HIV/AIDS AND IDENTITY RECOVERY:
STITCHING THE SELF BACK TOGETHER

by

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Dedicated to my mother, Jacqueline Schwan,
whose belief in me inspires everything I do.
Abstract

In this thesis I explore and evaluate the grounds upon which we can claim that community and activist art makes a difference in peoples’ lives. To do so, I examine an ongoing art project that seeks to transform the lives of American women with HIV/AIDS through artistic creation, the STITCHES Doll Project. To evaluate the efficacy of the Project, I position the Project in relation to the history of HIV/AIDS in America, popular and medical understandings of the illness, connections between HIV/AIDS and oppressive structures, representations of the illness, as well as Western conceptions of embodiment, illness, and identity. Against this history, I provide visual and textual analyses of several of the works produced through the STITCHES Doll Project, in combination with interviews and reports from participants themselves, to determine how these dolls affect these women’s sense of self and agency.

This thesis argues that Western understandings of the meaning of HIV/AIDS, combined with its physical, emotional, social, and psychological effects, violently erodes a sense of self for those who contract the illness. Specifically, I argue that because identity in the West is predicated upon self-control, self-containment, mental control, and a repression of embodiment, illness, and death, HIV/AIDS has been experienced at both a personal and cultural level as corrosive of identity. In response to such pain, the STITCHES Doll Project provides an opportunity for HIV+ women to use a variety of strategies to re-establish their identity. Strategies such as sharing the illness or displacing it, when enacted through the Project, can successfully assist in re-affirming identity for participants. I suggest that this is where the value of the Project is best situated, and that this case study provides reason to believe in the value and power of community and activist art. Nevertheless, the Project’s success at individual, social, political, and pedagogical levels is tempered by the challenges posed by cultural codes, discourses, institutions, and practices. In
light of this, my research explores how negotiation of these cultural codes, norms and practices helps to both re-build, as well as un-do, identity for participants.
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List of Abbreviations

AIDS ......................................................... Acquired Immune Deficiency Syndrome
CDC ............................................................. Centers for Disease Control and Prevention
HIV ............................................................. Human Immunodeficiency Virus
NAFTA ........................................................ North American Free Trade Agreement
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Chapter One
Introduction: Globalizing the Visual, Visualizing the Global

Picturing the World, Questioning the Discipline
The world, it seems, is both expanding and contracting. Globalization has resulted in the
“creation of a single global economy with universal rules set by big business for big business in
which a seamless consumer market operates on free-market principles, unfettered by domestic or
international laws or standards.”¹ The neoliberal project behind such a shift has included the
intensification of surveillance and societies of control, the globalization of capital, and relies upon
changes within the organization of systems of states through the development of such agreements
as NAFTA and constructions of superstates like the European Union.² While, as Cynthia Enloe
suggests, the international political system is constructed through “bank executive negotiating
overseas loans” and “soldiers landing on foreign hillsides,” globalization is continually and
pervasively manifested and performed in the intricacies of our daily lives.³ It is present in our
consumption, production, forms of labour, media, transportation, visual life, sexuality, methods of
communication, identity construction, leisure activities, and almost every other area of social,
cultural, and political life. Of interest in much recent scholarly research in the humanities, and
central to the success of globalization, has been the development of consumer capitalism. Indeed,
Frederic Jameson suggests that, since the collapse of Russian communism, religious

fundamentalism is the only alternative to American consumerism. This has produced major effects in the realm of cultural and artistic production worldwide. As Don Adams and Arlene Goldbard suggest, globalization substitutes “mass-produced imported products for indigenous cultural production” and encourages the privatization of public cultural-funding apparatuses. As a result, market forces determine cultural production, preservation and support, and “much of the cultural particularity that continues is expressed through purchases of clothing, recordings, concert and film tickets – through a process of market segmentation – rather than active participation in cultural life.”

Of importance for those of us who are interested in the preservation of indigenous culture, the nourishment of the arts, the assurance of autonomy and self-determinacy, and the development of community, we must ask: How has the project of globalization succeeded, what does its success mean, and how can we intervene? An important aspect of any answer to these questions is, of course, visual practices. Essential to the triumph of globalization is the success and increase of visualizing practices globally, and the globalizing of visual practices. In recent years, there has been a staggering increase in the capacity to visualize the world. The world has become increasingly visualized in multiple forms of mass media, forms that become, in many contexts, more and more accessible to both a greater extent and to larger audiences. As Paolo Favero suggests, “[i]n a constant communication flow we get more and more of the world and we get more and more accustomed to the idea that the world in itself can be ‘seen’ and, as Heidegger (1897) anticipated, be ‘pictured’.” This visual culture has been conceptualized as a “hegemony of vision” in the work of such theorists as Richard Rorty and Judith Adler -- texts that themselves

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5 Adams and Goldbard 19.
6 Adams and Goldbard 19.
are predated by Guy Debord’s 1967 study, *Society of Spectacle*, and Marshal McLuhan’s 1964 work, *The Guttenberg Galaxy: The Making of Typographic Man*. Debord’s and McLuhan’s texts suggested that the world would increasingly be imagined and conceptualized through media technologies. Indeed, both Umberto Eco and Jean Baudrillard strengthen such claims by suggesting that in media saturated contexts the representation becomes more real than the object or subject itself.⁸ It is uncontested that power is infused in these visual relationships, forms, and structures. The creation of identity positions is increasingly manifested and mediated in visual forms and the work of art is increasingly contextualized within a visual global economy of signs, all of which reflect, mediate, transform, transgress, or defend various international power relations.⁹

If visual practices are of major importance in the globalized world, how do we understand the work of art in this context? Can the work of art make positive and valuable changes for us in a globalized, consumer culture? These are central questions in relation to art production and the study of art, fields which are both in places of flux and indeterminacy (for separate, as well as shared, reasons). Western art history and criticism over the past several decades have made significant and oftentimes radical changes in attempting to understand the work of art in light of globalization and the development of new philosophies and epistemologies. Most specifically, art history has drawn from the development of identity politics and feminist criticism, critical theory, the linguistic turn, the visual turn, the growth of cultural studies, and the epistemic shift, all fields that influence, and are deeply influenced by, an increasingly globalized world. The work of the art historian and critic is now conceived as deeply complicated,

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⁸ Favero 65-6.
contextual, and political. In light of this, art historian James Elkins, in his introduction to *Is Art History Global?*, asks,

> What is the shape, or what are the shapes, of art history across the world? Is it becoming global — that is, does it have a recognizable form wherever it is practiced? Can the methods, concepts, and purposes of Western art history be suitable for art outside of Europe and North America? And if not, are there alternatives that are compatible with existing modes of art history?\(^9\)

To this, one might ask in response: are these the right questions? Why should we seek modes of art history that are compatible? Why should the modes of Western art history be the standard of comparison? What is at stake in defending the discipline as coherent, whole, or unified? Who should determine what constitutes "art history" and whether its existence as a discipline is defendable? Not only do Elkins questions have a clear Eurocentric basis, grounds enough to reject or reframe them, but they don’t cut to the heart of current, though perhaps shyly admitted, anxiety about any practice of art history, which I believe to be: *What are we doing and why is it valuable?*

This anxiety is related to, and in part inspired by, recent crises over the meaning and value of the work of art — crises that are themselves inspired in part by globalization. The arts in the West are currently in a place of crisis; it seems art, as it has been understood to date, is either under attack, or is being viewed as vacuous, superfluous, or erroneous.\(^11\) This disintegration of the meaning and value of the arts can be traced to multiple and varied sources. The “end of art”

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9 A similar assertion is made about identity in Judith Butler, *Bodies That Matter: On the Discursive Limits of "Sex,"* (New York: Routledge, 1993). Butler argues that identities are “constantly marshaled, consolidated, retrenched, contested, and, on occasion, compelled to give way” (105).


11 See Claviez, Thomas. “Aesthetics & Ethics: Otherness and Moral Imagination from Aristotle to Levinas and from ‘Uncle Tom’s Cabin’ to ‘House Made of Dawn’.” *American Studies* 163 (Winter 2008) xviii. Claviez argues, “[t]here are, in fact, three basic reductions that make the current dismissal of the aesthetic possible: 1) the equation of the aesthetic with art or beauty and the reduction of the questions of aesthetics to a philosophy of art or a philosophy of beauty; 2) the conflation, sometimes confusion, of aesthetic function and aesthetic value, so that the whole question of aesthetics is reduced to the problem of...
has boldly been declared by several intellectuals, most notably philosopher Arthur Danto, who claims that the distinction between art and life is under erasure. 12 According to Walter Benjamin, both authenticity and originality in art have withered and died. 13 Likewise, Richard Bolton argues that art is being degraded through commoditization and appropriation by corporate marketing because of its ability to operate as “the ideal commodity”: permanent, universal, and utopian. 14 He even suggests that art is being used to help construct the “postcommodity,” a new and self-reflexive commodity form that helps to fuel oppressive capitalist systems. 15 Similarly, Grant Kester argues, “[a]n increasingly dominant market system, fueled by the irrepressible fecundity of mass production, generates its own characteristic cultural forms (advertising, mass media), which threaten to usurp art’s role entirely, even as they erode the public’s ability to distinguish a Rembrandt from the cover of the Saturday Evening Post.” 16 According to this view, the threat of commodity culture is the potentiality that the meaning of the work of art is reducible to a set of (replicable) surface effects. Kester goes on to argue that this has resulted in a defensive artistic climate in which works become more and more obscure in an attempt to hold out against the corruption of propaganda by creating “increasingly formidable barriers” to interpretation. 17
This has resulted in semantic resistance becoming an end in itself. The extent of this strategy places art in the difficult position of being increasingly inaccessible, incomprehensible, individualistic, theoretical, and, according to many, elitist. Most importantly, for many, art has become irrelevant. Page Smith argues that for many observers, the arts “seem to be without direction and without the power to affect our lives.”

Thus, it appears that one of the major questions facing both artists and art historians today is: Can art make a difference and can contemporary art history account for this difference? It is this question that is the impetus behind my research and my concern regarding the present state of disciplinary art history. While all art may be analyzed within this register, I am particularly concerned with art that aims to directly and positively affect people’s lives, namely community and activist art. To explore whether and how such art might make a difference in peoples’ lives, I explore an ongoing community and activist art project that seeks to make a difference in the lives of American women with HIV/AIDS: the STITCHES Doll Project. Specifically, I 

refusing to communicate with the viewer (or at least with the kitsch-sodden viewer), the artwork asserts its difference from, and resistance to, banal mass culture” (38).

Kester, Conversation Pieces, 30-32. Kester goes on to argue that the art for art’s sake ethos promised “a morally pure, noninstrumentalized form of culture that would refuse the means-end rationality of economic exchange” (32). See also Justin Lewis, David Morley, and Russell Southwood, Art- Who Needs It? The Audience for Community Arts (London: Comedia Consultancy, 1986). Justin Lewis et. al. argue that “[u]nlike most forms of public provision, spending on the arts does not benefit those in need – or even a majority. The overwhelming trend revealed by audience research is that the beneficiaries of the traditional arts are, on the whole, a white, middle class, highly educated elite” (1).

Page Smith, Foreword, in William Cleveland, Art in Other Places: Artists at Work in America’s Community and Social Institutions (Westport, Connecticut, and London: Praeger, 1992) xv. Indeed, similar claims have been made in relation to philosophy, religion, and metaphysics, resulting in characterizations of our time as “postreligious” and “postmetaphysical,” buttressed by claims to “the end of philosophy.” See, for example, William Desmond, Art, Origins, Otherness: Between Philosophy and Art (Albany: State University of New York, 2003).

For an explanation of activist art, see Nina Felshin, Introduction, in But is it Art? The Spirit of Art as Activism, ed. Nina Felshin (Seattle: Bay Press, 1995) 9-30. Felshin defines activist art as art that involves “the innovative use of public space to address issues of sociopolitical and cultural significance, and to encourage community or public participation as a means of effecting social change” (9). This differs from political art in terms of “methodologies, formal structures, and activist goals” (9). For an explanation of community art, see Grant Kester, “Aesthetic evangelists: conversion and empowerment in contemporary community art,” Afterimage 22.6 (1995): 1-23. Kester argues that community art is inspired by social
investigate how this project affects each participant’s sense of self and identity, as well as how it challenges oppressive and problematic understandings of HIV/AIDS. To evaluate the efficacy of the STITCHES Doll Project, I position the project in relation to the history of HIV/AIDS in America, popular and medical understandings of the illness, cultural narratives surrounding who contracts HIV/AIDS, connections between HIV/AIDS and oppressive structures such as racism and sexism, representations of the illness, Western conceptions of embodiment and illness, as well as Western conceptions of identity. Against this history, I provide visual and textual analyses of several of the works produced through the STITCHES Doll Project, in combination with interviews and reports from participants themselves, to determine how these dolls affect these women’s sense of self, identity, agency, and control. Methodologically, my research intentionally positions the STITCHES Doll Project as part of a constellation of practices, texts, and politics based on the contention that the meaning of these artworks is not inherent or innate, but is culturally, socially, and politically imbedded. To address these multiple dimensions, I position myself and my research as transdisciplinary and as contributing to a variety of fields and areas of study simultaneously. I draw specifically from the disciplines of art history, philosophy, cultural studies, and women’s studies to analyze these works.

The intent of such an investigation is to consider reasons for believing that art can be powerful and transformative, specifically for those who are marginalized and oppressed by social and cultural institutions, including art institutions. To provide grounds for believing that art is valuable and compelling is to provide grounds for insisting on the importance of the study of art and art criticism in an era of globalization, consumer capitalism, and postmodernity. Art focused on an issue as enormous and pressing as HIV/AIDS is able to reveal what is at stake in both art issues and has less to do with product and much more to do with producing intersubjective integration and certain “pedagogical effects in and on the community” (1).
production and the study of art. As artist Jan Zita suggests, “AIDS brings an already-existing social debate – what is the purpose and value of art? – to a crisis point. It throws into relief the irreducible fact that artwork is based not simply (or romantically) on personal visions, but on social realities.” Consequently, this thesis aims to draw attention to the STITCHES Doll Project (which has not yet been addressed within the academic community), explore its value, provide justification for its funding, as well as contribute to a growing body of literature on community and activist art, activism and HIV/AIDS, and women and activism.

The STITCHES Doll Project - Art That Makes a Difference

The STITCHES Doll Project, begun by Kathy Gerus-Darbison and Candice Moench in July 1999, seeks to give women with HIV/AIDS opportunities to share their stories and experiences so that they may be “preserved for future generations to learn from.” The Project was designed to address the lack of focus on women’s issues in regards to HIV/AIDS and help heal some of the pain women with HIV/AIDS suffer from. To do so, Gerus-Darbison and Moench designed doll-making workshops in which HIV+ women are given “plain rag dolls” to decorate as an expression of their experience of HIV/AIDS. Workshop leaders encourage each participant to understand her doll as a literal embodiment of herself, and participants are subsequently asked,

23 Kathy Gerus-Darbison, personal interview, 10 July 2008. While the Project founders often refer to the doll-makers as artists, and maintain that the dolls they create are works of art, to preclude a lengthy discussion of what constitutes art, as well as the conflicts and confusions surrounding this question, I refer to the doll-makers as participants. While chapter seven does address some of these issues, future research might explore how this Project intersects with and/or challenges conceptualizations of the artist and the work of art.
24 It should be here noted that the dolls provided by the STITCHES Doll Project are regularly referred to as “plain rag dolls” or “simple rag dolls.” Both of these descriptions are culturally loaded and deserve
“[i]f my doll could talk, what would she say?”25 The doll’s “story,” referred to as its “monograph,” is recorded and displayed with the doll. These dolls and accompanying monographs are created in workshops hosted at agencies such as homeless shelters, hospices, therapy groups, sexual assault clinics, and hospitals. Once the dolls and their monographs are finished, they are given to the STITCHES Centre in Michigan where they are prepared to go on display. The dolls have been displayed at a variety of locations, including public schools, academic conferences, international conference on AIDS, and in various universities throughout North America. Since its inception, the STITCHES Doll Project has exhibited and toured the dolls in combination with informational displays or presentations on HIV/AIDS that are intended to educate the public about the disease. The Project aspires to increase compassion, overcome discrimination, and create solidarity through the creation and display of these dolls. Consequently, the function of the Project is frequently described and understood as therapeutic, pedagogical, and a form of social activism.

The central claim of my thesis is that the STITCHES Doll Project helps to recover a sense of identity and self for participants, and thus works as a helpful response to the disintegration of identity that the social and physical experience of HIV/AIDS produces. However, I argue that this recovery is always partial, and that the Project’s design may jeopardize identity-building mechanisms in a variety of ways. Nevertheless, I suggest that the Project is successful insofar as it provides participants an opportunity to re-establish identity, as well as the chance to negotiate cultural codes and discourses which may be experienced as oppressive and harmful.

