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## Unraveling Ethics: Illuminating the Moral Dilemmas of Research Ethics

**T**his essay offers a critical, reflective analysis of some of the sticky moral questions that can entangle feminist researchers as they work to transform a research proposal into an application for ethics committee approval. We write not as philosophers or ethicists but as feminist social scientists reflecting on our struggle to do ethical research and to be ethical researchers in an environment governed by a regulatory model of research ethics. Our story is constructed as two intersecting narratives. In the first section of our essay, “A Narrative about Ethics,” we relate our account of how ethical theory plays out in the real world, drawing on our experience of preparing the ethics applications for an interview study with “anorexic” teenage girls and our struggles with two pillars of research ethics policy: defining the research population and eliciting informed consent.<sup>1</sup> In the second section of our essay, “Ethics in Our Narrative,” we tease out the implications of the research ethics approval process for the people who participate in research and for those who desire to be ethical and moral researchers.

The enigmatic, gendered character of self-starvation and the unanswered riddle of its cause(s) and maintenance has made anorexia nervosa an alluring subject for scholars in many disciplines and fields (including cultural studies, women’s studies, and media studies) using a spectrum of perspectives (social, cultural, and biological) and epistemologies, from

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<sup>1</sup> A major point in our essay is that anorexia is a contested category and *anorexic* is a problematic label, particularly from girls’ standpoints. For this reason we are using the terms *anorexic* and *anorexia* provisionally and tentatively, in the absence of better words.

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positivism to critical poststructuralism. Amid this enormous corpus of published research there is a deafening silence about the ethics of doing research with “sufferers” in general or with teenage girls—the most frequently affected group—in particular.

Our essay seeks to address this glaring gap in the literature while also responding to the invocations from other researchers for empirical data and concrete documentation of the practice and implications of ethical decision making in human research: “the way ethical decisions are actually reached (as opposed to how they should be reached)” (DeVries and Subedi 1998, v).

Our essay also arises from particular, personal agendas: our desire to “do ethics right,” in terms of both complying with institutional ethics policy and being morally and ethically responsible to our research participants; our professional commitment to being critically reflexive about the morality of our interactions with research participants and the research ethics process; and a vested interest by one of us, as the chair of an institutional ethics review board, to see research ethics policy and ethics committees foster genuinely moral behavior and ethical research rather than cultivating cultures of counterfeit practice.

In penning this essay, our aim is to make visible, and therefore revisable, the moral dilemmas embedded in research ethics policy and its implementation by ethics committees, and to illuminate some of the implications these dilemmas carry for feminist research and feminist researchers. Michel Foucault ([1973] 1978) points out that even uttering knowledge that diverges from established discourses is a critical activity and an act of resistance. In this sense our essay is explicitly transgressive because it seeks to unravel the morality of the ethics approval process and the ethics of doing research. This is a dangerous but politically necessary conversation. The investments, dilemmas, and implications of researchers’ ethical decisions and moral choices are usually secreted away, buried, concealed, and hidden from public scrutiny, thereby crafting an illusion that “good” research is being done by “good researchers.” However, it is necessary to make the ethics of research transparent in order to identify the moral crevices of ethics policy and practice and to develop new and better ways of doing feminist research and being ethical feminist researchers.

## **I. A narrative about ethics**

### ***Constructing the indefinable subject***

Anorexia nervosa is a serious social issue and a potentially life-threatening problem affecting approximately 0.5 percent of females, primarily teen-

agers, and approximately one-tenth as many males (American Psychiatric Association 2000). Treatment for anorexia nervosa is difficult and prolonged. Approximately one-third of sufferers still meet diagnostic criteria five years after initial treatment, and studies report mortality rates of 5–8 percent from starvation or related complications (Polivy and Herman 2002). Even weight-restored anorexics may experience ongoing medical complications and long-term psychological and social problems that have a detrimental impact on their quality of life.

Clinicians and reviewers have criticized the absence of research into the life history and lived experiences of people with eating problems (e.g., Leder 1990). A particular gap is the absence of systematic, qualitative research about the experience of self-starvation from the standpoints of teenage sufferers. Our study sought to redress this silence and to generate understandings that might improve prevention and support programs in schools and in medical contexts.

We were well versed (and well rehearsed) in “getting through ethics” and had an intimate, insider knowledge about the thinking and machinations of ethics committees, accumulated from years of serving on and chairing such committees. We began preparing our ethics applications complacently confident that the task would be painless and pedestrian. But our interview study posed messy moral quandaries that challenged our ideas about the meaning of doing ethical research.

As a multisite study, our research project required ethics approval from several institutional ethics committees. In Australia, where we work, the national guidelines and policies governing research with humans are generated by the National Health and Medical Research Council (National Health and Medical Research Council 1999). Institutional compliance is required by federal law and monitored by the Australian Health Ethics Committee. Compliance is an employment condition for academics and a prerequisite for the receipt of national research grants. Typically, institutional ethics committees follow the national protocols, although local committees may interpret these differently during the review process. The protocols parallel those of other English-language countries. They include an explanation of the aims, rationale, and design of the research; a description of the target population and the procedures for recruiting participants and eliciting informed consent; an explanation of the methods of data collection and analysis; a statement about the risks and benefits for participants, and the strategies for dealing with possible physical or psychological distress; copies of the interview questions/questionnaires; and a letter to participants summarizing the information in the ethics application.

