Weighing the evidence: Risks and benefits of participatory documentary in corporatized clinics

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Abstract

This paper describes the effects of one U.S.-based public psychiatry clinic's shift to a centralized, corporate style of management, in response to pressures to cut expenditures by focusing on "evidence based" treatments. Participant observation research conducted between 2008 and 2012 for a larger study involving 127 interviews with policy makers, clinic managers, clinical practitioners and patients revealed that the shift heralded the decline of arts based therapies in the clinic, and of the social networks that had developed around them. It also inspired a participatory video self-documentary project among art group members, to portray the importance of arts-based therapies and garner public support for such therapies. Group members found a way to take action in the face of unilateral decision making, but experienced subsequent restrictions on clinic activities and discharge of core members from the clinic. The paper ends with a discussion of biopolitics, central legibility through corporate standardization, and the potential and risks of participatory documentaries to resist these trends.

Keywords

United States; Ethnography; Participatory research; Managed care; Evidence based medicine; Recovery; Arts therapy; Documentary; Psychiatry; Addiction

Introduction

I was driving to the airport when I saw I had a text. It was from Tia, the editor for the video self-documentary group at the psychiatry clinic:

"Can I call you*?? Terrible news…"

Hmm, that is unusual, I said to myself. Maybe we have to reschedule our editing session. After 20 minutes, I saw I had another text:

"Just got bad news from Carla about Larry…He was found dead in his apartment…"

My arms and legs went limp. I pulled over and dialed Tia.

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"Oh God. When did you find out? What is Carla going to do? She spent all of her free time with Larry!"

Tia and I went over the signs of trouble. Larry had been tottering on the edge of an alcoholic binge. Two weeks before, instead of talking about his latest pirated video software, Larry talked about his panic that he had been unable to pay his bills this summer. He reminded us that he was the kind of person who didn't look back once he started drinking. And he had passed out last week in his apartment. Larry waved it off, saying that he had just taken medications and that he could not afford air conditioning.

Larry wasn't the only one in a panic. The clinic that had been his safety net for the past seven years was faltering. Founded in the 1980's by alternative treatment advocates who combined medications with painting, photography, video, yoga class and gardening, it took up the corner of an old hospital building that sheltered people who were recovering from addictions, depressions, manias and psychotic episodes. Decisions were made by a patient government, and lunch was served by patients to patients in a kitchen that doubled as the clinic lounge. Long term patients and volunteer former patients had keys to the supply rooms so that they could roll out a video projector, a sewing machine, or a tool kit whenever the need arose. The leveling of clinical hierarchies and the therapeutic role taken up by patients were reminiscent of the therapeutic communities created by post-war British psychiatrists (Mills & Harrison, 2007).

But over the past three years, hospital managers were forced to make a change. State budget monitors deemed outpatient services too costly. Managed care Medicaid threatened to stop paying for long-term patients, a few of whom had been coming to the clinic for over a decade. Counselors were told to start discharge planning for patients who had been in treatment over a year, although there were few community based after-care services in the wake of State cutbacks. Art groups were no longer reimbursable; only one group per day, based on Alcoholics Anonymous principles, could garner a small payment, and was therefore required. Managed care Medicaid paid more for 15 minute medication checks with a psychiatrist than for hour-long psychotherapy visits, so the number of psychotherapists in the clinic dropped by more than one half within a year.

The most fundamental change, however, was that the trusted patients and volunteers who kept cameras loaded for photo group and microphones charged for music group were asked to return their keys. The clinic was shut down daily at four, and patients were not allowed to linger in the art room. The staff was re-educated about the distinction between a patient and a staff member; the staff who were too slow to learn – those who attended barbecues organized by patients in the city park, for example – were transferred to other units in order to "maintain better boundaries."

Just after his death, Larry's closest friends took note that "we didn't reach out to him like we used to." A week had passed and no one went to his door when he failed to answer his phone, because his closest friends were preoccupied with their own imminent discharge. The staff was aware of his relapse, and on the mandate of clinic managers to retain only patients who "show they are serious about treatment," the staff had given Larry an ultimatum that Larry felt he could not abide: voluntary hospitalization in order to return to the clinic.

This shift in administrative tone set up a conflict of therapeutic cultures that inspired participatory documentary-making by a core group of patients. Their documentary was intended to show the importance of creative arts therapies in recovery. Although their self-advocacy through documentary-making was not the only factor leading to the dissolution of the group, their documentary-making brought the conflict into relief as core group members were discharged from the clinic.