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To support these claims, I begin by arguing that the ability to produce a self-coherent identity in the West is culturally linked to mental or intellectual power, control, and agency over one’s body and phenomenological contact with the world. I suggest that this conception of identity is inherited from (however ill-conceived) Enlightenment ideals which tie identity to one’s ability to set ends for oneself upon which one bases one’s actions. According to this ideology, the capacity to set and achieve ends enables a degree of control and agency in one’s interactions with the world, thus grounding one’s identity. It is my contention that the HIV/AIDS virus interrupts the normative expectation of having control over one’s physical and social body (overseen by the mind), thus challenging one’s sense of identity. This loss is manifested physically, socially, culturally, and politically. At a basic physiological level, the virus creates a loss of control over the physical body for the individual who suffers from it, thus disrupting the sufferer’s normative expectations of having a body that can be ruled by the mind. This dis-ease is further exacerbated by how the virus operates discursively and socially. Panic around the loss of physical control is transposed into the social realm where HIV/AIDS is made to signify an internal and imminent threat, a pandemic, and a contagious pollution. This panic is further exacerbated because of the virus’s associations with particular populations, practices, sexualities, races, countries, and ethnicities that have historically been threats to white, colonial cultures. Further, this hysteria is crucially linked to a long history wherein societal concerns about diseases are used as justification for political control, fascism, homophobia, racism, sexism, and other forms of oppression.²⁶

Perhaps most importantly, the feedback loop between the physical and the socio-cultural severely exacerbates the loss of identity from which the person with HIV/AIDS suffers. I argue that the sense of panic the victim experiences, and the culture of panic created socially around the

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virus, is decisively related to how the virus operates physically. HIV/AIDS operates physically through the body “turning against itself.” In the case of HIV/AIDS, the so-called viral “invasion” of the body, a term used commonly in the media and scientific accounts of HIV/AIDS, comes from within. Because the illness’s point of origin is no longer definitively “Other” or external, the virus is presumed to be part of the self, blurring the lines between self and Other. This blurring is transferred and translated socially, where it becomes linked to fears of the cultural Other, the ethnic Other, the sexual Other, sexual deviance, and general conditions of poverty and dirt. Consequently, one’s body becomes a stranger and an Other to the self through HIV/AIDS because one has (increasingly) less power over it, less power to predict it, less power over how it signifies socially, and yet one is inextricably bound up with it. It is my suggestion that this lack of control and invasion from within creates a disjunction between the body and the self/mind of the person with HIV/AIDS, which in turn creates a sense of conflict and incompleteness within the identity of the person suffering from the illness.

I argue that it is this incompleteness and loss of selfhood that the dolls operate to address, metaphorically stitching back together the self of the individual suffering from HIV/AIDS. The desire to take control of one’s life is evident in many of the monographs accompanying the dolls, and it is the gaining of this control that allows the women to regain themselves and put their identity back together again. Indeed, the mere creation of the dolls can be read as acts of cohesion whereby the participants take the disparate parts of themselves and stitch them together. I suggest that this process is rewarding and valuable insofar as it helps reproduce identity in subjects whose identities are under attack physically, socially, culturally, and politically. Specifically, I analyze three strategies by which participants attempt to recover identity and eschew threats to subjectivity through the creation of the dolls: the sharing of illness and death, the rejection or refusal of illness and death, and experiencing illness and death for the sake of
another. I argue that this process of recovering identity is often discursively bound up with
notions of authenticity and reality because authenticity is conceptually linked to essence. It is by
virtue of this connection that we can understand claims that the doll reflects the “real me,” etc.

However, I argue that this process of reifying identity is always incomplete and always,
in part, fails. Specifically, I suggest that the Project’s design risks jeopardizing and eroding
identity-building processes. I argue that the Project operates to erode identity through taming the
illness by dehumanizing participants, homogenizing and simplifying participants’ identities and
experiences, and facilitating a loss of power for participants as a result of collecting and display
practices. In some cases, these creation and reception issues not only stunt identity-building but
exacerbate identity loss for participants. Nevertheless, the failure to completely re-establish
identity for participants also operates to ground the value of the dolls by associating them with the
lost and the irrecoverable. As Susan Stewart suggests, the value of the souvenir, not unlike the
STITCHES dolls, is in part a function of its partiality and its failure to capture increasingly
distant phenomenological experiences.27 Further, I argue that this inability to fully recover
identity is intensified by the participant’s inevitable acknowledgement that, while doll-making
may assist in the stitching back together of self, this solidification is only temporary and that
one’s sense of distance from death, which a strong sense of self engenders, will inevitably
deteriorate. Thus the dolls function to shore up identity even as they point to the impermanence
and preciousness of that gesture.

This argument, and the context and research it is dependent upon, is divided into a total
of eight chapters. Chapter two traces the development of several theoretical approaches within
the humanities that have come to be influential within art historical research and criticism. I

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27 For an analysis of the function of souvenirs, see Susan Stewart, “Objects of Desire,” in On Longing:
Narratives of the Miniature, the Gigantic, the Souvenir, the Collection (Durham, NC: Duke University
outline the ways in which these intersect in contemporary understandings of the body and identity, and the implications this has for my research on HIV/AIDS. The third chapter investigates the development of the HIV/AIDS pandemic in America and how oppressive systems, including racism, sexism, classism, and albeism, are significant contributing factors to the contraction and treatment of HIV/AIDS. Chapter four deals with the relationship between identity, the body, and illness, and looks specifically at how HIV/AIDS affects identity. I argue that HIV/AIDS operates to erase the subject physically, socially, culturally, and politically.

Chapter five explores the history of the representation of HIV/AIDS in relation to identity, focusing on activist and memorial art, as well as serial portraiture, in the United States. Chapter six examines the artwork created within the STITCHES Doll Project, arguing that participants are able to achieve presence and affirm selfhood through the creation of dolls that reflect their experiences of HIV/AIDS. Chapter seven explores some of the Project’s attributes that function to destabilize and dissolve the sense of self that the Project aims to shore up for participants. I argue that these attributes produce both creation and reception issues for the Project. Chapter eight concludes the thesis by arguing for the overall value and merit of the STITCHES Doll Project. I suggest that the success of any activist or community art project is in part predicated upon its capacity to navigate and negotiate cultural codes, norms, discourses, and practices. As previously suggested, I have organized my research in this way based on the contention that the dolls do not have inherent meaning but instead need to be analyzed in relation to the various contexts in which they were created and displayed. As a result, I do not begin my thesis with an investigation into the meanings of the dolls but instead begin with an exploration of contexts within which, in chapter six, they can be most fully understood.
Chapter Two
Reinventing Art History

Traditionally, historians in general and art critics in particular have tended to base their analyses and theoretical platforms upon the assumption that art somehow represents the embodiment or the concretization of basic values and fundamental truths that exist somewhere outside of history, beyond social mutation, external to political and economic reality. . . . The discipline of art history has never, until now (excepting in the work of isolated individuals regarded, institutionally, as tangential), been required to submit itself to the historical rigors of social and political fact, but has been nourished in the main by poetic insight and metaphysical speculation.

Kenneth Coutts-Smith, “Some general observations on the problem of cultural colonialism,” 1991

As Kenneth Coutts-Smith articulates, the demand on art history and criticism to justify its accounts has dramatically increased. With the development of feminism, critical theory, the cultural turn, post-colonial theory, queer theory, ethnic studies, the visual turn, and the epistemic shift, disciplinary art history has had to increasingly face its own colonial history, patriarchal lineage, racist and classist collecting practices, and exclusionary museum and gallery systems. In light of this, art historians have increasingly attempted to compensate for what is now often seen as a problematic canon, as well as a history of Eurocentric, sexist, racist, and colonial approaches. Specifically, this has meant that art historians have had to address how best to theorize the intersection of art history and the political. As Linda Nicholson suggests, “[f]or the art historian, the problem of how to think the political leads inevitably to the politics of art history itself.”

Consequently, in the last several decades, many art historians have developed and/or employed various revisionist models in their work. Nicholson groups these approaches into three, largely

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distinct, models. First is the social history of art, which builds upon Marxist thought and is embodied most specifically in the work of T. J. Clark. Second is the “supplementary” model, “that of the revivalists, the resuscitators of dead reputations and minor achievements.” Third is the pluralist approach, espoused primarily by Robert Rosenblum, which attempts to incorporate a much wider range of objects and styles under the purview of art historical research. These models seek to revise art historical research in light of recent demands to account for the discipline’s relationship with the political and ethical.

Each of these approaches has produced new knowledges and canons, both of which commonly intersect with fields such as women’s studies, ethnic studies, and post-colonial theory. Feminist art historians, for example, have attempted to bring attention to female artists that have been overlooked and ignored, as well as re-interpret artworks by women that have been dismissed as unoriginal, peripheral, poorly constructed, or not works of art at all. Art historians investigating display practices trace the history of colonial appropriation of non-Western objects and the relationship that these objects have to our sense of cultural identity. Other research has explored the connections between nationalistic imagery, the economy, and a government’s ability to galvanize support for its war efforts overseas. While the inadequacies of these approaches continue to be elaborated upon, their development has meant that art historians have increasingly been situated, and situate themselves, as reproducing and/or negotiating political processes, realities, and histories.

32 See, for example, Norma Broude and Mary Garrard, Feminism and Art History: Questioning the Litany (New York: Harper and Row, 1982). See also Rozsika Parker and Griselda Pollock, Old Mistresses: women, art, and ideology (New York: Pantheon Books, 1982).
33 See, for example, Hiller S. Staff, ed., The Myth of Primitivism: Perspectives on Art (UK: Routledge, 2004).
Such art historical revisionist projects have occurred simultaneous to, and been implicated in, reevaluations of visual signification, visual analysis, artistic evaluation, textuality, materiality, epistemology, and the conditions of culture. Specifically, the development of cultural studies, deconstructionism, poststructuralism, hermeneutics, and postmodern thought has meant that disciplinary art history has had not only to address its political nature, but also to reevaluate the very foundations of its understanding of visual signification. Cultural Studies, for example, insists on the instability of the meaning of visual texts and their social constructed, rather than inherent, meaning. Similarly, poststructuralist thought suggests that the meaning of a work of art is produced through a variety of systems of knowledge which coordinate to produce it. Such insights have meant that the study of art is no longer exclusive to disciplinary art history but is implicated in a multitude of fields studying human culture. This has lead to significant disciplinary blurring, as well as anxiety surrounding what it is that art historians are, or should be, doing.

This anxiety has been compounded by the development of visual studies and its perceived threat to the discipline of art history. The practice of art history and criticism has slowly but surely been challenged, and in some cases replaced, by the study of visual culture (visual studies). In contrast to conventional art history, the study of visual culture has

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37 W.J.T. Mitchell, “Showing seeing: a critique of visual culture,” *Journal of Visual Culture* 1.2 (June 2002): 168. Mitchell asks, “[c]an visual studies be an emergent field, a discipline, a coherent domain of research, even (mirabile dictu) an academic department? Should art history fold its tent and, in a new alliance with aesthetic and media studies, aim to build a larger edifice around the concept of visual culture? Should we merge everything into cultural studies? We know very well, of course, that institutional efforts of this sort have already been underway for some time at places like Irvine, Rochester, Chicago, Wisconsin, and no doubt others of which I am unaware” (168).
importantly insisted on the discursive, textual, and institutional constitution of images. W.J.T. Mitchell argues that visual studies rests on certain hypotheses, namely,

that vision is (as we say) a cultural construction, that it is learned and cultivated, not simply given by nature; that therefore it might have a history related in some yet to be determined way to the history of the arts, technologies, media, and social practices of display and spectatorship; and (finally) that it is deeply involved with human societies, with the ethics and politics, aesthetics and epistemology of seeing and being seen.38

As a result, visual studies has significantly undone the notion that images can be understood as natural symbols which communicate universally.39 Cultural studies theorists such as John T. Kirby and John Tagg insist that images are subject to particular historical relations, while Umberto Eco goes so far as to suggest that “everything which in images appears to us as analogical, continuous, non-concrete, motivated, natural, and therefore ‘irrational’, is simply something which, in our present state of operational capacities, we have not yet succeeded in reducing to the discrete, the digital, the purely differential.”40 While visual culture and cultural studies have a rapport and affinity for art history, art history has been reticent to accept visual studies and its presuppositions. Indeed, in some cases visual studies has been defiantly rejected by art historians. However, it has increasingly been suggested the grounds for this rejection are more than likely a function of territorial anxieties and inaccurate myths about how visual studies approaches visual texts.41

Consequently, the current crisis facing art history involves not only determining the relationship between the study of art and the political, but also includes a reevaluation of, and

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38 Mitchell 166.
40 John T. Kirby, John Tagg, and Umberto Eco quoted in Jay 270. See also W. J. T. Mitchell quoted in Jay 270. Mitchell argues that visual studies has even developed its own distinct language such that “we now comfortably talk about ‘the hermeneutics of seeing’, ‘iconic utterances’, ‘the rhetoric of images’, ‘linguistic signifiers’, ‘visual narratives’, ‘the language of films’,” all of which imply decoding processes (270).
41 Mitchell 169-70. Mitchell numbers among these myths the assumption that “[v]isual culture entails the liquidation of art as we have known it” and the concern that “[v]isual culture entails an anthropological, and therefore unhistorical, approach to vision” (169-70).
anxiety around, the foundations, methods, and role of the discipline itself. In part because of these conflicts, pressures, and theoretical developments, many current art historians draw from a variety of fields, methods, and theorists to justify hypotheses, assumptions, and objects of study. Indeed, art historians regularly rely on the work of theorists as disparate as Luce Irigaray, Jurgen Habermas, Slavoj Zizek, and Donna Haraway simultaneously. This enables art historians to approach a visual text from a variety of perspectives, allowing the work’s relationship to various social, political, and cultural discourses to become visible. However, with the “picking and choosing” of theories comes the risk of contradicting methods, hypotheses, and/or modes of analyses, and thus a threat to the validity of the resulting research. Consequently, while art history increasingly crosses disciplinary boundaries in the pursuit of comprehensive and politically attentive accounts of visual images, it risks eliding and confusing the histories and genealogies of the theories and methods it utilizes.

To forestall this potentiality in my own research, I here sketch a brief history of the development of feminism, the cultural turn, and the epistemic shift, to serve two distinct purposes. First, properly tracing the genealogy of these different schools of thought within the academy prevents an elision of various theories and epistemologies. It enables the capacity to see how, when, and why certain concerns and methods developed at different locations historically and intellectually, and how art history has inherited some of these methods and interests. To understand and justify the discipline of art history, and research undertaken within it, is to understand and appreciate these histories and inheritances. Second, I specifically choose to explore feminist research, cultural studies, and the epistemic shift because of their connection to my own object of research, the STITCHES Doll Project, and because I see my research as both contributing to these fields and as utilizing methods found in each. Insofar as I see the dolls created through the STITCHES Doll Project as objects that are imbedded in political, social, and
cultural contexts, histories and structures, I also see my analysis of them as embedded in the academic history of these competing and complimentary fields of research. Following a brief explanation of these three fields, I explain how this informs my methodology for understanding the relationship between the body and identity.

**Western Feminism: Roots and Legacies**

The development of feminist thought, methodology, analysis, and epistemology in the West has a long and protracted history and has been traced to differing historical moments according to various theorists. So-called first wave feminism, customarily dated to the nineteenth and early twentieth century, largely sought to address the inequality of rights between men and women, including specifically suffrage and the removal of legal obstacles to equality. In contrast, second-wave feminism, commonly dated from the early 1960s to the late 1970s, is principally associated with issues of equality and discrimination. Linda Nicholson argues that the second-wave was largely made up of two movements, the first a critique of domestic labour, the second the Women’s Liberation Movement, both of which sought to publicize critiques of patriarchy and explore the centrality of social organization to women’s oppression. Both of these movements

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developed theoretical frameworks to explain the historical origins of women’s oppression and its continuation, as well as to elucidate how and why it differs according to societal and cultural location. The demand for such accounts produced and entrenched divisions between liberal, socialist, and radical feminisms.