Research ethics policy positions research participants as the “object” of the research and assumes that these “subjects” form an identifiable, knowable constituency whose members share particular characteristics that distinguish them from others. Self-starvation resists such comfortable categorization. Anorexia nervosa is classified as a psychiatric disorder, but both physical and psychological criteria are used in diagnoses, including the maintenance of a very low body weight (less than 85 percent of “normal” for age and height), amenorrhea, fear of fatness, and distorted body image (American Psychiatric Association 2000). But self-starvation has shifting, multiple identities and assumes different guises at different times, ranging from continued noneating to restricted eating with excessive, compulsive exercise to erratic food restriction accompanied by binge eating and purging (Polivy and Herman 2002). Biomedical discourse constructs self-starvation as an organic disorder and a disease, but the origins and causes of anorexia are uncertain and contested. It has been variously explained as a biological pathology, a genetic predisposition, an affective disorder, and a cognitive deficit or dysfunction. Psychodynamic and psychoanalytical discourses, on the other hand, constitute anorexia as an outcome of a variety of family problems or as a self-pathology that is symptomatic of inadequate or unresolved psychosexual and ego development (see Malson 1998, 78–83, for a review).

Biomedical and psychological research explicitly constitutes self-starvation as an embodied entity and a distinct pathology that is located within the individual. The behaviors attributed to anorexia are positioned as abnormal biological and/or psychological problems that mark the anorexic as deviant and different from a generalized population of “normal” teenage girls. Through her constitution as “other,” the anorexic is positioned as physically and psychologically unable to act in or to protect her own interests, thereby justifying medical and psychological intervention to ensure a return to “normal” eating behaviors and constructing anorexia as the remit of the medical profession.

Despite the social and cultural power of such discourses, self-starvation has resisted colonization into biomedical and psychological categories. Many of the pathologies attributed to anorexics, such as erratic, disordered eating and obsessive concerns with weight and diet, are typical of many “normal” women; recovered anorexics commonly reject biomedical constructions of self-starvation, and many diagnosed anorexics do not identify as such, refusing diagnostic classification and medical intervention, and only presenting for treatment when pressured by friends or family. Moreover, much of the research used to construct anorexia as a biological or psychological problem has been based on quantitative research that has

been criticized as methodologically flawed, as construing causal relationships from correlation analyses, and for generating research findings that are inconclusive and/or contradictory (see Malson 1998).

In contrast, narrative therapy and community psychology constitute anorexia as existing outside the self and as having a distinct identity and agency for independent, autonomous action. Interpolating Cartesian mind/body dualism, it is the anorexia that takes possession and controls the self, rendering the subject powerless in the face of its determined will. The simultaneous disembodiment and personification of anorexia removes “the origins of distress from the interior psychological workings of the individual person [to] the surrounding environment” (Smail 1994, 6; see also Morgan 1999). In this frame the anorexic is constructed as a victim or a casualty of an uncontrollable, mightier force that is external to the physical and psychological self, erasing the stigma of pathology and exonerating sufferers from the blame attached to the condition.

Feminist scholars shed a different light on self-starvation by illuminating the multiple and contradictory ways that culture is entwined with anorexia. The anorexic body is constituted as an expression of social, cultural, political, and gender anxieties; as a metaphor for contemporary sociocultural concerns about consumption, personal display, feminist politics, and individualistic competitiveness; and as a site of cultural and social oppression (e.g., Bordo 1993; Fallon, Katzman, and Wooley 1994). Drawing on feminist perspectives, poststructuralist scholars elucidate how everyday discourses of femininity, body, and identity are implicated in a range of social institutions and discursive practices that conspire to produce women’s bodies as anorexic bodies (e.g., Malson 1998).

Defining the research population is an act of category construction with profound intellectual and moral implications. The multiple identities of self-starvation ignited sticky dilemmas about how we should describe anorexia nervosa in our ethics application and in the information letter to participants. Should it be presented as a “real” physical or psychological condition: a problem, disorder, or illness? Or should it be presented as a label or rhetorical device that positions young women as abnormal, deviant, and in need of treatment when they defy socially constructed notions of normal, healthy eating behaviors? In the light of the differing constitutions of anorexia, how could we establish a universal category that neatly defined the participants in our study? Which words should we use to address a girl whom clinicians classified as anorexic but who rejected the assignment of any medical or psychological problem and saw the label of *anorexic* as a (mis)representation by others? Could we invite her to share her experience of living with anorexia if she did not believe that she was

anorexic? We were anxious to adhere to the principle of respect for human subjects, but we worried about how to name those who volunteered to participate in our study. To brand a girl anorexic without consent was to deny her selfhood—one of the very issues the study aimed to address. To include only those girls who acknowledged their diagnosis would affect the research by failing to capture the complex spectrum of “anorexic” experiences.