Yet, through the process of documentation, the video group members educated themselves about the outside political forces that impinged on clinic walls. And the video project mobilized a group of patients that had a tenuous sense of their own value as persons. On film they portrayed themselves as people with creative talents who were worthy of public investment. They strove for a visual narrative that would raise public awareness of creative arts therapy for mental illness and addictions, in an environment of cutbacks to "non-essential" services in public clinics.

This paper examines the predicament of self-documentarians in the midst of a broad shift in clinical-institutional cultures toward expertise based on "evidence." Self-documentary gave group members a way to act in their own interests. But it was treacherous to politicize their treatment in a climate of technical expertise. Operating under the rubric of "evidence based medicine", managerial control undermined the social networks and peer leadership that had developed as a result of less biotechnology-focused, more social and community oriented approaches to treatment.

Methods

This paper describes a participatory, collaborative self-documentary project that unfolded as I worked as a psychiatrist, group therapy volunteer, and participant observer in an outpatient clinic in urban New York State that I studied between 2008 and 2012 as part of a larger ethnographic project on addiction treatment in outpatient clinics: here I provide my own analysis of the events that unfolded from the collaborative project. My data gathering began as a study of corporate and medical professionals' efforts to medicalize addiction, establishing it as a chronic physical illness, rather than a moral or social disorder, through the widespread use of newly FDA approved addiction pharmaceuticals (Hansen & Roberts, 2012; Hansen & Skinner, 2012). I soon saw the other side of this story, however: the ways that non-pharmaceutical, psychotherapeutic and creative arts approaches to mental health and addiction are being divested. I gathered this data as a participant-observer over a four year period, with a group of dually diagnosed patients (substance dependence plus mood or psychotic disorders), who were shooting a documentary film on the importance of creative arts to their recovery. I participated in this video production group weekly; I saw group members both inside and outside the clinic, at birthday celebrations, at field trips to performances, and at dinners. I was also privy to staff meetings in which patients, therapy groups, and clinic policies were discussed. I wrote field notes on these events, and conducted open-ended interviews with participants to get their interpretation of these events. As a part of the larger study of addiction treatment, I conducted 127 interviews with treatment program administrators and managers, pharmaceutical executives, policy makers, physicians, and pharmacists.

I thematically coded and analyzed narrative data from field notes and interview transcripts using established ethnographic iterative techniques of continuous comparison, and grounded theory development, as well as triangulation with available secondary data and confirmatory interviews with informants (Corbin & Strauss, 1997; Emerson, Fretz, & Shaw, 2011).

This research was conducted with oral informed consent procedures, data storage techniques designed to safeguard the confidentiality of participants' identities, and participant protection from court subpoena of the study's data as provided by a U.S. Health and Human Services Certificate of Confidentiality. These measures were approved by New York University's Human Subjects Investigation Review Board. As a result of these measures, the names, locations and dates of people and events described have been changed to conceal participant identities. However I have tried to accurately represent an ethos of ideological conflict that, while brought into sharp relief in this one clinic, I found pervasive in my

conversations with mental health practitioners and site visits to mental health treatment settings across the U.S.

Findings: a clash of clinical cultures – "recovery", community participation, and "evidence"

In 2004 the U.S. Substance Abuse and Mental Health Services Administration (SAMHSA) released their National Consensus Statement on Mental Health Recovery. Written on the basis of their convention of "110 expert panelists [who] participated, including mental health consumers, family members, providers, advocates, researchers, academicians, managed care representatives, State and local public officials, and others", it led to a series of technical papers and reports (SAMHSA, 2004, p. 1) written in an effort to establish recovery, rather than symptom reduction alone, as the goal of treatment in mental health centers across the country. SAMHSA defined recovery as "a journey of health and transformation enabling a person with a mental health problem to live a meaningful life in a community of his or her choice while striving to achieve his or her full potential", and offered "10 fundamental components of recovery" including self-direction, individualized and person-centered care, empowerment, holistic services, a non-linear path of progress, strengths-based assessments, peer support, respect, responsibility for self-care, and the fostering of hope (SAMHSA, 2004, p. 2).