In this context identity politics developed, emerging as a movement based on political action taken by those -- whether group or groups -- who perceived themselves as oppressed or discriminated against based upon a dimension or dimensions of their identity. Within the feminist movement, identity politics was originally manifested under the 1970s slogan “sisterhood is powerful,” a phrase meant to suggest not only that all women are sisters, but that all share the same conditions of oppression. Another 1970s slogan, “the personal is political,” advocated that power relations exist in all social locations and that one can only develop political opinions from one’s own standpoint position. However, as Nira Yuval-Davis argues, identity politics is based upon a system of thought whereby all the members of the oppressed social category are constructed as homogenous; all dimensions of social locations are reduced to the primary one. Thus there is no differentiation in this approach between categorical locations, social identities and political values. As a result, identity politics conflate individual and collective identities, therefore assuming that any member of any social category/identity can speak for all the

formed the basis of second wave feminism. *The Feminine Mystique* critiqued the social and cultural belief that women’s destiny necessarily is, and should be, composed of child rearing and homemaking.

Sandra Harding, “Introduction: Standpoint Theory as a Site of Political, Philosophic, and Scientific Debate,” in *The Feminist Standpoint Theory Reader: Intellectual and Political Controversies*, ed. Sandra Harding (New York, London: Routledge, 2004) 2. Harding suggests that these divisions were largely formed in relation to Marxian thought insofar as it was necessary to establish that women’s oppression was more basic than other forms of oppression. She points out that even if second wave theorists wanted to reject Marxian thought, they “not only had to produce an account of women’s oppression as theoretically compelling as Marx’s, they also had to establish some relation between their theories and Marxism” (2).


other members of the category, for with their consciousness properly raised, they all share the same voice: ‘as a woman’; ‘as a Black’ etc.\textsuperscript{50}

The first response to this criticism by those affected was to fragment and multiply perspectives such that groupings were made based on other identity positions (e.g. Black, disabled women, or indigenous, lower class women).\textsuperscript{51} Criticisms of identity politics emerged both within and external to feminism and participated in forming the basis for post-feminist analysis in the 1980s.\textsuperscript{52}

Nevertheless, the “unearthing” of the variable experience of patriarchy in relation to differing identity locations became the basis upon which much feminist research has been directed since the 1970s. Concerns regarding multiculturalism and feminism, gynocentrism, the essentialist debate, intersections of oppression, and cultural feminism have been loosely grouped into what is referred to as third-wave feminism, commonly dated from 1990 to the present, which sought to differentiate itself from post-feminism.\textsuperscript{53} Third-wave feminism often utilizes poststructuralism, discourse theory, queer theory, critical theory, postmodernism, and post-colonial theory to emphasize the fluidity of gender, sex, and sexuality, as well as to investigate the nature and extent of women’s agency in patriarchal cultures. This frequently results in different understandings of such phenomenon as pornography, bisexuality, derogatory language,

\textsuperscript{50} Yuval-Davis 284.
\textsuperscript{51} Yuval-Davis points out that consciousness-raising groups sought to unify women’s experiences of oppression and often neglected divergent accounts of what that experience was. Identity politics was criticized on the basis that the “common voice” was ultimately the voice of the white, middle-upper class, heterosexual, able-bodied woman (8). See also Alison Wylie, “Why Standpoint Matters.” in The Feminist Standpoint Theory Reader: Intellectual and Political Controversies, ed. Sandra Harding (New York, London: Routledge, 2004) 339-52. Wylie argues that this fracturing formed the basis of feminist standpoint theory, though subsequently both feminist standpoint theory and identity politics were characterized as relativistic (341).

\textsuperscript{52} Post-feminism refers to a range of reactions to feminism from the 1980s onwards, including critiques that the feminist project is misinformed, misdirected, problematic, or unnecessary. See Sarah Gamble, “Postfeminism,” in Feminism and Postfeminism, ed. Sarah Gamble (New York, London: Routledge, 2001 [1998]) 29-42.

or sexual assault. The research undertaken within these movements predominantly uses one or more of four approaches or methods: feminist empiricism, feminist standpoint theory, intersectional or transversal politics, or poststructural feminism, each of which is briefly explored here.

Feminist empiricism, one of the first theoretical approaches to the study of patriarchy, focused on constructing descriptive accounts of women’s oppression by addressing “who, what, where” questions (e.g., how many women obtain managerial positions in the workforce, what quality of healthcare do poor elderly women receive, etc.). Areas of interest have included biology, the law, and finance. Cara Carmichael Aitchinson argues that “[f]eminist empiricism, like liberal feminism, is concerned with reform rather than wholesale change. It seeks to make such reforms within existing structures and systems rather than by challenging the foundations upon which these structures are based.” Specifically, feminist empiricism can’t explain why certain structures of knowledge and power come into existence, are maintained, or negotiated. Carmichael Aitchison, for example, criticizes feminist empiricism for focusing on “the symptoms of gender-power relations within society rather than the underlying casual structures and cultures.”

A second approach to understanding patriarchy is feminist standpoint theory. Feminist standpoint theory, underpinned by identity politics, developed predominantly in the 1970s and 80s as a “feminist critical theory about relations between the production of knowledge and

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56 Carmichael Aitchison 211.
57 Carmichael Aitchison 211.
practices of power.” Feminist standpoint theorist Alison Wylie argues that the central insight of feminist standpoint theory is

the inversion thesis: those who are subject to structures of domination that systematically marginalize and oppress them may, in fact, be epistemologically privileged. They may know different things, or know some things better than those how are comparatively privileged (socially, politically), by virtue of what they typically experience and how they understand their experience.

Because standpoint feminism embraces a multitude of different positionalities, it includes various manifestations of Marxist feminism, Black feminism, radical feminism, and socialist feminism. In each case, the locus of power is accounted for differently. Regardless of these differences, standpoint feminism always aims to show that what we know, or can know, is structured by the material and social conditions of our lives, and that marginalized knowledges are valuable, insightful, and potentially transformative.

A third method used for understanding women’s oppression is intersectional and transversal politics. Intersectional and transversal politics attempts to solve some of the theoretical problems facing feminist standpoint theory by examining how various cultural and social categories and identities manifest and interact on multiple levels and at multiple times and locations. This approach posits that earlier models of oppression cannot explain why subordinated identity positions do not act independent of one another, but are often crucially linked and mutually informing. Within this research, emphasis is placed on exploring the ways in

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58 Carmichael Aitchison 209. Well-known theorists within feminist standpoint theory include Sandra Harding, Dorothy Smith, Nancy Hartsock, bell hooks, Susan Hekman, Patricia Williams, Elizabeth Spelman and Alison Wylie.
59 Wylie 339. Gender is one form of social differentiation that has epistemological significance. Consequently research is undertaken to identify how authoritative knowledge is partial and gendered, as well as how marginal knowledges inform and restructure processes of knowing (339-40).
60 Carmichael Aitchison 212. Carmichael Aitchison argues that Marxist feminism locates gender in relation to an account of economic and class relationships and thus seeks to account for the material base of women’s subordination, while socialist feminism argues that both patriarchy and capitalism operate together as a dual system in which neither is dominant. Radical feminism, in contrast, takes sexuality as the starting point of an analysis of the subordination of women (212).
which various systems of oppression intersect, collude, and collide. While the theory began as an exploration of how this occurs for the female subject, research has expanded to include discussions of all people.62

A fourth approach to analyzing patriarchy is poststructural feminism, which draws from literary theory, linguistic theory, psychoanalysis, political theory, queer theory, and cultural theory. Nonetheless, poststructural feminism remains difficult to define in part because of its resistance to stable and consistent definitions.63 The interests of poststructural feminism are in part the same as those of earlier strains of feminism, including concerns regarding the construction of knowledge, the relationships between material conditions and power structures, and the formation of subjectivity. However, its approaches, methods of investigation, and conclusions are often quite different. Among poststructural feminists, emphasis is placed on the ways in which language and discourse creates and limits the subject, and how this construction is linked to various forms of power.64 Many poststructural feminists explore the ways in which gender is constructed and performed through linguistic and discursive formats.65 In focusing on gender, sex, and sexuality, the concept of difference gained importance for feminist poststructuralists. Whereas difference was formerly denied, or denied importance, in feminist research, poststructural feminism often insists on the existence and importance of difference.

61 Wylie 341.
62 Yuval Davis 15-20. Yuval Davis goes on to suggest of central concern within both of these approaches is the employment of self-reflexivity by those involved, without a caveat that advocates of a particular group or theory be members of the constituency they advocate for. Intersectional and transversal politics have become increasingly prominent since Patricia Hill Collin’s reintroduction of the theory with Black feminism in the 1990s (15-20).
63 Feminist poststructural theory has been advanced by such influential theorists as Luce Irigaray, Helene Cixous, Julia Kristeva, and Judith Butler.
64 Carmichael Aitchinson 216-7.
65 See, for example, Judith Butler, “Imitation and Gender Insubordination,” in The Second Wave: A Reader in Feminist Theory (London, New York: Routledge, 1997 [1989]) 300-15. Butler famously argues that “[i]f gender is drag, and if it is an imitation that regularly produces the ideal that it attempts to approximate, then gender is a performance that produces the illusion of an inner sex of essence or psychic gender core; it
when considering the relationships between gender and power. Based on the work of Michel Foucault, many poststructural feminists address how power operates on a micro level within everyday structures. Specifically, these theorists illuminate various forms of agency taken up by marginalized persons, specifically women, and the ways in which regimes of power and truth are negotiated, transgressed, transformed, and disrupted.

The Cultural Turn: Cultural Studies and Its Methods

The general liberal consensus that “true” knowledge is fundamentally non-political (and conversely, that overtly political knowledge is not ‘true’ knowledge) obscures the highly if obscurely organized political circumstances obtaining when knowledge is produced.

Edward Said, Introduction to Orientalism, 1979

Historians tell us that we entered a new historical period in the late twentieth century. Over the last two decades, the term “cultural turn” has been coined to describe the move towards cultural analysis within the humanities and social sciences. This shift has been deeply influenced by the development of cultural studies and the sociology of culture, both of which attempt to move beyond critical and materialist modes of analysis and the linguistic turn of the earlier twentieth century. While methodologies utilized within cultural studies are not homogenous, in most cases “the angle of vision is shifted partially from attending to the cultural text and its meaningfulness in order to open up questions concerning the conditions of culture.” Deborah produces on the skin, through the gesture, the move, the gait (that array of corporal theatrics understood as gender presentation), the illusion of an inner depth” (312).


Carmichael Aitchinson 207-8.

Lupton argues that cultural studies is primarily concerned with “documenting and explaining the processes of producing and circulating meaning through the channels of the artefacts and practices of culture.”72 This shift has been so dramatic within disciplines such as art history and literary criticism that some theorists argue that all disciplines are ultimately becoming factions of cultural studies.73

According to Narendra Pachkhede, the primary concern of cultural studies is “describing and intervening in the way ‘texts’ and ‘discourses’ are produced in, inserted into, and operate in social formations and the everyday lives of human beings so as to reproduce, struggle against and perhaps transform the existing structures of power.”74 Cultural studies claims that the significance of a text cannot be inferred from its internal logic or form, but is best understood from its position in a “constellation of texts, practices, and interests.”75 In contrast to some feminist modes of analysis, the fact that a product has a particular form (e.g. a capitalist commodity form) does not determine how its meaning will operate ahead of time, or what the effects of those meanings will be.76 The field draws from symbolic interaction, semiology, Marxism, phenomenology, existentialism, linguistics, and postmodernism, among others, and the interactions between these fields have produced a number of interests and concerns. These have included a particular concern with “reflexivity and the social positioning of the researcher in

73 Important figures include Jacques Lacan, Michel Foucault, Frederic Jameson, Antonio Gramsci, Stuart Hall, Raymond Williams, and Edward Said.
74 Pachkhede 142.
76 See Felski, 511. Felski argues that “textual analysis is regularly augmented by both an account of practicess and here one may find one’s hypotheses disrupted by disorderly and recalcitrant facts that do not fit a favorite theory.” (511).
relation to his or her subjects,” an interest inherited by many disciplines within the humanities.77
Similarly, cultural studies often strives to reveal the instability of the concepts of culture, society, and identity, and thus often involves the re-politicization of epistemological formations and bases.78 Central to this is an overhaul of the concept of knowledge based on the rejection of the Cartesian subject. Knowledge is also reconsidered in relation to the multiple enunciative locations of the subject or object in relation systems of meaning, power, and truth.79 Within this view, the prevalent structures of patriarchy, capitalism, imperialism, racism, and so on, govern the identities available to individuals, as well as how those identities can be negotiated.80 This has lead to reworking conceptualisms of multiculturalism, in part by positing the necessary and perpetual incompleteness of all forms of identity and meaning: personal, political, social, and cultural.81

77 Pachkhede 141. Pachkhede argues that this helps to resolve “the dualisms of contemporary social theory, such as object/subject, theory/practice, action/structure, etc.,” thus asserting that research activity is not separable from the everyday world but is, at least in part, constitutive of it (141).
78 Hall 10. This is a concern that postmodernism, poststructuralism, poststructural feminism, and cultural studies share. All three disciplines suggest that, as Foucault articulates, “the subject is produced ‘as an effect’ through and within discourse, within specific discursive formations, and has no existence, and certainly no transcendental continuity or identity from one subject position to another” (Foucault quoted in Hall 10). See also Felski 501-17. Felski points out that within cultural studies, culture is often understood as neither organically whole nor radically disjointed and fragmented (which some sects of postmodernism and poststructuralism advance) but rather as a “multijointed and multihinged composite of often disparate elements” (511). As a result, research often tries to avoid resorting to totalizations of culture or radical isolationism (511).
79 Hall 1. See also Pachkhede, who argues that the concept of ideology is central to epistemological investigations in cultural studies. Pachkhere writes, “[t]he genealogical development of the concept of ideology can be traced from ideology as invoked by Marx and Engels, propagated by Lenin, Trotsky and other revolutionaries, theorized by Gramsci, Louis Althusser, and connected to culture by Williams, Thompson, Hall and their colleagues [at the Birmingham School]” (144).
81 See Homi K. Bhabha, “Culture’s In-Between,” in Questions of Cultural Identity, eds. Stuart Hall and Paul du Gay (London: Sage, 1996) 53-60. Bhabha argues, “Multiculturalism – a poranteau term for anything from minority discourse to postcolonial critique, from gay and lesbian studies in chicano/a fiction - has become the most charged sign for describing the scattered social contingencies that characterize contemporary Kulturkritik” (55). See also Frances R. Aparicio, “On Multiculturalism and Privilege: A Latina Perspective,” American Quarterly, 45.4 (December 1994): 575-88. Aparicio points out that if we define multiculturalism only as diversity and/or a tolerance for difference, we bypass “the differentials of power among groups that in fact keep some in dominant positions and others in subordinate roles” (576). See also John T. Lysaker, “A Liberal Sense of Alterity,” in Who, Exactly, Is the Other? Western and
Within cultural studies, two dominant strategies of analysis are hermeneutics and the discursive approach to understanding texts. Hermeneutics can be understood broadly as the study of interpretation. More specifically, Jurgen Habermas’ 1968 seminal hermeneutic text, *Knowledge and Human Interests*, describes hermeneutics as the production of knowledge through the interpretation of human texts and symbolic expressions. Contemporary hermeneutics addresses not only issues of textual interpretation, but also involves analyses of verbal and nonverbal forms of communication. It also seeks to consider prior aspects that affect communication, such as presuppositions, semiotics, and philosophy of language. This research is undertaken based on the supposition that signifying practices have an important and powerful role in determining power relations. Of centrality is the claim that the relationship between social reality and cultural texts is always mediated by the structures and processes of signification. Consequently, the importance of a cultural text is the way in which it mediates, transforms, or transgresses forms of signification. Interpretation is thus always founded on attempting to appreciate the specific rules of enunciation the text was subject to. Of import in this theory is “lived experience,” and thus the critic must consider how the text interacts with signifying practices in ways which transform lived experience. In contrast, the discursive approach rejects the hermeneutic binarism of text and experience and suggests that “[t]extuality is a productive practice whose (imaginary) product is experience itself. Experience can no longer serve as a mediation between the cultural and the social since it is not merely within the cultural but is the...

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*Transcultural Perspectives*, eds. Steven Shankman and Massimo Lollini (Oregon: University of Oregon Books, 2002) 5-14. Lysaker suggests that conceptualizations of multiculturalism are necessarily twinned with discussions of power and discussions of those individuals and groups of individuals who are oppressed, hence queer studies, postcolonial literature, etc. Discussions of multiculturalism have also used the concept of “the other” in order to generically refer to those who are disadvantaged and subjugated by dominant discourses, systems of power, and cultural habits (6). See also Stuart Hall, “Cultural Identity and Diaspora,” in *Identity: Community, Culture, Difference*, ed. Jonathan Rutherford (London: Lawrence & Wishart, 1990) 223-37.

product of cultural practices.”\textsuperscript{84} The discursive approach contends that experience is not considered separate from culture but is within the structures of signification. According to Louis Althusser, this meant that the subject is already a circuit of signification which \emph{determines} his or her phenomenological experience of the world.\textsuperscript{85} Consequently, the concern has less to do with whether a text is accurate or mystified, but with who is given access to what kinds of texts and knowledge and how this impacts his or her power.

