodies beyond those required for bare subsistence. To actively do something — like take vitamins or psychiatric medications — to ease their suffering or, worse yet, enable them to thrive — feels horribly, morally wrong. Conversely, restricting medications, knowing they are depriving themselves of care — even when they can’t directly feel the physical effects — feels like just compensation for the burden of their continued existence.

This existential angst is a core feature of eating disorders that is often overlooked in approaches that focus on cultural pressures about weight and body image or the social sanctioning of female desires and appetites of all kinds. While vitally important in how and why eating becomes a key mechanism through which these concerns are expressed, as argued elsewhere (e.g., Lester 2004, 2009) the driving issues at stake for people with eating disorders are far more fundamental. At heart, eating disorders are not about wearing a size ‘0’; they are about feeling unworthy to exist and sustaining an existence as a non-entity while relentlessly punishing oneself for the unforgivable crime of remaining alive.

Regulating food and eating is one obvious avenue for expressing and enacting this angst, but it is certainly not the only way. For example, people with eating disorders almost always have very specific restrictions and rituals concerning fluid intake (including water), although this is given scant attention in the clinical literature except as a complicating factor. They also regularly engage in all sorts of behaviors — such as refusing to use an umbrella in the rain — as ways of withholding care from the body. As medication use is increasingly viewed and promoted, at a cultural level, as a means of self-care, empowerment, and a step towards a better and more enjoyable life, medication restriction can become a powerful means of enacting and experiencing a moral practice of deprivation for these clients.

Medication restriction among people with eating disorders sits in dialogue with other reflections on the symbolic significance of medications in different ethnographic contexts (e.g., Biehl 2013; Ecks 2013; Etkin 1992; Whitmarsh 2008; Maskovsky 2005) and brings a new perspective to these discussions by highlighting the ways in which refusing needed or useful medication can become a private and personally meaningful practice, largely independent of the material or interpersonal effects of the refusal. What this suggests is that the symbolic significance of medications must in some cases be discerned by their selective absence. Unlike those studies that focus on the proliferation of pharmaceuticals as a component of larger processes of biomedicalization, then, medication restriction among women with eating disorders indicates that the cultural significance of biomedical intervention cannot be understood separately from the patient’s personal relationship to life and health itself as a worthy and valued goal. With this in mind, understanding these clients’ ‘non-compliance’ through the lens of moral self-management rather than as ‘acting out’ or ‘resisting treatment,’ pivots orientation to these behaviors and opens new opportunities for constructive collaborative work with these clients.

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Conflict of interest
None.

References