In part, our problem lay in deciding to listen to the different discourses and bodies of research about self-starvation. While our own epistemic faiths might question the merit of some of these, we could dismiss neither their potential as a source of insight into self-starvation nor the fact that they might echo the different ways that girls viewed self-starvation and their “condition.”

To help untangle these quandaries, we sought the advice of the institutional ethics officers. In Australia, to protect confidentiality and to prevent coercion of ethics committees, face-to-face discussions between researchers and committees are infrequent. Ethics officers are specialists in research ethics policy whose job is to help researchers “solve” messy problems before an ethics application is reviewed. The ethics officers were empathetic and supportive but uncomprehending: “If you can’t label the population, then the research isn’t possible.”

We intended to recruit from specialized treatment clinics for eating disorders where many girls had already been diagnosed (labeled) anorexic. The challenge we faced was how to describe the study’s population so that it accommodated girls’ perspectives and summoned the essential “anorexic” subject that the ethics officers and research ethics policy urged us to find. We considered the possibilities. We could privilege girls’ standpoints by limiting the study to girls who self-identified as anorexic and by excluding girls who did not accept their diagnosis. Or we could limit the study to girls diagnosed as anorexic. Option 1 (privileging girls’ perspectives) risked including girls whose emaciation and eating problems were the result of another, possibly undiagnosed psychiatric or biological condition and excluded an important group, namely, girls labeled anorexic who rejected the designation. Option 2 (a medical diagnosis) meant privileging the categorization imposed by others (doctors) over girls’ individual views and experiences. Further, as researchers familiar with clinical settings, we knew that a medical diagnosis of anorexia nervosa could not create a coherent category of person. Diagnoses were often inconsistent and changeable—they rarely met *all* diagnostic criteria for anorexia nervosa (American Psychiatric Association 2000) and were often revised days or weeks later as more information unfolded about each sufferer’s personal history. At its

best, a diagnosis of anorexia nervosa was an informed judgment at a particular point in time, but it could not guarantee the definitive, homogenous population that ethics policy and our ethics officers invoked us to find. Both options censored the particularity of some girls' experiences, and both required us to abandon our sensibility and moral responsibility to some potential participants. Both options altered the research focus and our original aim of illuminating the full range of experiences among all "anorexic" girls.

Dissatisfied with these alternatives, we floated the idea of using multiple descriptions to address the particularity and diversity of potential participants. One ethics officer flatly rejected the idea: "That would mean they're different populations. So you'll need separate ethics applications and approvals for each group." The other ethics officers were confused and mystified. They could not see the problem that troubled us. The doctors had made their diagnoses and issued the decree: "The girls are anorexic. The fact that some girls don't *agree* with their diagnosis doesn't mean they're not anorexic."

Of course, the easy way forward was to ignore the questions that troubled us. All we had to do was fill in the standard ethics review application, prepare generic information letters, get the consent forms signed, and start interviewing. While we struggled to construct a more morally acceptable description of the population, our research project stalled, our funders got restless, and our colleagues got fractious. We had secured highly competitive funding for the research, but this imposed constraints: a tight timeline, accountability indicators and reports, the delivery of designated outcomes. Colleagues vented their incomprehension and frustration at the delay: "What's the problem? All you have to do is fill in the forms and do it." There were no easy answers to our moral tussle, and we felt caught in Jacques Derrida's "double bind": an unsolvable dilemma where "one can only unbind one of its knots by pulling on the other to make it tighter" (Derrida 1998, 36).

Such stalemates nurture compliance. Confronted with either abandoning our anxiety or our study, we opted for a compromise by adopting the broadest, most inclusive category available: "girls who have received a medical diagnosis of anorexia nervosa." Our definition satisfied our ethics committees and enabled the project to proceed—albeit with a less inclusive population than we had intended—but it left us uneasy and uncomfortable. Knowing the capriciousness of clinical diagnoses, we worried about the intellectual and moral dishonesty of defining the study's population in this way. We were also conscious that privileging clinical diagnoses over girls' views and accounts affirmed and thereby invisibly reinforced the hegemony of biomedical discourses that construct self-starvation as "other." Our po-

sitioning as actively complicit in perpetuating this story undermined our ethical and moral responsibility to our participants and had troubling moral implications for our desired identities as ethical, feminist researchers, although—ironically—the ethics committees with whom we worked did not share our concerns. We hoped the processes for eliciting consent might compensate for the moral difficulties raised by our definition of the population, but informed consent carried its own moral difficulties.

***Speaking the unspeakable: The unknowability of informed consent***

Informed consent is a central canon of research ethics policy. The concept of informed consent assumes the transparency of a social and psychological reality that enables researchers to provide full and accurate information about the research to autonomous subjects who are able to make rational, informed choices. In Australia, the national protocol for informed consent involves giving participants (usually through an information letter) full, comprehensive, and accurate details about the research, including the demands, risks, inconveniences, discomforts, and benefits that might be involved. As we prepared our ethics application, complexities emerged about each of the four dimensions of informed consent, namely, the provision of full information about data collection, voluntarism and coercion, physical/psychological distress, and competence to understand and participate in the research.