\textbf{The Epistemic Shift: Postmodernism and Poststructuralism}

\textit{Postmodernism}

At the heart of the modern west is the culture of the Enlightenment. Assumptions regarding the unity of humanity, the individual as the creative force of society and history, the superiority of the west, the idea of science as Truth, and the belief in social progress, have been fundamental to Europe and to the United States. This culture is now in a state of crisis.

Steven Seidman, \textit{The Postmodern Turn: New Perspectives on Social Theory}, 1994\textsuperscript{86}

Postmodernism and poststructuralism, whose emergence over the last couple of decades is often referred to as the \textquote{epistemic shift,\textquote{ has occurred almost exclusively in the West, most specifically the United States and France, but also Great Britain, Germany, Canada, and Australia.\textsuperscript{87} Indeed, in many parts of the world, modernization remains the chief social, cultural, and political goal.\textsuperscript{88} Nevertheless, postmodernism has become a periodizing concept in the West \textquote{whose function is to correlate the emergence of new formal features in culture with the emergence of a new type of

\textsuperscript{83} See Lawrence Grossberg, \textquote{Strategies of Marxist Cultural Interpretation,\textquote{ in \textit{Bringing It All Back Home: essays on cultural studies} (Durham, NC: Duke University Press, 1997) 103-37.

\textsuperscript{84} Grossberg 125.

\textsuperscript{85} Louis Althusser quoted in Grossberg 125.

\textsuperscript{86} Seidman 1.

\textsuperscript{87} McGuigan 5.

\textsuperscript{88} McGuigan 1-2.
social life and a new economic order. While postmodernism has multiple concerns and utilizes a variety of theoretical approaches, the following addresses four major concerns distinctive of postmodern theory.

The first of these is the “death of the subject,” which refers to the postmodern contention that identity itself is an ideological construct, and that the Enlightenment concept of the rational, autonomous subject with agency is no longer defensible, indeed that is was neither existent nor defensible in the first place. Within this sphere of thought, identity is always performative, incomplete and in process. Consequently, postmodern theory often aims to locate the ways in which epistemological processes and power structures produce identities and subjectivities, rather than assuming that the rational, self-same subject produces them.

Second, postmodernism reacts against grand theories that seek “truth” or “reality,” including their tendency to conceptualize societies as totalities. This leads to a conception of the social world as decentered and unstable, a conclusion that in part draws from existentialist thought, including Jean-Paul Sartre’s contention that the existential truth of the human condition is man’s sense that he does not belong, that he is contingent. As Steven Seidman argues, “[p]ostmodernity is characterized by a loss of certainty and a ‘God’s eye point of view’ in the sphere of knowledge” as well as “a loss of a central, organizing principle governing society and a

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89 Frederic Jameson, “Postmodernism and Consumer Society,” in The Anti-Aesthetic, ed. Hal Foster (Washington: Bay Press, 1983) 113. Jameson goes on to suggest that the term postmodernism also includes “what is often euphemistically called modernization, postindustrial or consumer society, the society of the media or the spectacle, or multinational capitalism” (13).

90 Jameson 114-5. Foucault, for example, argues that the sexual subject is not, in fact, the natural source of sexual truths but that knowledges concerning sexuality produce sexual subjects. See Foucault quoted in Seidman 6.


92 See Lyotard quoted in Seidman 5. Lyotard argues that man’s alienation and estrangement is also attributed to the world becoming more and more decentered. He suggests that regardless of whether we are speaking of politics or the self, there is no unifying center, purpose, coherence, or ground of order (5).
unitary standard of cultural excellence or morality.” This is one of the most startling aspects of postmodernism: its total acceptance of the ephemeral, fragmentation, discontinuity, and chaos.94

Third, the epistemological consequences of these findings have resulted in the creation of postmodern systems of knowledge that are “less authoritative, less conclusive, and more pluralized than modernist systems of knowledge.”95 This is often manifested in a “vigorous denunciation of abstract reason and a deep aversion to any project that seeks universal human emancipation through mobilization of the powers of technology, science, and reason.”96 Laurel Richardson argues that the core of postmodern thought is itself doubt that any theory or method, genre or discourse, tradition or innovation, has a universal and general claim “as the ‘right’ or the privileged form of authoritative knowledge.”97

Fourth, postmodernist thought often investigates the increase in representational forms globally and the ways in which they transform time, space, and identity. Jean Baudrillard boldly claimed that capitalist societies, specifically that of the United States, are so absorbed with motion, speed, cinematic images, and technological fixes that they have created a “crisis of explanatory logic.”98 As Frederic Jameson argues, postmodern life has in part constituted a

93 Seidman 5-6.
94 See Fehr 2009. Postmodernism is often manifested in “deliberate ambivalence, purposeful uncertainty, high suggestability, and thorough ambiguity” (209). See also David Harvey, The Condition of Postmodernity: An Enquiry into the Origins of Cultural Change (Oxford, Cambridge: Blackwell, 1989). Foucault, quoted in Harvey, encourages us to “develop action, thought, and desires by proliferation, juxtaposition, and disjunction,” and “prefer what is positive and multiple, difference over uniformity, flows over unities, mobile arrangements over systems” (44).
96 Harvey 41.
97 Laurel Richardson, “Writing: A Method of Inquiry,” in The Handbook of Qualitative Research, eds. Norman K. Denzin and Yvonna S. Lincoln, 2nd ed (Thousand Oak, Calif.: Sage Publications, 2000) 517. Richardson goes on to argue that this has resulted in a willingness to look across disciplinary boundaries for various kinds of knowledge, and thus cross-disciplinary research (518).
“transformation of reality into images, and the fragmentation of time into a series of perpetual presents,” producing a social system that has difficulty remembering its own past.99

Poststructuralism

Poststructuralism, often problematically confused and equated with postmodernism, draws on the development of twentieth-century continental philosophy and includes such theorists as Julia Kristeva, Jacques Derrida, Roland Barthes, Jean-Luc Nancy, and Jean Baudrillard. While poststructuralism is infamously difficult to define, in its most general sense, poststructuralism seeks to link language, subjectivity, society, and power.100 Poststructuralism emerged in reaction to structuralism, which has two main thrusts within the field of semiotics. First, structuralism suggests that reference is a kind of myth, and that we can no longer speak about “the real” in a useful or objective way. Second, structuralism tries to dispel “the old conception of language as naming, which involves a one-to-one correspondence between the signifier and a signified. Rather, we read a whole sentence, and it is from the interrelationship of its words that a more global meaning – now called a ‘meaning-effect’ – is derived.”101 In contrast, poststructural practices operate on the assumption that sentences and texts have multiple meanings, purposes and existences. Poststructuralism argues that the analysis of underlying systems that structuralism undertakes is itself culturally conditioned and therefore subject to biases, misrepresentations, and manipulation by systems of power. To understand an object using poststructuralist principles requires understanding both the object itself and the systems of

99 Jameson, “Postmodernism” 125. See also Favero 66. Favero argues that contemporary life is largely coordinated through representation in capitalist societies, “[f]rom control cameras to reality shows, family albums, news, weather prognoses and satellite images we are, today, surrounded by practices that highlight where and who we are in relation to the outer world and also that we can always be represented and represent” (66).
100 Richardson 518.
101 Jameson 119.
knowledge which coordinate to produce it. Thus, of central concern is how knowledge is produced. Derrida, for example, critiques philosophy’s “logocentrism” by suggesting the predominant binary oppositions under which Western thought operates – presence/absence, meaning/form, mind/body, speech/writing, and so on – are unstable, arbitrary, and can be transformed. He suggests that efforts to establish foundations actually conceals a will to power.\(^{102}\) According to poststructural thought, “[k]nowing the Self and knowing ‘about’ the subject are intertwined, partial, historical, local knowledges. Poststructuralism, then, permits – nay invites – no, incites us to reflect upon our method and explore new ways of knowing.”\(^{103}\)

**Forming a Methodology: Identity and the Body**

In light of these emergent fields and philosophies and their impact on art history and criticism, how should we understand the relationship between the body and identity? Since the linguistic turn in the humanities and social sciences there has been increased concern for how language participates in the creation of subjectivity and social lives, and especially how the body comes to have meaning culturally.\(^{104}\) Crucial to this shift is the contention that the body is a symbol or sign, the product and object of the socio-cultural discourses which produce and regulate it. The body’s health, sexuality, identity, and agency are seen to be produced discursively, though a variety of competing interpretations of this discursive nature have developed.\(^{105}\) Within a functionalist framework, for example, Marxist understandings of the body emphasize how good health is important for the production and consumption of products within the capitalist system.\(^{106}\)

\(^{102}\) Seidman 9.
\(^{103}\) Richardson 518.
\(^{104}\) Lupton 6.
\(^{106}\) Lupton 8-11.
Similarly, poststructuralist thought has argued that illness is constructed and interpreted via social activity, and thus must be interpreted using social and cultural analysis. Feminist frameworks have suggested that illnesses are manifestations of oppressive political and social conditions. Each of these frameworks has the potential to reveal different dimensions of the meaning and value of the STITCHES Doll Project.

However, since the rise of concern about the communicative aspects of the body, many social theorists have focussed exclusively on the discursive experience of the body without linking this to the phenomenological experience of the physical body as traditionally studied by science and psychology. Indeed, some theorists have come to claim that the discursive construction of the body is ultimately so powerful that there is no experience of the body that is not discursive. Donna Haraway, for example, famously claims that “[b]odies . . . are not born: they are made.” But we can ask, as Laura Tanner does, whether “in studying bodily experience, we can legitimately claim that there is nothing beyond the text?” In actuality we are daily faced with the lived, physical, experiential impact of discourse on the body, and this physical experience comes to impact how we interact with the discourses that participate in determining our bodies. Maintaining and enforcing a binary between the physical and the discursive can produce harmful effects for the embodied subject. As Alexandra Juhasz suggests, “instead of deconstruction, the body must be specified back into existence, acknowledging the

107 Lupton 11. Lupton goes on to argue that “[t]he body is conceived of as a collection of practices, or ‘body techniques,’ which represent and regulate bodies in time and space. Bodies are regarded not simply as shaped by social relationships, but as entering into the construction of these relationships, both facilitated and limited by historical, cultural, and political factors” (22).
108 See, for example, Lisa Appignanesi, Mad, Bad and Sad: Women and the Mind Doctors (New York: W. W. Norton & Co., 2008).
109 Ussher 4.
110 Lupton 22.
111 Ussher 4.
material effects of race . . . class, gender, weight, disease, and other body-rooted instances of privilege.”

The following research proceeds based on the contention that the body is both discursively/socially and phenomenologically/physically constructed and experienced, and that these are constitutive of each other. As cleverly articulated by American historian Dominick LaCapra, “[a]lthough we cannot talk about the body outside the mediating discourses within which it is culturally constructed, we cannot, at the same time, disentangle knowledge or perception from the living-moving body through which we experience the world.” The hermeneutic tradition is based upon this very interconstituency of the physical and discursive body, and it is within this tradition that I explore the experiences of the victim of HIV/AIDS. Based upon Maurice Merleau-Ponty’s insight that there is no way to know the human body other than to live in it, and take account of the drama being played out in it, I attempt to make sense of the experience of illness and HIV/AIDS specifically.

This attention to the interconstitutive nature of the mind and body needs to be combined with a framework for understanding individuals’ explanations of their bodily experiences. To suggest that all narratives about the body are transparent, accurate, or authentic is, in part, to miss why it is that some narratives get told more often, that some are privileged more than others, that many often involve contradictions and ambiguities, that some are more private and others more public, that some are told with confidence and others with fear. Consequently, my reading of the narratives and testimonies told by the participants in the STITCHES Doll Project are situated in relation to larger cultural narratives about illness, the body, femininity, war, and race so as to

114 Maurice Merleau-Ponty quoted in Tanner 7.
highlight the institutional impacts of cultural thinking on personal narratives. As Corinne Squire
indicates, this requires understanding individuals’ narratives and responses “as texts, not as truths,
and as indicators of discourses and practices in operation, not as these discourses or practices’
proofs or foundations.” It is based on these insights that the following attempts to understand
the meaning and significance of the dolls, and their monographs, created through the STITCHES Doll Project.

115 Corinne Squire, “AIDS Panic,” in Body Talk: The Material and Discursive Regulation of Sexuality,
Chapter Three
America's HIV/AIDS Epidemic and Women: Thinking the Unthinkable

Ambiguous Meanings: HIV/AIDS Emergence in the United States

In examining cultural constructions of HIV/AIDS it is particularly important that we pay close attention to the ways in which certain biomedical and epidemiological “observations” of the “natural” literally come to embody previously held values, assumptions, and prejudices regarding race, class, gender, ethnicity, and sexuality.

Nancy Goldstein, Introduction to The Gender Politics of HIV/AIDS, 1997

It is particularly clear in the case of such AIDS science that discourse is material, and the material discursive. Scientific vocabularies around the condition have shaped diagnostic, treatment and prevention practices.


AIDS (Acquired Immunodeficiency Syndrome), a sexually transmitted disease, is caused by the HIV-1 virus that enters the cells of the immune system of the affected individual and destroys its capacity to fight diseases or other threats to the health of the body. HIV is slow-acting and is the sole or foremost causative agent of AIDS. Although individuals may live for years having the HIV-1 virus (known as “HIV positive” or “seropositive”), their immune systems are increasingly compromised, and they often contract incurable disorders, such as blindness, pneumonia, and diarrhea, or experience significant brain deterioration. AIDS arrived in the United States in 1981 and spread with staggering speed and strength. The U.S. Centers for Disease Control (CDC) began tracking the illness that year, but the ambiguity around the causes, effects, and risk
factors of HIV and AIDS created an inability to produce a consensus on the meaning of the illness. This resulted in the “inability of medical and socio-political bodies to fix HIV/AIDS unambiguously to particular groups, behaviours, or patterns of manifestation.” As Gabriele Griffin points out, there is no single, historical, uncontested meaning attributed to AIDS in part because AIDS manifests itself in countless diseases that the CDC then decides to attribute, or not attribute, to the underlying syndrome. While various combinations of drugs can defer AIDS symptoms or produce remissions, these drug regimes are rigorous and expensive, and a cure is yet to be found.

By “historical accident,” the disease arose in the United States primarily among gay men, particularly white, middle- and upper- class men in urban spaces. The fact that the illness began to appear in this particular population at the beginning of the epidemic deeply affected the speed and nature of governmental, media, and medical responses. Initially, the illness was characterized as the “gay plague,” a characterization which implied that the illness was a product of homosexuality itself. This connection both resulted in, and was seen to justify, a lack of governmental intervention. As the pandemic developed in the United States, such a characterization did not reflect the increasing risk of contraction to which all persons were subject, depending on the degree of their “risk-taking” behaviour. Indeed, because of such characterizations, many populations were neither educated about, nor aware of, their risk for contraction. In regards to women, characterizing HIV/AIDS as a (male) gay disease resulted in

121 Griffin, Introduction 5.
122 Goldstein 5.
123 Lorber 70.
an ideology in which women were not even considered able to contract the disease.\textsuperscript{125} Indeed, despite reports of similar syndromes developing in women as early as 1981, the CDC did not alter its definition of AIDS to include a single female-specific HIV-related condition for the first thirteen years of the pandemic.\textsuperscript{126}

As research progressed, AIDS was seen as belonging to the “4-H Club”: homosexuals, heroin addicts (intravenous drug users), hemophiliacs, and Haitians. Much scholarship on HIV/AIDS has revealed that the individuals who were disproportionately affected by the disease were considered within mainstream American culture to be expendable, immoral, dirty, and criminal, and that such belief resulted in extremely slow governmental response, media interest, and medical research.\textsuperscript{127} The nature of this response can also be traced to an unwavering interest in profit and desire to maintain class structures. It is still the case today that treatments and medications that are not considered profitable are simply not explored by pharmaceutical companies or made available by governments.\textsuperscript{128} It took years of consistent medical reports of the illness before those affected received any kind of governmental support. There has been extensive research into the multiple ways in which the American government’s response to the AIDS epidemic (not to mention its educational, institutional, medical, and media affiliates), has ignored the crisis, demonized the ill, withheld medication, and provided little or no funding for agencies assisting those who were affected by the crisis.\textsuperscript{129} President Ronald Reagan, for

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\item \textsuperscript{125} Goldstein, Introduction 8.
\item \textsuperscript{126} Lorber 70. See also Goldstein, Introduction 8. Lorber similarly argues that “[t]here were numerous medical reports that symptoms of women with AIDS were different from those of men, but it took protests at AIDS conferences and a lawsuit against the U.S. Social Security Administration before the CDC changed the list of diagnostic signs of AIDS, adding recurrent and virtually untreatable vaginal yeast infection and invasive cervical cancer” (70-1).
\item \textsuperscript{127} Sontag 110-21.
\item \textsuperscript{128} Kim Christensen, “How Do Women Live?,” in Women, AIDS & Activism, eds. The ACT UP/New York Women and AIDS Book Group (Toronto, ON: Between the Lines, 1990) 10. Christensen further observes that “[a] drug company can’t make a profit on a drug if the people who need it are too poor to pay a high price for it” (10).
\item \textsuperscript{129} Reed 180.
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example, delivered his first public speech on the AIDS epidemic on 31 May 1987. At this point, 36,058 Americans had been diagnosed with the syndrome and 20,849 had died as a direct result of its complications. Reagan’s speech was delivered six years after the first AIDS-related deaths in the U.S.\textsuperscript{130} We need only compare this response to the speed at which President Barack Obama recently responded to the Swine Flu to realize just how expendable these citizens were considered to be.