Psychiatrists and social scientists have described recovery as a development of the prior two decades, a reaction to pessimism and paternalism in mainstream psychiatry (Adeponle, Whitley & Kirmayer 2012). They have defined recovery in various ways, but their overall emphasis has been on placing the locus of control with the recoverer him or herself who ultimately defines his or her own milestones of progress. They have also emphasized that the recoverer develop a social role that transcends his or her sick role as mentally ill – one that draws on his or her capabilities and positive personal qualities, and therefore cultivates hope, healing and connection (Jacobson & Greenley, 2001). However, sympathetic observers have also pointed out these principles have had mixed success in application within health care systems (Hopper, 2007), and that recovery relies not only on processes internal to the recoverer but also on external conditions, such as institutional support, necessary for recovery (Jacobson & Greenley, 2001). Institutional support for enhanced social roles is not always a part of initiatives undertaken in the name of recovery: In California, for example, State policy makers working in the context of managed care have invoked recovery to justify reduction of mental health expenditures in the name of reducing dependency on services (Braslow, 2013). This is a use of the term recovery that Jacobson (2004) has called recovery-as-politics, in contrast to multiple other uses of the term, including recovery-as-experience (of the sufferer who adjusts to mental crisis), recovery-as-ideology (peer/consumer/survivor driven decision making), or recovery-as-evidence (of longitudinal improvement after mental crisis).

Corresponding to recovery-as-ideology is Community Based Participatory Research (CBPR), a movement in health research that strives to collaborate with members of the communities served to identify barriers to care and to design appropriate interventions. The approach, which requires researchers to collaborate with members of targeted neighborhoods and populations in research design and implementation, has been codified and promoted by major U.S. health research institutions including the National Institutes of Health, the Centers for Disease Control, and the Robert Wood Johnson Foundation (Jones & Wells, 2007). Advocates of CBPR have seen it as a way to address disparities in mental and physical health, making health care more accessible and relevant to low income and/or ethnic minority people that are often under-served (Wells, Miranda, Bruce, Alegria & Wallerstein, 2004), as well as building health systems that serve the growing number of

patients with chronic conditions that require community-based support (Tapp & Dulin, 2010).

Through its twenty year history, the clinic described here developed programs that resonated with the therapeutic philosophies of both recovery and community based participation. The holistic therapies that the clinic offered, including art, music, gardening, yoga and cooking groups, conveyed that the goal of treatment was not limited to symptom reduction, but rather included a sense of meaning and purpose in life. The historically democratic structure of decision making in the clinic, in which patients planned activities, and took on leadership and volunteer roles, created a sense of community through participation. Community building was especially important given the high rate of homelessness and of alienation from families among the patients, who were almost all Medicaid insured or uninsured, many of them referred from a local homeless shelter. Community building contributed to the long tenures of creative arts group members, and therefore enhanced therapeutic outcomes. This was significant because treatment retention is one of the main indicators of treatment effectiveness advocated by the U.S. Substance Abuse and Mental Health Services Administration and the National Institute on Drug Abuse (NIDA, 2009; SAMHSA, 2012); long term treatment retention is positively related to improved social functioning and reduction of substance abuse (NIDA, 2001).

The clinic's video self-documentary group fostered community building in that members collaborated in order to visually narrate their lives and recovery for each other and for the larger clinic. Their videos featured group members talking about childhood memories of emotional neglect, physical and sexual abuse, first loves and abandonment, recourse to drugs and alcohol, guilt and fear about domestic violence, successes and failures in parenthood, desperation and loss, entering treatment, and the hope of regrowth through creative arts. They represented themselves by using a wide array of sensory materials, including footage of group members in therapy, photos of group members as children, photos of their families, recordings of music and art by group members. The video group's approach therefore resonated with that of participatory ethnography (Harper et al., 2004; Hemment, 2007). When the clinic's video group decided to produce a piece that portrayed the value of creative arts in recovery to its members, and the reasons for mental health budget cuts to creative arts therapies, it took on a form of participatory action research.

The clinic was hit especially hard by budget cuts to mental health services in New York State – $204.9 million in cuts to Medicaid for mental health services between 2009 and 2012 (NAMI, 2012) and $46 million in cuts to the Office of Alcoholism and Substance Abuse Services in 2011 alone (NYAASAP, 2011). Psychiatric outpatient programs and community-based services were especially targeted for cuts, as scarce resources were consumed by emergency and inpatient care that the State was not in the position to deny. Of course, outpatient services are designed to reduce emergency and inpatient costs by stabilizing fragile patients who would otherwise require hospitalization, but State-level budgetary politics informed a culling of "expendable" programs.