Our study involved semistructured life-history interviews that sought to illuminate the ways that self-starvation shaped participants' lives, relationships, and subjectivity. To comply with the ethics policy requirement to provide full information, we dutifully prepared a list of interview questions for potential participants. But semistructured interviews are inherently emergent, reflexive, and messy, and the planned focus of an interview can easily shift as new issues and accounts emerge. Like all diligent researchers, we cautioned potential participants in the information letters that an interview could take unexpected turns and that new questions might arise as girls' narratives raised new substantive or theoretical issues. The ethics committees were satisfied that we had fulfilled our ethical obligations and provided full, complete, and accurate information about the research, but we were less convinced. At best, our warning provided a predication of what might happen during an interview. At worst, our assurances were deceptive because they created an illusion of a certainty that we could not guarantee.

The matter of voluntary, noncoercive consent proved trickier than we had imagined. The clinics we planned to recruit through were enthusiastic about the research, but we were advised that institutional ethics clearance

and approval to recruit participants would only be granted if the clinicians were coinvestigators in the study. This edict, it was explained, was non-negotiable and necessary on the grounds that the girls were under clinical care and the clinicians would protect the girls' interests.

This unexpected requirement created an awkward political predicament by compromising our position as independent researchers who worked in (rather than with) clinics, and put at risk our capacity to report findings that might be critical of the clinics and/or clinical practice. Another, shorter stalemate ensued while we discussed how to handle this unexpected turn. We could take the moral high ground and refuse to comply with the institutional requirements. Or we could comply and hope to "manage" the situation. Or we could try to negotiate a different arrangement. Option 1 (the moral high ground) seemed likely to lead to our being excluded from the clinics and would seriously threaten the feasibility of the research. Option 2 (compliance) meant collaborating with the clinicians and raised a bevy of uncertainties. Option 3 (negotiation) seemed hopeful but reckless. Colleagues urged us to comply, explaining that the clinicians were busy (men) who would not interfere if we were agreeable and cooperative. Rather than follow this advice and set aside our moral concerns or abandon the potentially positive outcomes of the study, we decided to negotiate. There were lengthy, sometimes tense, but ultimately successful discussions with the clinicians. Together we developed a strategy to minimize the compromises to the study by agreeing that the original team would be responsible for the project design and implementation, and that we would work together to review the data analysis and to develop ways to use girls' perspectives and accounts to inform and to improve clinical practice. The alliance has been productive and mutually supportive and has resulted in valuable changes in clinical practice.

The positive outcome to our political quandary did not remove the implications for participants that might flow from an alliance with the clinicians. A precondition of informed consent is that it is voluntarily and freely given. The concept of free will is premised on an autonomous liberal humanist subject who is able to make rational and independent judgments regardless of her context. Here the ontological difficulties are the presumption of a stable, decontextualized subject and the discounting of the multiple power relations that work visibly and invisibly to constitute the subject and her interaction with others (Foucault 1977, 1988). We worried whether genuine informed consent was possible given the clinicians' connection with the research. To what extent could girls exercise agency given their subordinate position in the world they cohabited with the clinicians? As patients, might the girls read the clinicians' association with

the study as coercive or as an inappropriate incentive to participate? Would girls resist participating in the study to irk the physicians or attribute greater importance to participating out of a misplaced perception that it might please their doctors? Would the girls hesitate to share their stories given the clinicians' involvement? Could girls feel able to voice concerns about their treatment given their subordination to the doctors' authority in the clinic?

The third obligation under the principle of informed consent is to provide information about the potential for psychological distress or discomfort. The risk of distress is generally considered minimal when the probability and magnitude of harm are not greater "than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests" (Santelli et al. 1995, 274). Yet how individuals experience distress can be uncertain and disguised, and predicting the potential for distress can be difficult (Latvala, Janhonen, and Moring 1998). Although a growing body of evidence suggests that qualitative research poses little risk of distress and that telling your story to an interested listener has emotional and therapeutic value (Kleinman 1988; Corbin and Morse 2003), the individual histories of anorexic girls suggested that the interviews might revive distressing, secreted traumas. These girls were more likely than the general population to have experienced stressful life events such as the death of a close relative or family breakup or to have experienced depression, low self-esteem, and concerns about identity and control. Clinical literature has postulated relationships between anorexia and a range of family problems, including enmeshed, critical, or coercive family environments; insecure attachment; and physical and sexual abuse in families (see Polivy and Herman 2002 for a review). Although some of this research has been questioned (e.g., Eisler 1995), we could not ignore the possibility that the biographies of some girls might encompass complex, difficult family relationships. Nor could we ignore the possibility that distress might be triggered by the accumulation of painful experiences associated with self-starvation: multiple, long-term hospital admissions; repeated, failed clinical interventions; physical self-harm, including attempted suicide; and extended separation from education, work, friendships, and social interaction.