The contraction of AIDS continues to be regularly attributed to identity, as opposed to risk practices, which almost categorically results in a demonization of those who contract the illness and the positioning of the illness within a moral framework.\textsuperscript{131} Nancy Goldstein argues that “[f]or many years, the only stories that could be told, as directed by the CDC’s definition, were ones in which demonized identities gave proof of their own promiscuity, profligacy, and dereliction by falling prey to a disease that told the truth of their sins as marked on their bodies.”\textsuperscript{132} HIV/AIDS was understood as a visual sign of moral degeneracy.\textsuperscript{133} It is within such a context that we can understand why media reports of individuals with HIV/AIDS invariably mention the source of their infection, thus enabling moral adjudication.\textsuperscript{134} In contrast, the more accurate association of infectious diseases is with the \textit{structures} of human society, such as

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\item \textsuperscript{130} Richard Meyer, “This is to Enrage You: Gran Fury and the Graphics of AIDS Activism,” in \textit{But is it Art? The Spirit of Art as Activism}, ed. Nina Felshin (Seattle: Bay Press, 1995) 59.
\item \textsuperscript{131} Goldstein, Introduction 8.
\item \textsuperscript{132} Goldstein, Introduction 8. Goldstein argues that the history of the definition of AIDS “reads as a virtual textbook of the ways in which prejudice becomes naturalized as biological fact” (7).
\item \textsuperscript{133} See, for example, Katie Hogan, \textit{Women Take Care} (Ithaca and London: Cornell University, 2001). Hogan argues “[i]t is not that women are ‘trapped’ by their bodies; rather, the impact of HIV on their bodies is ignored or transformed into moral narratives” (20).
\item \textsuperscript{134} Lupton 92. Lupton argues that media reports of people with HIV/AIDS invariably mention the source of their infection “so that we know whether they are ‘guilty’ of homosexual activities or injecting drug use, or ‘innocent’ victims who have been infected through no ‘fault’ of their own, such as recipients of blood transfusions, children born to women with HIV infection or heterosexual women who simply fell for the wrong man without knowing that they were injecting drug users of bisexuals” (92).
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urbanization, class and gender inequalities, racism, migration, and the perpetuation of poverty.\textsuperscript{135} As Ruth Morgan Thomas suggested in 1992, it is time to move away from the concept of “high risk” groups and their assumed behaviour and instead recognize that “it is how people engage in specific high risk activities that can put them at risk.”\textsuperscript{136}

AIDS continues to be an epidemic largely for poor, urban men and women, most of whom are Black, Asian, or Hispanic and primarily heterosexual in their relationships.\textsuperscript{137} More recently, research has been undertaken to explore why these populations are more likely to contract the illness and what the barriers are to reaching these populations with education, support, medical care, and counseling. The following briefly looks at how women, especially women of colour, as well as women with disabilities and those who are economically disadvantaged, are uniquely affected by the illness and its social construction. It is primarily this population that has participated in the STITCHES Doll Project.

\textbf{Women and HIV/AIDS: “You’re Not That Kind of Woman”}\textsuperscript{138}

The AIDS epidemic is talked of as “exceptional” and has been treated as a “special case” in public health. In actuality, though, AIDS is not an exception – the problems of this epidemic are the problems of Western and non-Western care systems writ large, with the same issues of gender, class, and race.

\textit{Judith Lorber, Gender and the Social Construction of Illness, 1997}\textsuperscript{139}

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\item[136] Ruth Morgan Thomas, “HIV and the Sex Industry,” in \textit{Working with Women and AIDS: Medical, Social, and Counseling Issues}, eds. Judy Bury, Val Morrison, and Sheena McLachlan (London and New York: Routledge, 1992) 71. Thomas insightfully points out that “[t]he fact that a person accepts money for sexual services or injects drugs or has sex with someone of the same gender does not in itself put them at risk of HIV infection” (71).
\item[137] Lorber 70.
\item[138] Mary Fisher quoted in Hogan 50. Renowned AIDS activist Mary Fisher explains, “I cannot count the number of times I’ve been told variations of the following story. An ordinary woman – you, me, your wife, one of our friends – goes to an ordinary physician. The woman is in her twenties or thirties or forties . . . Having reviewed her life and having scanned the HIV statistics in America, she says to her physician, ‘Perhaps I could have a test for AIDS.’ And she hears the response, ‘You don’t need that – you’re not that kind of woman’” (50).
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As Goldstein astutely suggests, women’s risks for HIV/AIDS include poverty, racism, classism, sexism, incarceration, isolation, lack of access to health insurance or medical care, illiteracy, homophobia, sex work, sexual abuse, domestic violence, alcohol and drug abuse, and an ideology of heterosexual romance that demands that women never question the fidelity of their male, presumably monogamous, sexual partners or put any “demands” on men (like condom usage) that might interfere with the male prerogative to enjoy sex. ¹⁴⁰

This list makes it apparent that the risk factors for women are numerous and intersecting. Conservative accounts often describe such risk factors as drug use or sex work as “free choices” so that they can justify the claim that those who engage in them “deserve what they get,” thus excusing a lack of governmental support or intervention. While at first glance some of these choices may appear more “free” than others (in the sense that one “chooses” to use drugs but does not “choose” to be fired), all of them, including drug use, are deeply linked to oppressive ideological systems and their material effects on women’s lives. To explore this, the following briefly considers the ways in which conceptualizations of HIV/AIDS are informed by patriarchy and the medical community, as well as racism, classism, patriarchy, and ableism.

**Women, the Medical Community, and HIV/AIDS:**

Feminist sociologist Rose Weitz argues that, not unlike other political processes, “the social construction of women’s bodies develops through battles between groups with competing political interests . . . [and] serves as a powerful tool for controlling women’s lives by fostering material changes in women’s lives and bodies.”¹⁴¹ In regards to the scientific and medical community, feminist writers have emphasized that not only are women the primary targets of the expansion of medicine, but that previous justifications for patriarchy have turned into scientific

¹³⁹ Lorber 89.
¹⁴⁰ Goldstein, Introduction 5.
ones. Research has revealed how male-controlled and technology-dominated healthcare has jeopardized women’s health, how women’s knowledge about healthcare has been expropriated by the medical community, and analyzed the ways in which sexual politics are inherent in conceptions of sickness and health. Critical medical sociologists have argued that medical norms and standards are regularly based on white, male, middle-class bodies, and thus that women who menstruate, became pregnant, or experience menopause are, by definition, ill. Indeed, within discussions surrounding AIDS, the female imagery of menstruation has been used to describe HIV/AIDS. Female bodies, especially diseased female bodies, have regularly and historically been understood as dangerous, tenuous, and lacking in identity, subjectivity, and agency, thus meriting scientific intervention.

In relation to the AIDS crisis, this understanding of the female body as disordering and ill, combined with a patriarchal health care system, has resulted in significant health risks for women. Because the female body is historically understood as already diseased, and HIV/AIDS has been constructed and understood as a virus that affects men almost exclusively, women’s experiences and issues with the illness and its treatment are often overlooked. Only now is it becoming apparent that the treatment of HIV/AIDS in women has been based on clinical trials of drugs tested exclusively on men. For women who suffer from unpleasant drug effects, the result of such exclusionary studies is that doctors end up informing them that they are imagining the effect, or that the effect is unknown, uncommon, and/or untreatable. Women are “frequently dismissed as neurotic or depressed when reporting symptoms that are not easily definable, easily

143 Lorber 40.
144 Lorber 87.
explained.”145 This lack of research on women’s bodies in relation to the illness and the medical treatments related to it has resulted in late, under-, and mis-diagnoses of women.146 For example, as Katie Hogan points out, a standard practice in treating HIV is the use of viral load measurement to determine whether an adult patient should be taking protease inhibitors. Recent research reveals that the viral load in a woman’s body is not equivalent to the viral load in a man’s body, so that “what appears to be an innocuous viral load in men is, when measured in women, a sign that the woman’s immune system is seriously compromised and she should begin taking protease inhibitors.”147 This is just one example of many that reveal how HIV/AIDS research done exclusively on men significantly disadvantage women.

Hogan’s informative text, Women Take Care, argues persuasively that refusal on the part of the scientific community to research the effects of HIV/AIDS on female bodies is a result of the need for women to be caregivers in this pandemic, as well as a nostalgia for separate spheres. She suggests that this is part of a desire to reconstruct woman as innately maternal, nurturing, and “good,” in contrast to the “bad” woman who is seen as “sexually alluring, predatory, diseased, and pathological.”148 Such binaries reveal the need to characterize and stereotype women within patriarchy, a need which is all the more exacerbated in relation to illness, and HIV/AIDS in particular. This has resulted in a multitude of emergent stereotypes about what “kind” of women contract HIV/AIDS. Alexandra Juhasz argues, for example, that there are essentially six types of women in AIDS narratives: “middle-class, single yuppie; unmarried, procreating woman of

147 Hogan 4.
148 Hogan 12-22. This category of “goodness” is also inextricably bound up with a race and class, thus white, economically privileged women are often seen as unfortunate victims of the illness, while women who are ethnic minorities or economically disadvantaged are seen as bringing the illness upon themselves, and hence are morally reprehensible (12-4).
color; the teenager forced to say no; the procreating white wife; the promiscuous prostitutes (the African/Haitian woman gets tossed in this category as well, because of her presumed promiscuity); and the unseen and therefore unsexed lesbian.  

What both Hogan’s and Juhasz’s research suggests is that the refusal to admit that certain kinds of women (read white, wealthy, successful) contract the disease, and the assumption that other kinds of women (read poor, minorities, prostitutes, etc.) deserve it and bring it on themselves, reveals a desire to maintain the good woman/bad woman dichotomy. The “good woman,” in this equation, is neither a threat nor a site of alterity, while the “bad woman” is expendable, and ultimately, not really a woman at all. As Hogan suggests, “[f]or the average physician to ‘accept’ that women are at risk would require him or her to rethink the cultural category of ‘good woman.’ ”

Consequently, as Carol Keeley argues, “[w]omen are still dying sooner after diagnosis than men because the average physician can’t accept that women are at risk and so misdiagnose their condition, delaying treatment.”

Similarly, the androcentrism present within scientific thought regularly regards woman as merely a reproductive subject or as a potential contaminator of “innocent” populations, including children and male sexual partners. As Judith Lorber argues, “[t]he focus of attention in clinical trials and the mass media has been on women’s potential to infect men and babies, not on their potential to be infected.” This is particularly true for women in the sex industry. During the emergence of the HIV/AIDS epidemic, sex workers were commonly described as “pools of contagion,” “reservoirs of infection,” and “vectors of transmission,” individuals who were

149 Alexandra Juhasz quoted in Rodriguez 25. Paula Treichler is also quoted in Rodriguez as similarly suggesting that there are specific identities available to women in relation to AIDS: “loving helpmate/swinging single, Madonna/whore, good mother/bad mother and so on” (25).
150 Hogan 20.
151 Carol Keeley quoted in Hogan 20.
152 Goldstein, Introduction 10.
153 Lorber 71.
“selling death.” Consequently, interest in the health of prostitutes to date has largely been in relation to the risk they pose to straight men’s health, and “rarely is it suggested that a sex worker test her HIV status is order to seek treatment or to better govern her own life.” Similarly, the women most at risk for contracting HIV/AIDS, such as those in the sex industry, often see primary health care practitioners in settings in which the concern for public health overrides individual concerns. Despite increasing interest in women and HIV/AIDS in more recent years, research on women and HIV remains underfunded and inclusion of women in clinical trials remains low.

**Racism, Classism, Patriarchy, Ableism, and HIV/AIDS:**


Mario Cooper, co-director of the 1996 Harvard AIDS Institute Conference on AIDS in African Americans, insightfully states that “except for possibly slavery, nothing in our history will have killed so many Black people in such short time as AIDS.” By 1992, African-American women

155 Leonard and Thistlethwaite 179.
156 Denenberg 31. Sontag similarly argues that “[e]very feared epidemic disease, but especially those associated with sexual license, generates a preoccupying distinction between the disease’s putative carriers (which usually means just the poor, and, in this part of the world, people with darker skins) and those defined – health professionals and other bureaucrats do the defining – as ‘the general population’” (11).
157 Rodriguez 25.
159 Hogan 104.
represented the largest growing population infected with AIDS in the United States. According to a 1994 report, 75% of women with the disease are women of colour, the majority of which are poor, and many of whom, though not most, are injection drug users. The majority of these women do not have housing of their own, if they have a shelter of any kind at all. In the context of the HIV/AIDS crisis, a lack of education, healthcare, and career opportunities results in poor, minority populations, particularly women, struggling to survive in situations where there is a much greater risk of contraction of HIV/AIDS to themselves and their dependents. If they do contract the illness, these populations have a decreased ability to pay for consistent or high-quality medical attention related to early detection and treatment of opportunistic infections. Consequently these women often end up suffering more from the illness (i.e. contracting more opportunistic infections and receiving less care for them) and dying earlier.

Why is it that these particular populations are so disproportionately affected by HIV/AIDS? Within the context of the United States, the intersection of racism, classism, patriarchy, and ableism, as well as other oppressive systems, are directly related to who contracts, suffers from, and dies as a result of HIV/AIDS. If we reflect on how these systems collude and reinforce one another in the lives of poor, African-American women, it becomes clear why this population’s health is particularly at risk when it comes to HIV/AIDS. Consider that racial minorities often suffer many kinds of discrimination and deprivation, especially economic, vocational and educational deprivation, putting them at significant risk for poverty. The poor, it

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163 Christensen 7.
is well known, often have difficulty accessing healthcare, and the healthcare they do receive is often of questionable quality.\textsuperscript{164} Women are greater risk for poverty because they suffer generally from inferior economic status for a variety of reasons, including, for example, the national economic dependence on free domestic labour, as well as patriarchal conceptions of women’s capacity for rationality and strength. Similarly, it has been documented that disabled women may be targeted for sexual assault because they are perceived to be “easy prey,” and thus are at greater risk for contracting HIV/AIDS through sexual assault than able-bodied women. Likewise, as Ruth Morgan Thomas points out, the disabled are more at risk for poverty because of employment discrimination and accessibility issues at schools and universities. Even from this brief exploration, it is clear that the intersecting causes for poverty, ill health, and lack of vocational and educational opportunities find their roots in oppressive systems such as racism, classism, patriarchy, and ableism, and how in turn increases the risk of contracting HIV/AIDS. What is unique about the HIV/AIDS crisis is its ability to put into relief how the intersections of these systems have real, material effects on the lives of those who are positioned as marginal, deviant, immoral, and expendable.