The hospital's management was not uniform in its response to these trends. One division director was outspoken about the value of arts therapies and other social therapies as not only clinically effective, but also cost-effective in preventing relapses that call for expensive emergency and inpatient care. He had, in fact, conducted his own study of an arts-based therapy among psychiatric inpatients that demonstrated better outcomes among those receiving the therapy than those not receiving it. He used this study to defend the arts-based programs in his division. Among those overseeing mental health services for the City there were also a staunch defenders of social therapies and recovery as the goal of treatment. But these administrators were swimming against strong currents in the form of deep budget cuts,

State level performance measures (such as short lengths of stay) that guided local reimbursements, and waning public support for complex, long-term therapies that most members of the public do not understand or see as necessary to health care.

Managers began to tell clinic staff that they were to move long term patients out of outpatient programs and into (increasingly scarce) community based services. They needed to show larger numbers of patients served, and shorter wait lists for outpatient treatment. Their clinical rationale was that patients had to move on with their lives, and not become dependent on clinic services in the way that they were dependent on drugs. This discourse of "dependency" caught on quickly among these addiction services administrators: they were already therapeutically oriented to stamping out dependencies on substances, and on relationships that were abusive, co-dependent, or enabling of drug use. In an environment in which the administrators felt they had few other options, and in a U.S. culture that places a premium on autonomy, they found comfort in the thought that shorter courses of treatment could help patients to become independent.

In the midst of these financial pressures, public clinics were also attempting to respond to calls for enhanced quality of care. Increasingly, the quality of health services had been gauged by hospital accrediting agencies (such as the Joint Commission on Accreditation of Healthcare Organizations, JCAHO) according to adherence to "evidence-based medicine" (EBM). The "evidence-base" was narrowly defined, focused on treatments with demonstrated efficacy in randomized clinical trials, which could be measured dichotomously using medical records (e.g. percentage of patients who are prescribed a first-line medication for their diagnosis), and are used by agencies to rate the performance of hospitals and clinics. In the clinic described in this paper, the management's efforts to enforce EBM was evident in the staff trainings and record keeping practices devoted to ensuring that all patients received timely psychopharmacological assessments and prescriptions, that newer addiction pharmaceuticals were offered to patients meeting treatment criteria, and that rates of "polypharmacy" (prescription of more medications than necessary) were going down.

As pointed out by Williams and Garner (2002), this narrow interpretation of evidence based medicine has led to a focus on randomized controlled trials as the only acceptable evidence for efficacy, and on pharmaceuticals to the exclusion of psychosocial treatments. Pharmaceuticals are the most likely treatments to be studied in randomized clinical trials, and the presence or absence of a prescription in the patients' records is relatively easy to document. Other qualities of treatment providers and treatment setting, as well as the preferences of patients, are left out of this algorithm, and a paradox has developed as "doctors are now being urged at one and the same time to take users' wishes for treatment into account and to follow the edicts and restrictions of EBM" (Williams & Garner, 2002, p. 11).

Compared to pharmacotherapies for mental illness and addiction, social therapies have little "evidence" base as defined by EBM. The "evidence" forms a closed loop in which therapies which have a resourced constituency (such as pharmaceutical manufacturers) and some demonstrated efficacy are funded for further study, and those therapies without clinical data supporting their use or without a powerful lobby do not. Although the few studies of art therapies that have been published indicate a positive relationship between arts and outcomes, clinical trials of creative arts therapies are rare (Bungay & Clift, 2010; Leckey, 2011; Ruddy & Milnes, 2005; Stuckey & Nobel, 2010). So arts-based therapies are among those with the least data to arm proponents in the emergent era of EBM, and they are marginal to the already marginalized and under-funded area of mental health and addiction treatment.

Participatory self-documentary

The video self-documentary group that Tia and Larry had been involved in had evolved over the course of a decade. Founded by two patients with film editing experience and a staff member with art therapy training, the group had produced a variety of short videos that were written, casted, acted, filmed, and edited by group members. Group leaders saw video production itself as part of the recovery process itself: when they welcomed new members, they described the collaborative problem solving required to produce videos, the discovery that group members made of creative talents that they did not know they had (such as script writing, acting or editing), and members' reflection on their struggles with addiction, mood swings, and psychosis as part of the recovery process itself. When describing the benefits of participating in the group, members often used terms that echoed those of the SAMHSA expert panel on recovery, such as holistic treatment, peer support, respect, and hope.