Given the biography of self-starvation, even distributing an interview protocol in the interest of informed consent carried the possibility of resurrecting upsetting or deeply troubling past memories. Yet ethics policy and privacy legislation prevented us from accessing information that might tell us about the best way of interacting with particular participants. Given the situated chronicles of girls' lives, we worried that acquiescing to a

“one-size-fits-all” strategy abdicated our moral and social responsibilities to our potential participants.

Self-starvation also problematizes the question of competence to provide informed consent. Under Australian law, young people under the age of majority are considered competent to participate in research without parental consent if they understand the procedures and implications of research. Relevant to any decision about waiving parental consent is the level of risk involved in the research (Brooks-Gunn and Rotheram-Borus 1994; Levine 1995; Rew, Taylor-Seehafer, and Thomas 2000). In practice, ethics committees set nominal ages at which they consider adolescents capable of independently consenting to participate in research. Each of the ethics committees involved with our multisite study set different age barriers for consent, ranging from fourteen to sixteen years.

Age barriers for adolescent consent have been hotly contested (e.g., Brooks-Gunn and Rotheram-Borus 1994; Brody and Waldron 2000). Research indicates that young people (fourteen years and older) have a capacity to understand research and make decisions similar to that of adults (Meade and Slesnick 2002) but may be affected by lack of experience or by emotionality (Dorn, Susman, and Fletcher 1995) and have trouble understanding the different goals of therapy and research (Brody and Waldron 2000). Some evidence also indicates that acute malnutrition can cause temporary cognitive impairment and that anorexic patients below a certain weight are unable to participate effectively in treatment (e.g., Bruch 1988) or, by implication, to provide informed consent. The capacity of adolescents to reason and to make decisions about the risks and benefits of participating in research can also be limited by stress. Hospitalization and the physical and psychological symptoms of anorexia can be stressful, and anorexics have a higher than average likelihood of experiencing problems like anxiety disorders, obsessive-compulsive disorders, and depression that can inhibit the ability to make informed choices about participating in research. These considerations may not be relevant in every case of self-starvation, but the different age limits set by ethics committees obliged us to treat all potential participants under the age of sixteen years (the maximum, nominal age limit identified by our ethics committees) as lacking decision-making capacity and needing parental protection and consent to participate in research.

Parental consent, however, is not a panacea for the ethical difficulties of consent. The tacit assumption underpinning the idea of parental consent is that parents know what is in the best interests of their daughters and are capable of protecting their interests. Parents, however, are likely to be positioned in similar power relations as their daughters with regard to the

medical team and could be influenced to provide consent by a hope that participating in the research could help their daughters (Brody and Waldron 2000). Although the imbrication of families in self-starvation is a complex and contested area, difficult family relationships or histories could affect the decision of some parents to give or to withhold consent. Parental consent is a double-edged sword, protecting some girls and erasing other girls' potential for agency by increasing the opportunity for parental coercion.

We presented our case for relinquishing age barriers and parental consent to the institutional ethics officers, but they advised that all ethics committees were immovable on these issues. The concern was not with the legitimacy of the arguments we presented but with the financial threat of a litigious parent or caregiver. With no option but to acquiesce on this count, we circumvented the restrictions imposed by our committees by using a different form of consent involving "ongoing consensual decision-making" (Ramos 1989, 60) before, during, and after the interviews so that participants had repeated opportunities to withdraw or to qualify consent. This strategy could not guarantee the knowability of informed consent or obviate unseen power relations, but it offered a greater degree of empowerment by providing girls with multiple opportunities to qualify and negotiate their involvement in the research.

## II. Ethics in our narrative

### ***The knotty problem of universalism and the essentialized subject***

The ethics framework that regulates Western research and guides the decision making of ethics committees is based on the concept of a universalized rational subject and an ethic of justice derived from Kantian moral theory. The presumption of the universalized subject takes for granted that the experiences of the dominant social group can be generalized and taken as true for all others. In this frame, consensus about moral behavior and ethical practice is unproblematic because all rational subjects will acknowledge that the agreed universal moral principles are in the interests of all subjects.

Research ethics policy combines Kantian rationalism with the social contract theories of liberal philosophers like Thomas Hobbes, John Locke, and John Rawls. In the contractarian model of social relations any ethical and moral problem can be resolved by using the liberal principles of equality, fairness, and reciprocity, and a public system of rights and responsibilities in the form of laws, procedures, and protocols (Benhabib 1987, 85). Margaret Walker describes the progeny of Kantian rationalism

and social contract theory as the theoretical-juridical model of ethical theory, comprising “a set of law-like moral principles or procedures” that are transhistorical, transcultural, and couched in the language of scientific objectivity to appear dispassionate and authoritative (1997, 36).

Ethics committees grew out of a positivist tradition of biomedical research that evolved in tandem with the theoretical-juridical model of ethics. Positivist research takes for granted the existence of a putative knowable reality, and that objective, universal truths can be revealed through empirical scientific data collection and explicit, transparent, experimental research operations and procedures (Harre and Secord 1972). The conceptual foundation of positivism has been widely challenged, but its assumptions continue to underpin the philosophy and processes embedded in regulatory frameworks for research ethics, particularly when biomedical agencies have an influential role in developing and monitoring ethics policy and practice.