This explanation, however, does not clarify how the lack of support, intervention, and concern exhibited by government, media, and the scientific community is and was perceived to be justified. Not surprisingly, this justification is also rooted in racism, sexism, classism, and ableism. Consider, for example, the popular notion that poor, African-American women who engage in drug use or are part of the sex industry “get what was coming to them” when they are diagnosed with HIV/AIDS. How are such statements substantiated? Certainly one way is through the historical and contemporary construction of Black women as hypersexual and as unable to control their “animality,” a construction easily perceivable in both past and present

\textsuperscript{164} Thomas 81.
mainstream cultural production. This conception reaches back into the Middle Ages, and, as Sander Gilman points out, by the eighteenth century, Black women had become identified with deviant sexuality in general.165 Such views were inherited by the medical community in a variety of forms, and have often resulted in the widespread conclusion that the supposed hypersexuality of the Black woman is the cause of her contraction of the illness.166 Consequently, she is held responsible for, and thus deserving of, HIV/AIDS. This is reflected in media constructions of the illness as well. Evelynn Hammonds argues that representations of HIV/AIDS “use race to shore up racist ideas that African-American women’s sexuality is categorically different than ‘white’ heterosexuality.”167 Hammonds goes on to argue that the concentration on the African-American mother/welfare queen diverts attention away from historical and contemporary neglectful treatment of all African-American women.168

The history of such racism in the United States is extensive and has been enacted in a variety of ways through healthcare policies. This history poses particular risks for minorities who seek healthcare for HIV/AIDS insofar as they have many reasons to distrust those in positions of power within the medical establishment. As activist Marion Banzhaf explains,

The United States has historically enacted policies of health care discrimination and outright genocide . . . When the country was first colonized, it was giving small-pox-infested blankets to Native Americans. In the 1950s, under Operation Bootstrap in Puerto Rico, it was conducting massive sterilization of women. In the 1960s, when revolutionary groups such as the Black Panthers and the Young Lords were trying to organize, there was a sudden accessibility of heroin in Black and Puerto Rican communities. Today such discriminatory policies are closing city hospitals, cutting Medicaid funds, denying funds to expand drug treatment programs, withholding

166 Gilman 210.
168 Hammonds 118.
treatment for AIDS based on inability to pay, and, as a result, allowing poor people of color with AIDS to die.¹⁶⁹

Beyond this, there are many other reasons why African-Americans avoid medical institutions, both currently and historically, and thus risk contracting and living with HIV/AIDS without healthcare. Frequently services are located outside of poor communities of colour, waiting times can be extremely long, and many underprivileged persons of colour have indicated they don’t want to “deal with being disrespected by medical staff for not understanding medical terminology.”¹⁷⁰ Similarly, there have been disturbing reports that many African-American women face discrimination-based moral scrutiny in regards to their reproductive choices when they seek healthcare. Statistically, African-American women undergo significantly more forced sterilizations because of their HIV status or drug use.¹⁷¹

Patriarchy itself puts women at risk of contracting and suffering from HIV/AIDS, as well as receiving less care and support throughout the illness. Statistically, women tend to stay with male partners when they contract and suffer through the illness, while men often abandon their children and partners when they become HIV infected or ill.¹⁷² Jean Baker Miller suggests that this is a direct result of the societal expectation that women “care for the ill and the disabled.”¹⁷³ Patriarchy also compromises women’s sense of self and self-esteem, making it more difficult for women to assert themselves in ways that protect their health, especially if this requires confrontation or conflict. Jane Wilson argues that the experience of powerlessness from which many women suffer is linked to the social phenomena of economic, political, and psychological oppression. Wilson explains that “[m]ost of the women with whom I have worked have

¹⁷⁰ Battle 287.
¹⁷¹ Hammonds 121.
¹⁷² Springer 37.
¹⁷³ Hogan 6.
internalized their powerlessness which often leaves them with feelings of despair, defeatism and fatalism. It leads them to accept aspects of their world and of themselves which they know to be contrary to their own best interests.”

Patriarchy also asserts itself in sexual relationships, particularly heterosexual relationships, commonly resulting in situations where women have much less power than their male partners. This increases the risk of contracting HIV/AIDS because sexual barriers almost exclusively require consent from both partners. As Wilson points out, “women may fear the repercussions of taking a stand about contraception and protection, let alone suggesting that they should avoid intercourse.” All of this suggests that HIV/AIDS tends to exacerbate already existing forms of oppression, and that HIV/AIDS is exacerbated, both biologically and socio-culturally, by these forms of oppression as well.

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175 Springer 38.
Identity and the Diseased Body: Mortal Threats

The increasing secularization of western societies, the dependence on rationality and individualism which are legacies of the Enlightenment, the increase in average life expectation and decrease in numbers of deaths from infectious disease, the turn to biomedicine and science as the ultimate weapons against illness, disease, and premature death, have generated discourses and practices which tend to deny the fragility and mortality of the human body.

Deborah Lupton, *Medicine as Culture*, 1994\(^\text{177}\)

The panic [around HIV/AIDS] revolves around notions of bodily vulnerability, debilitation and death; sexuality, and homosexuality especially; racial Otherness and foreign contamination; pleasure; and scientific and other epistemological uncertainties . . . Science brings horror under control.

Corinne Squire, “AIDS Panic,” 1997\(^\text{178}\)

Research undertaken within poststructuralism, cultural studies, and women’s studies, as well as numerous other disciplines, has insisted that the construction and preservation of identity requires a moratorium on death and mortality. Jean Baudrillard, for example, contends that social survival depends upon a prohibition against death and a strict separation between life and death.\(^\text{179}\) Insofar as identity stands as an important marker of social existence, meaning, and intelligibility for the individual in the West, culturally we have developed numerous strategies for distancing ourselves from death and eschewing threats that would disintegrate our sense of identity or our belief in its importance. A significant and looming threat to identity is the experience and/or realization of the fragility of the human body and its inevitable disintegration.\(^\text{180}\) As John T. Lysaker suggests, “we try to exclude death’s reality and its disruptive implications from our dreams of autonomy, 

\(^{177}\) Lupton 1.
\(^{178}\) Squire 51-8.
\(^{179}\) Baudillard quoted in Tanner 60.
\(^{180}\) Lorber contends that HIV/AIDS itself has been characterized as a social metaphor for human fragility (86).
self-possession, etc. We may do this by ignoring death entirely, or – in a more philosophical vein – we may do it by trying to capture death in a ‘concept’.\(^{181}\) This chapter is divided into two sections, the first addresses how identity is culturally constructed and how this relates to illness, while the second investigates how HIV/AIDS, specifically, affects identity. In this section I argue that the cultural belief in the power of science, faith in the voluntary nature of robust health, and the socio-political investment in conceptions of the ideal body ward off threats posed to identity at the individual and cultural level. I argue that this suggests that identity is culturally understood as involving a separation between the mind and body within which mental control over the body is foundational.

One of the most acute and pervasive strategies for dealing with the threat of mortality has been the development of scientific and medical inquiry, an area of human culture that is expanding. Catherine Kohler Riessman argues that “more and more of human experience is coming under medical scrutiny, resulting in what Illich (1976) has called ‘the medicalization of life’.”\(^{182}\) Medicalization involves two interrelated processes: first, certain conditions or behaviours are given medical meaning and second, medicine becomes a disciplinary tool for controlling problematic experiences and securing social norms.\(^{183}\) As Deborah Lupton similarly suggests, “there is an increasing dependence upon biomedicine to provide the answers to social as well as medical problems, and the mythology of the beneficent, god-like physician remains


\(^{182}\) Riessman 48. Riessman suggests that “it is now considered appropriate to consult physicians about sexuality, fertility, childhood behavior, and old-age memory problems. It is important to note that the medical profession’s jurisdiction over these and other human conditions extends considerably beyond its demonstrated capacity to ‘cure’ them.” (48). Riessman goes on to suggest that “[m]edicalization is a particularly critical concept because it emphasizes the fact that medicine is a social enterprise, not merely a scientific one. A biological basis is neither necessary nor sufficient for an experience to be defined in terms of illness. Rather, illness is constructed through human action – that is, illness is not inherent in any behaviour or condition, but conferred by others. Thus, medical diagnosis becomes an interpretive process through which illnesses are constructed” (49).
dominant.” This dependence has been founded upon the marketing of medicine as being capable of pacifying all illnesses, physical discomfort, and bodily struggles, which has consequently fostered a false sense of security. Individuals in the Western world today doubtless feel further away from illness, death, pain, and suffering than we imagine previous generations and ancestors did because of this deep cultural faith in scientific medicine. This faith is supported by mass media images which insist that youth can be preserved, death can be delayed, aging processes can be erased, common illnesses can be avoided and prevented, and well-being is entirely available (at a price). Consequently, our socio-cultural understanding of science helps to ward off an acknowledgement of our mortality.

In Western discourses surrounding science and scientific discoveries, robust health is consistently positioned as a choice. This operates to assure the possibility and availability of good health for all, thus enabling a cultural rejection of death and dying. Rhetoric within North American culture involves regular warnings to “[w]atch your appetite. Take care of yourself. Don’t let yourself go.” As Susan Sontag argues, “[l]imits have long been set on the indulgence of certain appetites in the name of health or of the creation of an ideal physical appearance – voluntary limits, the exercise of freedom.” As a result, responsibility for personal health is increasingly placed on the shoulders of the individual who should have avoided unhealthy lifestyles, prevented illness, and/or quickly and effectively responded to illness with medication. After all, many advertising campaigns and scientific studies suggest that health is

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183 Riessman 47-8.
184 Lupton 1.
185 Lupton argues that “[t]he signs of aging have become so abhorrent and pathological that they are conceptualized as having distorting effects – they mask the real” (39). This faith in the medical establishment is particularly topical in relation to HIV/AIDS insofar as “AIDS research operates as the touchstone of scientific advances on the body” (51).
186 Sontag 166.
187 Sontag 166.
188 Lupton 31. Lupton argues that “[c]ontemporary public health directed at ‘health promotion’ throws its forces on the individual by associating the so-called lifestyle diseases with individual behaviours. Health
ultimately there for the taking, the implication being that individuals who suffer from illnesses are, in the end, morally responsible for them. As Sontag suggests, patients who are told that they have unwittingly caused their disease are also made to feel that they deserve it.\footnote{Sontag quoted in Lupton 91.} In relation to the HIV/AIDS pandemic, HIV/AIDS is often represented as a punishment “for living unhealthy lives, for taking health risks, for excesses of diet and lifestyle, for weaknesses of will, self-indulgence and addiction.”\footnote{Sontag 58.} As Laurence J. Kirmayer astutely suggests, “[s]ickness makes the patient’s stewardship of the body suspect.”\footnote{Laurence J. Kirmayer quoted in Lupton 90.} Thus, the potential for good health is culturally assured through positioning ill health as the result of poor choices (moral and otherwise). This distances the threat of death insofar as it places robust health within everyone’s grasp. The presumption here appears to be the supposition that if anyone has the ability to triumph over disease and death, it no longer poses such a considerable threat.

In what ways is this culturally concretized? Integral to this discourse is the construction of an ideal body that embodies this potentiality. The ideal body is one that is consistently healthy, “functioning”, and controlled; a body that symbolizes a triumph over death and disease. As Susan Stewart suggests, the idealized body denies the possibility of death insofar as it creates a transcendent realm, a “realm of the classic,” thus disallowing death.\footnote{Stewart 145.} This ideal, healthy, and functioning body, and its association with immortality, is constructed through, and reflected within, visual representations. Images of the ideal body surround us in textbooks, billboards, television shows, artworks, and magazines, all of which operate as evidence for the myth of the ideal body and the unrestricted availability of health. Just as common as visual representations of the idealized body are images of death and disease, both of which often function similarly to deny

\footnote{Stewart quoted in Lupton 92.}
the individual’s own death and to assert his or her ability to conquer mortality. Elisabeth Bronfen argues that our relationship with images of death is often disassociative, such that “[t]here is death, but it is not my own.”¹⁹³ She suggests that “[t]he aesthetic representation of death lets us repress our knowledge of the reality of death precisely because here death occurs at someone else’s body as an image.”¹⁹⁴ Visual representations of death also use strategies such as humour and comedy to distance the viewer from a realization of his or her own inevitable death. As Lupton argues, “the fearful is made harmless through being made comic; in some cases it looms as a threat, controlled only by being made visible.”¹⁹⁵ Indeed, as Sander Gilman contends, the very act of visualizing is also an act of control.¹⁹⁶

Perhaps most importantly, this faith in science and the ideal body reveals a significant cultural conviction in the seperability of the mind and the body, as well as a belief in the need and capacity for mental power, control, and agency over one’s own body. The construction of the normative body as one which is “locked down” by the mind is perhaps one of the strongest and most pervasive inheritances from Enlightenment thought. Within this framework, one experiences control over one’s body when one has physical, mental, intellectual, and emotional agency to act upon the world with self-determined will. It is this control and agency that we culturally consider to be the basis of identity. This is evidenced by the fact that we commonly delimit embodiment (both explicitly and implicitly) to the aged, ill, disabled, and dying,

¹⁹² Stewart 132.
¹⁹³ Elizabeth Bronfen, Over Her Dead Body: Death, femininity, and the aesthetic (Great Britain: Manchester University Press, 1992) x-xi.
¹⁹⁴ Bronfen x. However, as Bronfen goes on to articulate, the death of another can signify in two ways, “it names one thing (I am spectator/survivor of someone else’s death, therefore I can tell myself that there is no death for me’) and means something else, (‘someone else is dead, therefore I know there is death’)” (x-xi). It is here that Bronfen articulates how images of death have a dual function of articulating anxiety about death while facilitating the denial of one’s own death (x-xi).
¹⁹⁵ Lupton 74.
¹⁹⁶ Sander Gilman quoted in Tanner 74.
individuals who appear to be inseparable from their bodies. Such individuals are not considered fully subjects and on that basis are regularly excluded from cultural and political life. Indeed, Western culture naturalizes and idealizes the normative, healthy, and functioning body so much that bodies that diverge from this expectation are out of place and, in some cases, literally unthinkable as bodies and subjects. As Laura Tanner argues, “[t]he body that does not appear normal is both visually and conceptually out of place, which is evidenced by the lack of facilities for differently abled bodies.”

Psychologically, this produces a schism between the mind and body at the individual level to the extent that healthy and able-bodied individuals can be surprised at times to remember that they do, in fact, have bodies. We seem to forget that “[w]e have bodies, but we are also, in a specific sense, bodies; our embodiment is a necessary requirement of our social identification so that it would be ludicrous to say ‘I have arrived and I have brought my body with me’.” And yet, it seems, this is most often how we imagine ourselves. As Julia Kristeva argues, although the body is constitutive of identity and embodiment is central to subjectivity, materiality and corporeality must be denied so that the subject can feel unified and whole.

Within this framework, illness poses a significant threat to the separation of body and mind, and thus operates as a serious threat to identity. When a person is ill, the presence of the body is undeniable. Because the presence of the body has likely been suppressed or, at a minimum, considered peripheral and controllable, it can feel like the body is taking over. As Elaine Scarry argues, the pain of illness pins the subject to his or her body such that the body is felt to overwhelm the outer world and inner world to the point where the body comes to subsume

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197 Tanner 8-9.  
198 Tanner 23.  
199 Turner quoted in Lupton 20.  
200 Julia Kristeva quoted in Tanner 23.  
201 Lupton 20.
all else. Similarly, Kirmayer argues that when the body is healthy, the mind can support the illusion of the separateness of the mind and body and affirm the superiority of the mind. In contrast, when one becomes ill, the fundamental nature of the body is exposed – that the self is, after all, inseparable from the flesh. Accordingly, sickness is a threat to rationality in so far as it challenges self-control. Hence we can understand Susan Bordo’s claim that the ideal body is one that is contained and locked down. Illness, in this cultural climate, thus operates to erode the foundations of identity insofar as individuals deemed ill usually do not have the luxury of supporting the illusion of the separateness of mind and body.

If bodily illness threatens identity in its ability to reveal the interconstitutive nature of the mind and body, it is worth considering whether all ill bodies equally pose this threat. That is to say, it is important to ask two specific questions: first, whether all bodies are equally perceived as capable of performing the mind/body division foundational to identity, and second, whether illness in particular bodies are perceived to be more threatening. The following suggests that particular individuals are perceived as less able to obtain personhood because of various oppressive systems and inheritances, including patriarchy, heteronormativity, and racism. Consequently, when illness occurs in bodies that are already perceived as tenuous sites of identity, these individuals are often seen as more threatening and dangerous and thus worthy of oppressive political control.

Many theorists have suggested that the normative body is the white, healthy, heterosexual, and abled male body. This, too, in an inheritance of Enlightenment thought. As was demonstrated within chapter three, individuals who diverge from this standard are often

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202 Elaine Scarry quoted in Tanner 42.
203 Kirmayer quoted in Lupton 87. See also Talcott Parsons quoted in Lorber 41. In 1951 Talcott Parsons first described the sick role as a form of deviance, similar to crime, insofar as the ill are unable to participate in normal social roles (41).
204 Susan Bordo quoted in Lupton 37.
associated with embodiment, illness, dirt, disease, death, and contagion, and thus are seen to pose a threat to rationality, culture, community, and nation. This is evidenced by the fact that disease in such bodies often results in both an increase in medical and scientific concern (because these bodies are seen as more contagious or diseased than the “norm”) as well as a decrease in medical and scientific concern (because these bodies are already marginal and less important). In relation to HIV/AIDS, as explored in chapter three, medical interest often increases when non-normative bodies pose threats to normative ones. Insofar as “deviant” bodies take a human form, they pose a threat to the equation of human = male = rational = subject and thus signify death and disease.