Given that group leaders saw creative process as central to the recovery value of video production, some of the videos were fictional, some humorous; at times the group used elaborate costumes and sets, acting from scripts. The videos were shown at parties and special screening events for clinic patients and staff. They were performative, but in production group members were focused on their therapeutic value. The group leaders invited me to join the group when I expressed interest in learning video techniques. Over the ensuing three years, along with other group members, I wrote scripts, held cameras, and edited footage. I also participated in decisions about future projects, and how to intervene when a group member was in trouble.

One year into a financial and administrative restructuring of the clinic, the video group's leader expressed concern that the hospital might eliminate art therapy programs. The signs were there, she said: the management deemed arts-based groups unreimbursible, and art therapy was eliminated in the adjacent clinic.

I clenched my jaw. The group was an oasis of acceptance and productivity in the otherwise isolated daily lives of people living on the margins. The group's endangerment was a product of political expediency, I thought, which called for a political response. I reasoned that the group's work spoke for itself, so it should be shown to potential supporters outside of the clinic.

Amid sarcastic remarks that the group might not be around long enough to see a new project to completion, I asked the group if they would want to make a video for the public. After a few seconds of silence, Jack, an avid reader who had long reported to us on mental health budget cuts from the New York Times, took off his glasses and leaned into the table. "I think we should do it. For people who don't know what recovery is, let alone why tax dollars should support people sitting on their a- - -s and drawing". Nora, just back in the group after three days in the hospital, said "This is the only group I look forward to. I want to let people know what difference art makes for recovery".

As the focus of filming shifted to creative arts in recovery, group members became more articulate and impassioned about the value of art groups. One member who had been rejected by his family, and had come to the clinic from a homeless shelter, told the group "you are my family". Another member said "I never saw myself as a real artist before now. But now I see I have something. Despite my bipolar disorder, and the mess it has made for me, I can make things".

Making a video for public distribution turned out to be complex. Hospital lawyers determined that the consent forms that group members had used for years were invalid, and that anyone who was shown in the footage would have to sign a new form. Some subjects in

the group's footage had graduated the program or dropped out of treatment and could not be reached for consent, so their image could not be used.

Then there were group members who had been lively subjects and actors in previous video projects made for in-clinic use, but were ambivalent about telling their stories to the public. Larry had not been ambivalent. He insisted on staying behind the camera, saying he did not want his business "all over YouTube".

A year into the project, a number of group members were preoccupied with their financial stresses. They found that their Medicaid coverage was being cut, Medicaid applications and renewals were being turned down, and their medical bills ballooned with each day that they came to clinic. One member gripped the edge of the table as she listed the medical bills for which collection agencies called her. "I don't understand", she said. "Even in Puerto Rico they have a better system than this. I got my treatments, and I didn't end up in the hospital like I did here. Don't they get it that I cost them more money if I'm sick?".

Larry chimed in: "Don't even get me started. I get disability for my back, but they take $300 of that out each month for bills that Medicaid says I need to pay from when I wasn't qualified. After my rent that leaves me $120 to live off for the month. $120! I have to squeeze my food, transportation, phone, utilities out of that. I can't turn on air conditioning. I can only come here once a week because I have a copay.[1] How the hell am I supposed to survive?".

In earlier times, the clinic staff allowed Larry to attend group without registering when he was behind on payments. But an atmosphere of rule enforcement, oversight and downsizing now prevailed, in which staff members with over a decade of seniority feared for their jobs. Larry was being priced out of a public clinic.

> "I'm so mad about this. I want people to know how bad it is. I don't care anymore – if we're going to talk about this, I want to get right in front of the camera. People need to know!"

The group decided that the documentary should not only demonstrate recovery through creative arts, but should also probe funding for art in mental health care and the policy decisions that were narrowing the treatment options. Because I knew many of the decision makers, I offered to contact policy makers and sympathetic clinic managers for interviews on camera.

Ultimately the piece that video group decided to make would combine personal narrative of patients in the clinic about the role that creativity had played in their recovery, with interviews with managers, policy makers and patients about the ways in which the health care system currently worked against creative arts as a part of mental health treatment. Its primary goal would be to convey to audiences who knew little about mental health treatment a sense of what recovery in its fullest sense was, and to convey the role of creative arts – broadly defined as any activity stimulating the imagination, a sense of purpose and meaning, ranging from visual art and video to cooking and gardening – in fostering recovery. At the same time, the piece was to make a political intervention, by calling attention to the ways that cutbacks in health services and the narrow way that some administrators defined mental health care, as medication management alone, were endangering programs that promoted recovery. The group planned to document their experiences with creative arts therapy in order to call health budgetary priorities into question.