The positivist biomedical model of research ethics has had exceptional discursive power and has been taken up and imposed on disciplines such as the social sciences and humanities, even when these disciplines employ radically different epistemic frames and forms of data collection and analysis. The widespread infiltration of the positivist model of research ethics has worked to visibly and invisibly inscribe the management, surveillance, and control of research ethics in ways that appear natural, benign, and eminently reasonable to “any rational subject.” Most researchers accept the requirement (if not the desirability) of ethics review before research commences. Yet the biomedical model also casts research ethics in a shroud of scientific neutrality and universal certainty that crafts an illusion that ethics approval means ethical research, begetting a compliance approach to research ethics and to the ways that researchers think through ethical questions.

The presumption of a universalized, rational subject that is at the heart of Kantian moral theory and modern research ethics policy is inherently problematic because it constructs the self as disembodied and disembodied, without sensibilities, history, or physicality. All research projects face the challenge of finding the “generalized subject” who describes the research population. The theoretical and practical difficulties of this task are rarely openly paraded and discussed, and the task is rarely as problematic as in our narrative. Fewer difficulties arise, for example, in defining the population for a research project about the life histories of “schoolgirls.” But the embodiment of self-starvation is both profound and ambiguous; different discourses attach conflicting meanings to the anorexic body (and mind), and the biography of self-starvation is singular and diverse at the

same time. Our experiences highlighted the difficulties of constructing a definitive, universal category of the anorexic subject and threw into sharp relief the illusion of the universal subject of Kantian discourse.

The problems of consent illuminated the gulf between the embodied singularity of research participants and the disembodied, humanist subject of the ethic of justice and positivist research. An amalgam of legal edicts (e.g., privacy legislation) and local practices by ethics committees (e.g., prohibition of any contact between researchers and participants before written consent is given) curtail researchers' capacity to engage with and learn about research participants before beginning the research. These constraints were designed to protect participants and to prevent coercion. At the same time, they prevent researchers and potential participants from developing the personal relationships that make it possible to address the diverse singularity of research participants in the design of a research project and in research ethics protocols.

Erasing the singularity of research participants has grave moral implications. Public conversations about self-starvation, the anorexic body, and the anorexic subject have been dominated by voices of doctors, psychologists, medical researchers, sociologists, and feminists. Following Carol Gilligan (1982) and Sandra Harding (1987), a primary aim of our study was to bring girls' standpoints into these public discussions and to open up new theoretical possibilities by hearing the voices and silences smothered by the conversations of others. The definition of the research population offered to our ethics committees satisfied their expectations and requirements, but it narrowed the research focus by excluding a range of potential participants (e.g., girls who rejected their diagnosis) and (re)configured the study's aim to illuminate the diversity among all "anorexic" teenage girls. The result was a disconcerting paradox: the act of defining the research population erased the particular and individual differences among potential participants, ignoring "the plurality of modes of being human, and differences among humans" (Benhabib 1987, 81) and, in doing so, disregarded one of the four fundamental principles of humanist research ethics policy—respect for persons.

***Power, politics, and the embodiment of self and "others"***

Power and politics are inextricably entwined with research ethics. The legal requirement to receive ethics committee approval to conduct research in ways that are acceptable to ethics committees (and to ethics officers) explicitly subordinates researchers to the authority of research committees. The ethics approval process also creates a hierarchical power relationship between researchers and participants when it constructs researchers as

objective, dispassionate scientists with the knowledge and expertise to reveal “truths” about their research “subjects.” Bestowing such an identity positions researchers as superior to their participants, who become the less knowledgeable, passive “objects” of the research and of the researcher. In the case of anorexia, assigning a differential status to researchers and participants through the ethics process replicates the power relations, politics, and public discourses that disempower anorexic girls by constituting self-starvation as different, deviant, and other. When researchers acquiesce to the requirements and interpretations imposed by ethics committees, they are drawn into a position that is vulnerable to perpetuating and reinscribing the hegemonic discourses and practices that construct anorexic girls as other. In this way, the ethics process reconfigures the aim of the research in unintended ways and overlooks questions of moral and ethical responsibility to research subjects in favor of conformity with normative protocols and practices.

Historically, feminists have directed their attention to the colonizing power of discourses about gender, race, and class and to the ways these subjugate and exclude particular groups by constituting them as other. For feminists, the priority has been to show how discourses and practices usurp the rights and capacities of “others” to speak (and act) for themselves by authorizing different voices (e.g., fathers, politicians, lawyers and courts, welfare agencies) to speak in their stead. In Australia, Aboriginal Australians, historically the nation’s most marginalized social group, have fought hard to be recognized and to be appointed to research ethics committees so that indigenous people have a say in research ethics. Our experiences illuminate the extent to which the ethics process constructs and silences individuals and social groups, and the extent to which the ethics process can shackle researchers’ efforts to interrupt or transform the conditions that perpetuate the assignment of particular groups as other.