Historically, bodies that have been understood as deviant and divergent include female bodies, homosexual bodies, and non-white bodies. Female bodies have classically symbolized deviance and excess, particularly in their capacity to threaten boundaries and borders.\(^{205}\) Bordo, for example, observes that women are commonly described as “talking too much, having too much emotion, too much need, taking up too much space, and being too much there.”\(^{206}\) Bronfen similarly suggests that femininity is “culturally constructed as the superlative site of alterity.”\(^{207}\) Homosexuality has also been understood as posing immense threats to rationality, identity, and nation, in particular because it has operated as a threat to heterosexual identity. Historically, there has been a longstanding equation of homosexuality with the diseased, the irrational, and the unnatural.\(^{208}\) Indeed, gay sexuality has been culturally understood as so contagious that to even speak about it is to risk being infected by homosexual desire.\(^{209}\) Within such accounts,

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\(^{206}\) Susan Bordo quoted in Malson 237.

\(^{207}\) Bronfen x. Bronfen goes on to argue that both death and femininity “point to a reality beyond and indeed disruptive of all systems of language” (xii).


homosexuality threatens the possibility of control over the body’s desires, and thus precludes the grounds for identity development.\footnote{Edelman, “Plague of Discourse” 306-7. It is worth adding here that the discursive constructions of both homosexuality and AIDS parallel each other insofar as being characterized as parasitic and contagious, and thus the significations of each work to reaffirm the other.} While the female body is conceived of as excessive and the homosexual body as contagious, the racialized body is often seen as diseased. Indeed, this is particularly apparent within the rhetoric and cultural myths regarding HIV/AIDS. As Sontag suggests, the discussion of the origins of HIV/AIDS, particularly, makes apparent racist and colonialist connections between disease and the racial Other. Sontag writes, “[t]he subliminal connection made to notions about a primitive past and the many hypotheses that have been fielded about the possible transmission from animals . . . cannot help but activate a familiar set of stereotypes about animality, sexual license, and blacks.”\footnote{Sontag 140. See also Paula A. Treichler, “Beyond Cosmo: AIDS, Identity, and Inscriptions of Gender,” in How to Have Theory in an Epidemic: Cultural Chronicles of AIDS (United States: Duke University Press, 1999) 235-77. Treichler similarly argues that “racist fears about the perversity of previously separated racial groups coming into contact, ‘dark Africa’ being exposed through industrialization and the cutting down of rainforests, and widespread speculation about the ability to trace back HIV/AIDS to African primates, all provide pop-scientific ‘evidence’ to suggest connections between the black body and disease” (246).} Thus, the female body, the homosexual body, and the non-white body are all seen as sites of disease, disorder, and irrationality prior to the contraction of any illness, and as a result are seen as threats to both rationality and identity. Consequently, contraction of illness within such bodies exacerbates the threat illness poses to identity, both individually and culturally.

**HIV/AIDS and Identity: Erasing the Subject Physically and Socially**

Our understanding of the AIDS epidemic requires us to sort out an extraordinary number of difficulties about identity. These have serious implications for women: perhaps no
area of AIDS commentary has been more consistently confusing and problematic as gender – for AIDS experts, AIDS educators, clinicians, and media commentators as well as for women themselves. 

Paula A. Treichler, “Beyond *Cosmo*: AIDS, Identity, and Inscriptions of Gender,” 1999

While the previous section establishes that illness threatens mental control over the body, and thus threatens identity, it has yet to be explained how this happens in the case of HIV/AIDS. This section evaluates the connections between the biological and the social in relation to HIV/AIDS to understand exactly how HIV/AIDS threatens identity. Specifically, I argue that HIV/AIDS operates biologically through the body turning against itself and erasing its own identity. I argue that this is paralleled and exacerbated in the social realm, wherein the visible signs of personhood begin to disappear as a result of the illness. HIV/AIDS has consequently come to embody and symbolize postmodern anxieties about identity, and the disintegration of identity that HIV/AIDS causes is exacerbated by the cultural erosion of the concept of identity itself. As a result, I suggest that HIV/AIDS needs to be theorized not only as a localized occurrence, but as part of a culture that is particularly invested in issues of identity.

Further, I explain that the loss of self characteristic of HIV/AIDS is socially exacerbated because of the societal panic around the illness. Based upon my research, I suggest that the following are the cultural characteristics that make HIV/AIDS so susceptible to widespread panic:  
1) moralizing about epidemics has, in the twentieth century, been restricted to illnesses that are

212 Treichler 235.

213 See Lee Edelman, “The Mirror and the Tank: ‘AIDS,’ Subjectivity, and the Rhetoric of Activism,” in *Writing AIDS: Gay Literature, Language, and Analysis*, eds. Timothy F. Murphy and Suzanne Poirier (New York: Columbia University Press, 1993) 9-38. Edelman writes, “AIDS, then, can be figured as a crisis in – and hence opportunity for – the social shaping or articulation of subjectivities because, in part, the historical context within which AIDS in the West achieved its ‘identity’ allowed it to be presented as a syndrome distinctively engaging identity as an issue. In fact, whatever the direction from which we approach the subject of AIDS, we are brought up against our own constitution as subjects of (and in) ideology and the fact that we are forced to recognize that the politics of AIDS as a subject of discourse is inseparable from the politics of the subject itself – inseparable, that is, from the ideological construction and the cultural fantasmatism of agency” (12-13).
transmitted sexually, 2) science has no defence against HIV/AIDS, 3) HIV/AIDS has been contracted by individuals who are already struggling against oppression in the dominant culture, 4) individuals usually know (or think they know) how they contracted HIV/AIDS, and thus there is the suspicion of guilt and the assignment of blame, 5) HIV/AIDS regularly flushes out identities that may be hidden, closeted, or culturally taboo, 6) HIV/AIDS is discursively constructed as linked to national boundaries and borders, 7) HIV/AIDS is historically linked to representations of stigmatized illnesses, such as syphilis, and 8) some politicians utilize the panic around this illness to strategically ensure their political success.\textsuperscript{214} I argue that these circumstances have colluded to produce cultural panic and hysteria around HIV/AIDS in America.

HIV/AIDS operates very uniquely at a cellular and biological level. HIV subverts the immune system’s capacity to understand what belongs to the body and what is foreign.\textsuperscript{215} This constitutes a complete inversion of the normative role of the immune system, the very existence of which is supposed to enable a distinguishing between self and not-self.\textsuperscript{216} Lee Edelman suggests that “HIV, like metaphor, operates to naturalize, or present as proper, that which is improper or imported from without.”\textsuperscript{217} Edelman refers to this as “parasitic transcription.”\textsuperscript{218} HIV operates through a parasitic overriding of the immune system such that the simulation of an immune response ends up exacerbating the disease rather than assisting in its eradication.\textsuperscript{219} As Sontag argues, it is uniquely the case with AIDS that the body’s own cells become the invaders.\textsuperscript{220} The body turns against itself as if in mutiny, creating a psychological schism in

\textsuperscript{214} Sontag 112-5. See also Edelman, “Plague of Discourse” 301. See also Lupton 65-75.
\textsuperscript{215} Edelman, “Plague of Discourse” 310-11.
\textsuperscript{216} David Black quoted in Edelman, “Plague of Discourse” 301.
\textsuperscript{217} Edelman, “Plague of Discourse” 310.
\textsuperscript{218} Edelman, “Plague of Discourse” 311.
\textsuperscript{219} Edelman, “Plague of Discourse” 311.
\textsuperscript{220} Sontag 106.
which the body that is preyed upon is the source of its own undoing. What is even more
terrifying about this virus is that this internal contamination is understood as permanent and
irreversible.221

Having contracted HIV/AIDS, the individual appears to be colluding in his or her own
disintegration not only at a biological level, but at a social and visual level as well. The illness
acts upon the body to disable and disfigure, making the individual less and less able to control or
take care of basic functions, as well as less capable of facilitating the construction of a social
self.222 As Tanner points out, “[a]s the marks of critical illness literally overwhelm the features of
the person with disease, the gaze often locates the subject in a body that seems to announce its
identity as the process of its own destruction.”223 Identity itself, in this progression, becomes less
and less present and more and more absent. It is this lack, this presence of absence and death,
which can make the body of the severely ill patient abject.224 Through the wearing effects of the
illness, individuals become reduced to signs of death and the body becomes seen and experienced
as increasingly inescapable.225

How the disease operates at the cellular level, and its effects on the body of the
HIV/AIDS patient, are thus mimetic. Both involve the disintegration of the subject’s body and
identity which occurs from inside him or herself at what appears to be an intentional level. This
person becomes an Other to him or herself through the act of confronting the self as a stranger,
and more specifically, a stranger who is intimately constitutive of oneself yet fundamentally
hostile to one’s physical and social survival. Interestingly, Roberta McGrath suggests that “HIV

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221 Sontag 108.
222 Sontag 109.
223 Tanner 22.
224 Tanner 9. Quoted in Tanner, Julia Kristeva claims that abjection is “above all a revolt of the person
against an external menace from which one has the impression that it is not only an external menace but
that it may menace us from inside” (9).
– which is the simulacrum of DNA – is the first human retrovirus, perhaps the first post-modern
disease. 226 Similarly, HIV/AIDS operates through destruction of the foundations of identity –
the very cornerstone of postmodern theory. It would thus seem that within the context of
postmodern culture, a culture in which the death of the subject is articulated, HIV/AIDS is not
just a site of identity destruction, but implicated in a larger intellectual overhaul on the idea of
subjectivity itself. 227 Consequently it seems feasible that the panic around HIV/AIDS is in part
related to the ways in which it is wrapped up with prevalent postmodern anxieties and identity
issues. Within this context, it also seems likely that the panic over identity issues exacerbates the
loss of self for the person with HIV/AIDS.

This erosion of self is also exacerbated socially in ways beyond its linkage to postmodern
angst. Specifically, the import of this loss of self is importantly linked to how the illness is
perceived by society, and this perception becomes part of a feedback loop that ends up further
eroding identity, which in turn heightens panic around the illness once more. As Michael C.
Clatts and Kevin M. Mutchler suggest,

To say someone has AIDS is to say much more than a person is experiencing exposure of
fragile organs to the ravage of common infections. It is to say that he or she is a certain
type of person, socially and morally defined . . . the metaphoric predication of AIDS
opens door to the dark and musty cellar of cultural association of the profane, the defiled,
the denied, the unsown, the forbidden, the feared. 228

The ways in which the perception of the disease exacerbates the erosion of the identity of the
patient are numerous, interwoven, shape-shifting, and implicated historically. There are two
ways that I organize the ways in which I take this to occur: first, at the psychological or psycho-

225 Tanner 43. This makes clear why embodiment is linked to severe illness insofar as both are experienced
and seen as, ultimately, inescapable.
226 Roberta McGrath quoted in Edelman, “Mirror and Tank” 11. See also a similar argument made in
Donna Haraway, “A Cyborg Manifesto: Science, Technology, and Socialist-Feminism in the Late
Twentieth Century,” in Simians, Cyborgs and Women: The Reinvention of Nature (New York: Routledge,
1991) 149-81.
social level; that is, how the illness relates to the human fear of mortality, and second, how the illness relates historically and politically to oppressive tactics that seek to control this fear of mortality, and associated notions of contamination, dirt, Otherness, the foreign, and the unknown. Both are briefly explored here.

Shared mortality is at the heart of cultural fear around HIV/AIDS, which is then transposed into other areas of cultural life. In viewing the body of the ill patient, either personally or through representation, the diseased body threatens to unveil the corporeality of the individual doing the looking.229 While, as was previously mentioned, images of the dying body work to distance death, it is also the case that they bring it closer. As Tanner argues, “[b]ecause the object of the gaze announces not only difference but sameness, the subject’s recognition of a shared mortality lends power to the very threat the healthy gaze would dispel.”230 Indeed, as the illness progresses, those surrounding the ill person increasingly seek out any presence of identity in the physical body of the ill person, a process that ends up eroding the strict division between subject and object. As the ill subject becomes more and more abject as the illness progresses, the person watching can’t help but confront the object that is the human body, and thus the reality of embodiment and death.231 Representations of the ill are, therefore, born out of society’s need to make order in a frightening world, “to draw (literally) the boundaries between ourselves and the diseased Other so as to provide control over the randomness of disease.”232 Thus the face of the patient is always a continuous one – the site of the continuous projection of our fears of mortality.

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228 Michael C. Clatts and Kevin M. Mutchler quoted in Lupton 57.
229 Tanner 23. Tanner goes on to argue that this is why doctors and nurses are more likely to avoid contact with patients as they approach closer to death (23).
230 Tanner 24.
231 Tanner 39.
232 Gilman quoted in Lupton 65.
Gilman suggests that “[h]ow we see the diseased, the mad, the polluting, is a reflex of our sense of control and the limits inherent in that sense of control.”

How this fear and anxiety around mortality is then transposed into cultural, social, and political theories, experiences, choices, stereotypes, and alliances is particular to the disease that produces the fear and the way it signifies within those realms. Sontag, for example, goes to great lengths in *AIDS and Its Metaphors* to show how fear of mortality invoked in HIV/AIDS, syphilis, and cancer are all manifested in different ways depending on how the illness operates biologically and socially. The particular panic and hysteria that developed around HIV/AIDS is well documented. This panic is reflected such nomenclature as “epidemic,” “plague” and “state of emergency,” and has resulted in a rallying of defensive methods and mobilization of military tactics. As has been previously explored, HIV/AIDS is seen to defuse the boundaries between healthy/sick, heterosexual/homosexual, self/Other, pleasure/pain, male/female, control/passivity, victim/enemy, self/nation, body/mind, and many other binaries. It thus seems natural that military imagery and language would be used to “barricade” and “shore up” these divisions.

Within this rhetoric, “[t]he survival of the nation, of civilized society, of the world itself is said to be at stake – claims that are a familiar part of building a case for repression.”

This panic around the illness is also translated into the medical realm. The way in which Western medicine understands HIV/AIDS, how it is described in medical language, and the way in which patients are treated, are all affected by the cultural panic around the disease. This assists in perpetuating, as much as destroying, the panic and loss of identity that the patient experiences. Corinne Squire insists that scientific vocabularies surrounding HIV/AIDS are rooted in this cultural panic and “AIDS science is itself heavily influenced by the patriarchal, heterosexist,

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233 Gilman quoted in Tanner 74.
234 Sontag 14.
235 Sontag 132-4. See also Tanner 60-1.
racist assumptions that lead to partialities or omissions, apocalyptic warnings, melodramatic over and under statements. Indeed, the medical counter itself has been characterized as the ultimate site of social, political, and ideological control and surveillance. Ivan Illich, for example, argues that modern medicine is both physically and socially harmful because of the control medical professions yield which, he argues, results in a dependence upon medicine as a panacea and removes autonomy from individuals to control their own health. In the face of the knowledgeable doctor, the ill patient is forced to acquiesce, give up government over his or her own body, a power which, as has been shown, is so central to identity. Thus the medical establishment can actually operate to increase cultural panic around HIV/AIDS and assist in the erasure the identities of those with HIV/AIDS.

Given this, the question becomes why has there been such widespread political and social panic over this particular illness? Why is there such hysteria around HIV/AIDS? While numerous causes might be explored here, there are eight particularly significant reasons why HIV/AIDS has created this kind of hysteria culturally. First, moralizing about epidemics has, in the twentieth century, been restricted to illnesses that are transmitted sexually. As a result, the development of HIV/AIDS, both individually and nationally, is immediately situated within a moral context. As Lupton suggests, “the emergence of a new outbreak of disease becomes an

236 Sontag 173.
237 Squire 52. Squire argues that science is ultimately always fighting panic through control, isolation, and visualization (52).
238 Foucault quoted in Lupton 23.
239 Ivan Illich quoted in Lupton 11.
240 Foucault quoted in Lupton 24. Foucault argues that in the medical encounter the patient is questioned and exposed in a situation where he or she is asked to give up jurisdiction over his or her body without knowing why the procedures are carried out (24). See also Tanner 41. Tanner argues that in “order to render the disease visible, the medical gaze must factor out the person with illness; seeing the patient as an embodied subject then emerges not only as inconsequential but as counterproductive” (41).
241 Sontag 144-5. See also Foucault quoted in Lupton 27. Foucault’s argues that “the individual’s sexuality has reached such importance that it constitutes the person’s subjectivity” (27).
occasion to question the tenants and moral values of everyday life.”  

Second, science has no defence against the illness, and thus the cultural construction of science as omnipotent is challenged.  

Science, as was suggested earlier, has been a very successful tool for distancing death in Western culture. Third, as was suggested earlier, it has occurred for individuals who already face oppression, and thus the threat the disease poses to identity is heightened.  