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[1]Larry owed a copayment to his insurance plan with each clinic visit.

Taking the back the keys to the clinic

One person who was eager to have decision makers answer his questions, and to hold them accountable, was Juan. Juan had been referred to the clinic for treatment of his heroin addiction by a men's shelter five years before. Since his entry into treatment he underwent a transformation, finding housing in a men's recovery house, and completing a vocational rehabilitation program that landed him an internship in the information technology department of a local hospital. The secret to his success was active participation in the groups offered by the clinic, especially the visual art group. There he lost himself for hours creating paintings and collage that ultimately won him prizes in state wide art competitions.

At first, when the staff began introducing him as "an artist," he waved it off, saying "I never had an art class in my life. I don't know what I'm doing". Over the months, he said that less and less, but he was still suspicious. "Too much good stuff is happening," he said with one corner of his mouth smiling. "There'll be trouble soon".

He did allow himself to send a post card to his younger brothers and sisters that advertised his award-winning piece in local gallery. This was a big move with a troublesome family. His father, a one-armed veteran who came home from combat dependent on morphine, had had his best friend, a fellow Korean War survivor, to inject heroin into his remaining arm. He died of AIDS. His mother died of alcoholism shortly after. Juan, as the oldest, took responsibility for his brothers and sisters when his parents could not, but moved out at nineteen when the pressure got too great. In the decades that followed, most of Juan's brothers and sisters served time for drug and sex-related offenses, and they resented him for leaving. He lost touch with them when he became homeless; he had convinced himself that he did not need their verbal abuse. When I asked how they'd respond to his post card, Juan said with his customary dryness, "They'll be jealous. They hate me".

The first sign of trouble after the management instituted "cost effective, evidence-based" clinic procedures was that Juan could not stay late in the art room. Patients could not be left in the room without staff supervision. Rather than spending time with patients in the art room after group, the art therapist had to return to her office to fill out clinic forms, and hold one-on-one counseling sessions with patients behind closed doors, rather than the informal talks in the art room. This meant that she was no longer privy to the details of group members' lives, details that had previously been shared around art table. This also meant that Juan could no longer meditate on his collages. For two years, Juan had held a set of keys to the art room. He was usually the last person to leave, and guarded the art supplies vigilantly. But under new administrative pressures, the art therapist asked him to return the keys.

Juan's first response was to linger in the art room as long as possible, telling staff that he was cleaning the coffee maker. Clinic managers moved the coffee maker to the staff room. Juan wrote them a letter asking why he had been evicted from the art room. He was then recast in staff meetings as someone who "has been in the clinic too long, because this program is for stabilization only". Staff members were asked to develop a discharge plan for Juan. They ran into two roadblocks: the first was that Juan became acutely anxious and reported "my bipolar is spinning out of control:" he was no longer "stable." The second was that there was no community-based service to which Juan could be referred.

The management solved this problem by fiat, declaring Juan stable and ready for discharge. As the day of his departure approached, Juan was more and more argumentative. He confronted group members about arriving one or 2 min late for meeting, and accused group leaders of being "hypocrites" when they did not call on him as quickly as he felt they should. After telling his psychiatrist clearly that he was craving heroin and that the violent

and racing thoughts of "my bipolar" were coming back, the clinic staff was forced to extend his stay in the clinic. They drafted a behavioral contract, however, and had Juan to sign a statement that he would cooperate and "not question the decisions of group leaders", that he would only be present in clinic during his assigned groups, and that he would no longer attend video or art groups.

Three weeks later, Juan was found in the art room, and was determined to be in violation of his behavioral contract. Shortly after he was discharged. As one clinic manager said, "we can only help patients who are ready to help themselves".

"We don't reach out like we used to"

In a new bid for "quality assurance," three staff members were reassigned, and several long-term patients were discharged.

Anna, a therapist, began getting visits from administrators who questioned her notes on patients, and scoured her patients' charts for errors. For years, counselors came to her for advice on how to manage the outbursts of complicated patients, and more importantly, for how to manage their own reactions. Dozens of therapy interns learned basic technique from Anna as they passed through the clinic each year, enabling exponentially more patients to get individual therapy than the clinic budget allowed. Yet, Anna believed in social therapy and therapeutic communities, and encouraged the staff to organize social events inside and outside of the clinic; some managers now scoffed that she "confused the boundaries between patients and staff". Sensing the winds, Anna applied for a transfer to another unit. After her departure, the flow of therapy interns stopped, and counselors made their own way with suicidal, explosive patients.