***The (im)possibilities of becoming an ethical researcher***

The explicit purpose of ethics policy is to summon into being ethical research and ethical researchers. Yet corridor conversations and conference banter among researchers are often sprinkled with rumblings about ethics committees. A common complaint is that the ethics approval process is an intrusive, onerous obligation that delays (or obstructs) the “real” work of research. In such conversations, ethics committees and researchers are invariably positioned as binary opposites: powerful versus powerless, dictatorial versus subjugated, rigid and dogmatic versus flexible and responsive, methodologically ignorant versus methodologically knowledgeable. Reflective ethics and moral action are forestalled when researchers see

“ethics” as a barrier, rather than a facilitator, to ethical research. Researchers’ discomfort with the ways that ethics processes can position researchers as other than ethical is evidenced by the imperative researchers feel to find new ways of doing ethical research—implementing post hoc strategies to circumvent difficulties with prescribed ethics procedures, abandoning research that cannot “fit” the rules or interpretations of ethics committees, constructing elaborate justifications for processes that deviate from the interpretation of ethics policy by local committees, or paying only lip service to the ethics review process.

We incorporated strategies in our recruitment and consent procedures to try to address our complicity in the othering of anorexic girls. In itself, this act illustrates the moral circularity of trying to be ethical researchers and comply with the protocols of ethics policy and practice. Developing consent processes that were morally responsive to the singularity of self-starvation meant thinking outside the existing protocols, endeavoring to connect with relational sensibility to the concrete “otherness” of the girls who might be in our study, and *then* recrafting our understanding of the girls in a realist epistemology and language that fit the ethics regulations and the expectations of our ethics committees. Although our ethics committees endorsed the outcome, we were struck by the irony that the intellectual work of caring about participants within an ethic of justice involved (momentarily) relinquishing all conceptual links with formal ethics procedures and expectations.

The positivist biomedical model casts research ethics as a decontextualized set of principles and procedures for all scenarios, in which researchers are seen as disembodied and dispassionate scientists who are disengaged and removed from the ethics process. Yet our narrative showed that research ethics is deeply embedded and implicated in the social context. Factors like project timelines, the requirements of funding bodies, the local practices of different ethics committees, personal relationships in the research setting and with ethics officers and committees, and ethics committees’ anxiety about litigation all play a potent, if sometimes mute, role in decisions about ethics. Researchers are embodied in the ethical process: meeting and negotiating with ethics officers and others in the research setting; refining the research design to address ethical issues; writing and rewriting ethics applications; and wrestling with decisions that kindle an array of intersecting emotions, including discomfort, anxiety, relief, anticipation, optimism, and hope. The practice of decontextualizing and disembodied ethics occludes the investments researchers bring to “getting through” the ethics process and the role these processes can play

in privileging particular voices and eroding the relationship between participants and researchers.

Our narrative foregrounds some of the tensions researchers encounter in trying to take up an identity as an ethical researcher in a regulated framework of research ethics. The rigid prescription or interpretation of ethics policy can affect the design of research, undermining its value and nurturing inadequate or even poor research. Nor does compliance with the edicts of ethics committees guarantee moral decision making or moral action. Derrida (1990) cautions that unqualified compliance with laws and regulations creates the very thing they were designed to avert: people relating to each other instrumentally. The ethics approval process confronts a similar difficulty because it is “designed in terms of the greatest good for the greatest number. [The ethics process is] useful to refer to, but [it is] not necessarily humane or even just in every situation because [it] perpetuate[s] tension between the universal and the particular” (Byrne Armstrong and Horsfall, forthcoming).

Our experiences suggest that research ethics policy and processes provide guidance but not definitive solutions to questions about ethical research and moral behavior. Rather, formulaic rules and practices are vulnerable to nurturing unethical and amoral behaviors whereby researchers pay lip service to the ethics approval process knowing they have committed to processes that are conceptually flawed or impossible to implement. In such a climate, the ethics process fosters deception and cultures of counterfeit practice, destroying the very thing it seeks to create: ethical research.

#### ***Dreaming the (im)possible dream: Imagining future possibilities***

The epistemic tensions between the discourses of the universal, rational subject of scientific realism and those of the multidimensional, particular, and social subject of interpretative, qualitative research create messy moral dilemmas. Despite the advances of recent decades, feminist research straddles a prickly divide in trying to craft research to fit ethics policies and practices when ethics committees employ a biomedical model of research and when dialogue between researchers and ethics committees is constrained.

Rather than succumb to the normalizing power of the ethics process, feminists have challenged the notion of research ethics as a codelike set of rules that regulates moral action (e.g., Gilligan 1977; Benhabib 1992), and researchers have urged reform of the processes for approving qualitative research (Parker 1990; Corbin and Morse 2003). Some ethics committees have developed more sophisticated, flexible understandings of in-

terpretive research practice, often as a result of struggles over the kinds of issues we raise and by appointing knowledgeable practitioners of interpretive research to ethics committees. Yet many committees continue to use the same criteria to judge interpretative and positivist research, reluctant to relinquish the (illusionary) comfort that complying with research ethics means ethical research (see Corbin and Morse 2003, 335–36).