The next person to be visited was James, the clinic manager. James was from a Southern Baptist family, and was himself in recovery from crack cocaine. Most staff saw him as a valuable resource who knew the habits of each patient and intervened before problems reached a head. He identified with the patients, and held no punches when he talked to administrators. "Let me call [the director] and tell him you can't be left hanging like this with no prescription and no appointment!" His voice bellowed down the hall within earshot of clinic managers. But months later, an anonymous complaint was filed through human resources: "employee is acting outside of his professional training and intervening in clinical affairs". And "employee is resistant to correction".

James saw no reason to change. He had been the major domo of the clinic for over a decade, and knew its logic inside out. Every year he ensured that the clinic got the highest scores upon inspection from State regulatory agencies. "What are they going to do? Get rid of me? Try it!".

And try it they did. It started with a warning issued in the presence of a human resources officer and a union representative. It then moved to a remedial plan the required James to report to higher management once a week to review feedback from his superiors. James could not hide his resentment when younger, less experienced social work managers explained to him, slowly, in third grade English, how to conduct himself in the office that he had run for a decade. Finally, James came to work one morning to find a notice on his desk that he had two days to vacate.

He called his union representative. The dismissal was changed to a transfer to another unit.

I saw James in the hallway two months later. "It was Him – *He* knew where to place me. I couldn't take not one more day of that place. I tell you, I never worry because I'm truly in God's hands".

Roberto did not show the same equanimity. A counselor in the clinic, he had been asked not to sponsor the annual picnic in the park that he had held for his current and former patients. He did not argue; one of his former patients sponsored the picnic and he attended. Roberto was abruptly transferred to another unit. A few months after his transfer, an administrator called his supervisor and asked him to reprimand Roberto for keeping in contact with his former patients. Apparently Roberto had received a string of visits from former patients during his shifts; not trusting the new counselors to which they had been assigned, they sought his advice in moments of crisis. For his part, Roberto worried about his former patients and used every opportunity to pass by the clinic lounge, explaining "the staff lounge is so nasty on the other unit – I'd just as soon come up here where at least I know the microwave is working". Apologetically, Roberto's supervisor told him that he'd gotten an official request that Roberto use his own staff lounge.

"They think I need to separate from my old patients" Roberto said.

The fates of long term patients were even less certain than those of the staff.

Carla, who had been Larry's best friend, was discharged. Carla lived alone in a small apartment that had belonged to her abusive parents before they died. She survived on monthly disability checks for her bipolar disorder. Before Larry's death, Larry lured Carla out on the weekends to photograph parks and festivals around the City. Other than those outings, Carla rarely left her apartment except to attend groups. The clinic's administration spoke of Carla's "dependent personality" at staff meetings and insisted that after a decade of group attendance, discharge would force her to find new outlets. But Carla, who had been a lifelong recluse, could not bring herself to visit the clubhouse – a mutual support organization for people with psychiatric diagnoses – recommended by her counselor. Carla asked the clinic director to return to the clinic as a volunteer, but was turned down because "it might encourage your dependency on the clinic."

A similar fate befell video group members Julian, Fatimah, and Philip, who in the year before Larry's death had often turned to each other, half in jest, and said "you're next!" "No, you're next!" All had been in the video group for five years or more. All were, in fact, discharged over the ensuing months. Although a high rate of discharge permeated the entire clinic, Their work on the video project likely accelerated their discharge. In staff meetings, oblique reference was made to the management's directive to discharge "troublemakers".

Managers were working in an environment of scarcity and job insecurity that fueled their anxiety. The idea of a group of patients making a video that might negatively portray management sent terror through the division. In an environment of distrust, it was the long term patients, those at the core of a system of mutual peer support, that were threatening because they could mobilize others.

Conclusion: risks and harms of participatory documentary

Nikolas Rose in *The Politics of Life Itself*, writing in the vein of Foucaultian biopower about the increasingly biomedical basis for regulation of populations, and for regulation of the self, describes the rise of "somatic expertise" – of "multiple subprofessions that claim expertise and exercise their diverse powers in the management of our somatic existence" (Rose, 2007, p.6). He juxtaposes this enforcement of expertise with popular demands for "patient choice," and a discourse of bioethics "about the value of different forms of life, styles of life, [and]

ways of living" (Rose, 2007, p.97). In the tension between these opposing forces shaping the biomedical subject, he argues, lie the biopolitics of our times.

The standardizing and surveillance interventions introduced to the clinic during this study were designed to enhance *legibility*, as described by Scott (1998). Those hospital managers who wished to make hospital procedure uniform, and centrally consolidate control over clinical activities, were advocating modernist methods of statecraft that reduced local knowledge and complexities into a grid, permitting centralized visibility and planning. Analogous to failed nineteenth century European forestry techniques that Scott describes as clearing underbrush vital to the ecosystems supporting the trees, "evidence based" clinic procedures destroyed the social connections sustaining patients who confronted isolation and threats to their survival every day. In a macabre enactment of Max Weber's iron cage of bureacratic rationalization, they discarded the local knowledge of line staff and patients' peers that guarded tenuous lives.

Centralized planning and decision making also introduced a problem of communication in one-sided power relations; local, pragmatic intelligence that might prevent systems inefficiencies (in this case, with lethal consequences) cannot be transmitted back to increasingly hierarchically minded leadership. The more centralized and unilateral organizational leadership is, the less valid information it can extract from subordinates at the local level (Scott, 1990). In the case of Larry's clinic, subordinates attempted to resist the centralizing trend by conveying local knowledge, in the form of a public narrative about the value of therapies that were being cut. These patients worked against the depersonalizing and disciplinary ethos of new "evidence based" clinic policies by practicing peer support, engaging in group therapy, and ultimately using the group to create a public voice to question clinical policies.

Ironically it was the potential of participatory self-documentary to empower patients that put the participants at risk. While many call for expansion of biomedical care to counter structural violence – such as the death and illness caused by policies preventing access to healthcare (Farmer, 2005) – the patients described here experienced structural violence *because* of the expansion of biomedical management; neoliberal management that re-framed the mutual support and affirmation of group members as dependency, and conflicted with the patients' understanding of recovery as the cultivation of social connection and identity through group membership. Ultimately "evidence-based" interventions were defined by corporate, rather than therapeutic, entities. For-profit managed care Medicaid plans were able to set the terms of encounters with patients, directing therapists to limit relationships rather than build them. The broader lesson is that community-based participation in health systems is rendered even more difficult by privatized funding and governance of health systems: managed care companies answer to shareholders, not to calls for democracy.

Most disturbing about biocorporate administrative strategy is its impersonal ethos of interchangeability. The total institution and paternalism of 1960's psychiatry ward, momentarily challenged by an ideal of community-based treatment, has been replaced in the current era by clinics without relationships. The ecological bonds of doctor-patient/peer–staff relations have been broken in favor of universal treatment guidelines, derived from statistical probabilities of symptom reduction based on large randomized controlled clinical trials. "Evidence based" managed care breaks up treatment into reimbursable units that are independent of one another. The end effects of this fragmentation are invisible at the level of bureaucratic records. Their accounting systems negate the natural history of patient recovery and therapeutic community.

Another effect of mechanical limits to patients' length of stay, set by universal treatment guidelines and motivated by State budgets, is to deplete the network of connections and accumulated knowledge that staff and patients build over time. Patients and line-staff are prevented from accumulating social and cultural capital by a regular turnover of both patients and staff. Yet, the accumulated capital of knowledge and contacts among long term patients and staff is the primary resource that the clinic can offer people for whom daily survival is in question. On the local level of clinical routines, only ethnographic description, such as self-documentary, captures what these strategies of disruption mean for people caught in the crossfire.

Ultimately I was the one that suggested that the video group go public. As an ethnographer, helping the group to document its story was the political action that I knew to take. Larry's death weighted heavily on me, as did the death of the ties that bound clinic patients and staff together as group members were discharged. At the time of this writing the documentary is not yet complete. Remaining video group members continue to edit; managers no longer target them, but have quietly eliminated the group's budget and erected a wall in the center of its production room in order to create more "clinical" space. Most group members who were discharged have relapsed. These events have not dampened my commitment to ethnography and self-documentary as tools for social change, but they have shown me that they can have both constructive and destructive consequences, in a clinical environment that can be hostile to the relationships and forms of agency that documentary and ethnography honor.

Acknowledgments

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