Feminists have challenged Kantian rationalism as a basis for ethical and moral action and proposed an ethic of care and responsibility as an alternative to the universal subject and the explicit separation of self and others embedded in an ethic of justice. Gilligan (1977) has argued that an ethic of care involves fundamentally different moral concepts than an ethic of justice. It comprises a morality based on responsibility and relationships rather than rights and rules, is grounded in concrete circumstances rather than abstractions, and is expressed as an “activity of care” rather than as a set of rules.

Despite the challenges posed in our narratives, we are reluctant to relinquish the idea of an ethics approval process given the long history of researchers denying, abusing, or sacrificing the rights and interests of subjects in the name of knowledge, science, and research. We are also hesitant about an ethic of care in the absence of a moral framework. Such a model presumes the knowability of the “other”; is susceptible to being reduced to a vague, unruly form of empathy; and, as Joan Tronto (1999, 113) points out, makes a claim for a morality based on subjectivity that is vulnerable to relativism or solipsism.

Feminists have proposed that discourse ethics offers a way forward through a morality based on the interdependence of a care ethic and justice, whereby specific cases and claims in particular contexts can be considered within a framework of moral principles (Benhabib 1992). Such an approach would draw on justice principles to guide decision making but would accommodate multiple epistemologies; consider the specificity of individual cases in particular contexts; take both difference and a sensibility to the embedded and embodied particularity of participants and researchers as central to ethical decision making; include processes to encourage and nurture dialogue among researchers, participants, and ethics committees; and constitute ethics as an ongoing process of critical reflection, action, and accountability throughout the research rather than as an act of compliance and approval at the beginning of the research.

In our vague imaginings—our partial dream—the research ethics process would become an ongoing collaborative process shaped by dialogue and responsive relationships that are guided (but not dictated) by principles of

justice. Thinking of research ethics as a continual process of collaboration would open up opportunities to dissolve the (mis)conception that ethics approval means ethical research; to erase the differential power relationships among researchers, ethics committees, and participants; and to interrupt the mechanisms that make researchers and research complicit in the “othering” of research participants.

### III. Conclusion

The aim of our narratives is to make visible, and therefore revisable, the dilemmas that surround research ethics policies and their implementation by ethics committees and the implications these carry for research participants and for researchers. The multiple constitutions of self-starvation and the embedded and embodied diversity of “anorexic” girls erase the assumptions that a research population is a homogenous constituency and that informed consent is a conceptually coherent or morally painless act. Rather, the universal, rational subject of an ethic of justice is an illusionary desire, and complying with research ethics processes does not necessarily mean that the ethics processes respect the singularity of participants. Our narratives illuminate how sensibility to power relations, biographical pathways and life experiences, and the identities of the researchers and participants—the “others” of ethics policy—can be obliterated in a compliance model of research ethics and how the research context and institutional structures and practices can fashion ethical decisions and moral actions that curtail sensitivity to “others” and constrain the possibility and practice of feminist research.

The dual aims of research ethics policy are to respect and protect research participants, on the one hand, and to cultivate ethical researchers, on the other. Yet when prescribed ethics protocols fail to engage with the concrete lives and work of participants and researchers, the policy and practice of research ethics functions to construct both researchers and participants as contrary to, different from, and other to its aims. Our narratives illuminate that writing an application for ethics committee review is not a simple or straightforward process. It entangles researchers in tricky moral decisions around complying with the ethics process, appearing to be an ethical researcher, and being an ethical researcher. The decision making involved in preparing ethics applications positions researchers in an awkward moral space between compliance and defiance, legal and transgressive action, instrumentality and sensibility to others. In this space, the rules are unclear, but the moral risks are high.

We do not aim or pretend to offer a definitive solution to the concerns

raised in our narratives. Nor do we underestimate the difficulties of transforming established, institutionalized ethics processes, particularly if there are vested interests in protecting and preserving the status quo. Our point is political. Despite advances in the theorizing and practice of feminist research, it is easy to underestimate or to fail to see the ways in which the social, organizational, and cultural practices of the research ethics process work as conceptual and concrete barriers that impede feminist research approaches and position feminist researchers in ideologically uncomfortable spaces. It is equally easy to underestimate the extent to which we, knowingly and unknowingly, take up locations in these uncomfortable spaces and, in doing so, become complicit in preserving the very things our work seeks to erode.

Foucault argued that ethics is not based on or constrained by any legal or religious system but evolves from reflectivity and is indivisible from the self and an aesthetic of existence (Dreyfus and Rabinow 1982). The formal conventions of the ethics review process do not exempt researchers from sensibility to the particular, embedded, and embodied “others” or from doing the intellectual work of reflexively analyzing the ethics and morality of their decisions or actions. Nor do they erase the political imperative for feminist researchers to lead the way in developing better processes for ethical decision making and moral action in research.

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