Fourth, because individuals often know, or think they know, how the illness was contracted, there is a threat of both guilt and blame. Fifth, HIV/AIDS can, and often does, reveal identities that are hidden or culturally taboo, thus threatening the social survival of the person with the illness.  

Sixth, because of its discursive connections to national boundaries and borders, it increases anxiety around maintaining demarcations between self and Other.  

Seventh, HIV/AIDS is part of a continuum of stigmatized illness with which it is associated, including syphilis.  

And lastly, eighth, the panic around the illness can be manipulated politically to ensure success and consolidate control.  

As Sontag suggests, “[a]uthoritarian political ideologies have a vested interest in promoting fear, a sense of the imminence of takeover by aliens – and real diseases are useful material.”  

These are perhaps the most significant reasons why HIV/AIDS continues to be a galvanizing point around which cultural conflict and discourse over control, identity, and death revolve. The cultural panic around the illness is produced by a variety of circumstances colluding

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242 Lupton 90.  
243 Edelman, “Plague of Discourse” 301.  
244 Edelman, “Plague of Discourse” 301.  
245 Sontag 112.  
246 Lupton 65-6. Lupton argues that “[w]hile military imagery may overly connote decisive action and the refusal to ‘give in’ to disease, at a deeper level of meaning this discourse serves to draw boundaries between Self and Other by representing the body as a nation state which is vulnerable to attacks by foreign invaders, invoking and resolving anxieties to do with xenophobia, invasion, control, and contamination” (65).  
247 Gilman quoted in Lupton 74.  
248 Edelman, “Plague of Discourse” 301.  
249 Sontag 149.
in particular ways which position the illness, and those with it, as frightening, dangerous, and lacking in identity. The individual with HIV/AIDS is thus in a process of erasure physically, socially, culturally, and politically.
Chapter Five
Representation of HIV/AIDS and Identity

HIV/AIDS and Representation

Almost all of the intellectual discourse surrounding AIDS for the first decade of the epidemic, Thomas Yingling argues, focussed on one goal: “to secure a subjectivity for the person with AIDS that was not simply an erasure of his or her previous subjectivity, that did not simply read the illness as the end of meaning.”

Thomas Yingling quoted in Laura Tanner, Lost Bodies: Inhabiting the Borders of Life and Death, 2006250

The physical, social, political, and discursive erasure of the person with HIV/AIDS is profoundly painful and frightening. Because identity is the primary grounds upon which we exist in the world, understand our phenomenological experiences, and perceive ourselves as authentic subjects, the erosion of identity is one of the most painful effects of the disease. But what can be done to ease this pain? As Thomas Yingling above suggests, there is a long academic history of attempting to recover the identity of individuals with HIV/AIDS, a history that is paralleled within the visual realm as well. Many American artists have struggled to articulate the widespread pain and suffering caused by the AIDS epidemic, as well as return humanity to those who are stigmatized and oppressed because of their HIV status. Despite the extent of such efforts, artistic representation of the illness has proved difficult for a number of reasons. Given the severity of the HIV/AIDS epidemic, its connection to identity, its exacerbation of various systems of oppression, the persistent ambivalence around its meaning, and the cultural panic it has caused to the United States, HIV/AIDS has produced a crisis of representation. Even though HIV/AIDS is an under-determined condition, it first emerged in the public realm in particularly visual forms, especially visually over-determined media such as films, installations, videos, and

250 Thomas Yingling quoted in Tanner 41.
posters. Gabrielle Griffin argues that “[n]o parallel cultural proliferation can be found for other conditions which are in some respects similar, such as cancer, for example.” Such an abundance of representational work speaks to the ways in which this illness engages a multitude of cultural concerns, particularly in relation to identity issues.

Artistic expression has been one of the dominant approaches in attempts to negotiate identity and HIV/AIDS. The following provides a brief overview of three artistic genres in which HIV/AIDS has been explored within the United States: activist art, memorial art, and serial portraiture. What is common to the works discussed, and most artwork dealing with HIV/AIDS, is their focus on the relationship between identity and illness. This supports chapter three and four’s claims that identity is central within discourses and imagery pertaining to both illness and HIV/AIDS. More specifically, my analysis investigates how these artworks reveal that we culturally construct identity as disembodied, and embodied persons as lacking identity (as chapter four argued). This suggests that to make positive changes in the lives of people with HIV/AIDS, identity needs to be an important focus for artists, activists, theorists, social workers, and so on. This chapter does not seek to give a comprehensive account of the artwork responding to HIV/AIDS, or to explore all of the dimensions of the works discussed. Instead, it aims to orient the reader to landmark works produced in the U.S. in response to the AIDS crisis and their connections to issues of identity. This provides a context through which to understand the STITCHES Doll Project and its articulation of identity issues in relation to HIV/AIDS.

Griffin 5. Reed similarly argues that “[i]t became clear that in an ‘information age’ and a ‘knowledge economy’, more than ever knowledge was power, power knowledge. The war over HIV/AIDS was going to be very much a ‘discursive’ battle, a battle over the meaning of words and images. This was surely not something wholly new in a social movement, but the extent to which ‘semiotic’ warfare became self-conscious and central to the work of ACT UP was unprecedented” (185).
HIV/AIDS and Activist Art: ACT UP and Gran Fury

Some of the most persuasive claims for the transformative possibilities of cultural politics have come from theorists and activists (many of whom function as both) involved in combating the AIDS crisis. . . . Because AIDS is not simply a medical or scientific problem but also involves a crisis of representation, it demands not only political activism but what David Crimp has called “cultural activism.” . . . Success within the art world is not the primary goal of artists working within the context of AIDS activism, and communicating only to an art audience is a limited accomplishment. Thus, cultural activism involves rethinking the identity of the artist as well as the role of production, distribution, and audience in determining a work’s significance.


The activist art that emerged and proliferated in response to the AIDS pandemic in America was, and is, astounding in breadth, quality, quantity, and variety. Particularly in the 1980s and 1990s, artists, activists, theorists, actors, academics, poets, and healthcare providers came together in unique ways to produce art that would educate the public, pressure the government, challenge the media, and support the cause. Perhaps the most effective, powerful, and memorable of American activist art collectives responding to the crisis was ACT UP, and its off-shoot graphic collective, Gran Fury. Indeed, the AIDS Coalition to Unleash Power, or ACT UP, has been characterized as “one of the most dynamic and successful social movement groups of the late 1980s and 1990s.” ACT UP formed in New York City in March of 1987 in response to the growing horror of the HIV/AIDS pandemic and the lack of governmental response, holding its first protest in March of that year (fig. 5.1). The group describes itself as a “diverse, non-partisan group united in anger and committed to direct action to end the AIDS crisis.” ACT UP had multiple and complex origins, drawing from the women’s health movement, earlier activist groups such as

252 Ann Cvetkovich, “Video, AIDS, and Activism,” in Art, Activism, and Oppositionality: Essays from Afterimage, eds. Grant Kester and Richard Bolton (Durham, NC: Duke University Press, 1998) 182-3. Cvetkovich goes on to explain that “[i]n its simplest sense, ‘cultural activism’ refers to the work of gathering and disseminating information – in this case drawing attention to the inadequacies of government and medical policies and educating people about the prevention and treatment of AIDS. In the absence of a cure for AIDS, the dissemination of information is one of the only ways to save lives” (182).
253 Reed 179.
254 Reed 182.
the Silence = Death Project, the more politically tame Gay Men’s Health Crisis, and numerous groups devoted to gay and lesbian liberation. The organization grew rapidly, and by the beginning of 1990 more than one hundred chapters had developed across the United States and around the globe. ACT UP continues to be active globally and utilize unique tactics for social change (see, for example, fig. 5.2).


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255 Reed 182
Affiliate activist group Gran Fury formed in 1988 out of a small group of ACT UP members following the success of ACT UP’s New York art exhibition, *Let the Record Show*. It took the name Gran Fury to reflect its members’ rage about the pandemic, referencing in its name the model of Plymouth sedan used by the New York City Police. Gran Fury, not unlike ACT UP, described itself as a “band of individuals united in anger and dedicated to exploiting the power of art to end the AIDS crisis.”²⁵⁶ Though Gran Fury was organized as an autonomous group, it worked in close alliance with ACT UP New York and has been characterized as its “unofficial propaganda ministry and guerilla graphic designers.”²⁵⁷

The success of ACT UP and Gran Fury has been attributed to their unique creativity, particularly to their use multiple artistic forms, especially visual and performing arts, and the ways in which they used these forms to challenge the government’s and media’s packaging of the
epidemic. As T. V. Reed points out, ACT UP’s visual strategies often operate through a politics of shaming. Reed writes,

Through demonstrations, flyers, posters, informational media actions, newspaper advertisements, letter-writing campaigns, civil disobedience, and sit-ins and small ‘zap’ actions in corporate, government and media offices, the group sought to draw attention to shameful government sluggishness, shameful corporate profiting, and shameful media bias.

Visual pieces were often located in places where the group’s work might be mistaken for mainstream media productions, including bus shelters, billboards, newspaper vending machines, and subway trains. Regularly placed on transit buses, the “Kissing Doesn’t Kill” campaign poster (fig. 5.3), for example, sought to combat the well known stereotypes about who contracted HIV/AIDS, as well as to respond to what both groups thought was the underlying cause of the epidemic -- multiple forces of oppression manifested through the government, corporate culture, and mainstream society. These systems of oppression were regularly targeted by both groups in their artwork.

Fig. 5.3. Gran Fury, Kissing Doesn’t Kill, 1989-91, bus panel, 136” x 28”. Gay and Lesbian Alliance Against Defamation, <http://www.commercialcloset.org/common/adlibrary/adprintdetails.cfm?QID=344&ClientID=11064>.

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258 Reed 180.
259 Reed 193.
260 Meyer 54.
261 Meyer 52-3.
Of all of the images produced by ACT UP and Gran Fury, the most well known and perhaps the most powerful image is the SILENCE = DEATH poster (fig. 5.4). The stark text of SILENCE=DEATH stands out from the ironic appropriation of the Nazi symbol for homosexual men imprisoned in death camps, the pink triangle. The uncertainty of the message and its refusal to give too much away, combined with its austerity, has often been interpreted as “strategic ambiguity” that encourages discussion of HIV/AIDS, invokes associations of genocide, and encourages its audience to consider who is silenced, who is dying, and who is responsible.

Fig. 5.4. Gran Fury, SILENCE=DEATH, 1986, Offset Lithography, 24” x 29.” AIDS Coalition to Unleash Power Website, <http://www.actupny.org/reports/silencedeath.html>.

Issues of identity were not only foregrounded in such representations; they were central in many of the works, and much of both groups’ work focused on reversing the demonizing of certain identities. Gran Fury’s poster, “Read My Lips” (fig. 5.5), not unlike the “Kissing Doesn’t Kill” campaign, operates to force “divergent” sexualities into the public sphere, reverse the blame.

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262 Reed 190.
for the disease, and encourage discussion about sexuality and safety. The images work to normalize and dignify sexual practices that had previously been understood as perverse, thus pushing viewers to reconsider common narratives about the disease. As was previously suggested, HIV/AIDS is regularly associated with identity as opposed to action, and thus by changing perceptions of the identities that were associated with the development of the pandemic, ACT UP and Gran Fury sought to change the terms of the debate over how best to handle the crisis. Nonetheless, this strategy often required an essentializing of identities, which proved problematic in other ways. Lee Edelman suggests that both homophobic and antihomophobic forces alike produce “discourses that reify and absolutize identities . . . [and] make clear the extent to which both groups see the AIDS epidemic as threatening the social structures through which they have constituted their identities for themselves.”²⁶⁴ This is a risk that both ACT UP and Gran Fury had to take in attempting to change public perceptions of “divergent” identities and sexualities, and unfortunately this often chanced producing rigidity around what exactly constituted homosexuality, bisexuality, and so on. Indeed, any activist artwork that seeks to challenge the cultural construction of marginalized identities can fall prey to the same processes of marginalization, co-optation, colonization, and homogenization that it seeks to reject. Consequently, the strategies used by ACT UP and Gran Fury reveal the extent to which identity becomes an important political and cultural battleground for activists and artists responding to AIDS in America.

²⁶³ Reed 190.
²⁶⁴ Edelman, “Plague as Discourse” 306.
HIV/AIDS and Memorial Art: The AIDS Memorial Quilt

Activist art was not the only area of art production that reflected the horror, enormity, and political nature of the pandemic; American memorial art has played a powerful role in combating the disease by focussing on the identity of those who have died from the illness. Most outstanding of these is arguably the AIDS Memorial Quilt, produced through the Names Project Foundation. The Quilt consists of individual panels sewn together in blocks of eight, each block measuring approximately twelve feet and each individual panel measuring approximately three foot by six foot (see, for example, fig. 5.6). Each panel of the Quilt, often constructed by friends or family members, commemorates the life of a person who has been lost to HIV/AIDS. This enormous Quilt seeks to serve a multitude of functions, but aims specifically to provide a creative means for remembrance and healing, to effectively illustrate the enormity of the AIDS pandemic, to increase awareness of HIV and AIDS throughout the
general public, to assist others in providing education on the prevention of HIV infection, and to raise funds for community-based AIDS Service Organizations (ASO’s).265

Fig. 5.6. Photographer Unknown, *AIDS Memorial Quilt Block*, various dates. BEAT AIDS Online, <http://www.beataids.org/index.php/about/>.

The Quilt was begun in November 1985 by gay rights activist Cleve Jones and the first panel was made by Jones himself in memory of his friend, Marvin Feldman. Jones collaborated with Mike Smith and several other activists to organize and publicize the Quilt’s creation through the development of their organization, the NAMES Project Foundation. Almost immediately the response to the Quilt was enormous; panels were sent from all over the country to be added to the Quilt, including specifically those cities that were hit hardest by HIV/AIDS, such as New York, Los Angeles and Atlanta. The Foundation set up a workshop in San Francisco where panels were sent and volunteers worked tirelessly to assemble the Quilt. The inaugural display was held on

11 October 1987 at the National Mall in Washington D.C., during the National March on Washington for Lesbian and Gay Rights (see fig. 5.7 and fig. 5.8). A staggering half a million people came to see the Quilt that weekend which included a total of 1,920 panels. The Quilt was nominated for the Nobel Peace Prize in 1989 and continues to be the largest community art project in the world. Today, the Quilt contains over 91,000 names of people who have died as a result of AIDS and is 1,293,300 square feet in size.266

What is perhaps most powerful about the Quilt is its aim to publicly preserve the identities of those who have died from AIDS and mourn their deaths, refusing to allow these identities to be forgotten. The Quilt serves as a powerful testament to the impact of AIDS on individuals and communities, and continues to be a poignant reminder of the need for continued support and awareness in the fight against this disease.


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individuals to become statistics. To this end, Quilt panels often include private mementos, bits of used clothing, favourite jewellery, and short stories to represent the unique lives of those portrayed. If Maurice Merleau-Ponty is correct in suggesting that “things are the prolongation of my body and my body is the prolongation of the world,” then the objects that friends and family members choose to include on the Quilt attempt to stand in for the absent body.267 Laura Tanner maintains that grief actually emerges out of “an embodied subject’s inability to reach through the image to touch a lost body.”268 Consequently, as Elizabeth Hallam and Jenny Hockney suggest, the most potent markers of memory are often those that are associated with the body and seek to stretch the divide between the living and the dead.269 This is certainly reflected in the Quilt which, as poet Richard Doty points out, often includes objects that touched the body of the person represented. As Tanner points out, the Quilt includes such objects as “a Garfield cap stained brown where it would have touched the forehead of its wearer, Levis jeans ripped at the knees, children’s shoes worn unevenly at the soles.”270 These objects which were physically changed through contact with the body, “mark the evidence of time, the acclimation of the object’s body to human bodies.”271 Such objects continually bring the viewer back to the physicality of those individuals in their uniqueness, reminding the viewer that individuality is always embodied and the body is inseparable from the person “in it.” Consequently, these objects invoke the tendency to penetrate objects and attempt to find the subject “within,” while simultaneously constructing a subject whose object body is impossible to look past.272 In this way, the Quilt operates to

267 Merleau-Ponty in Tanner 178.
268 Tanner 127.
269 Elizabeth Hallam and Jenny Hockney in Tanner 177-8.
270 Tanner 206. Tanner goes on to argue that “[a]lthough these objects remain susceptible to analysis and generate multiple meanings, they resist appropriation as mere symbols insofar as they insist upon continually returning the viewer who would trace their semiotic effects to their origin in an individual body” (206).
271 Richard Doty in Tanner 204.
272 Tanner 190-2. Tanner positions herself in contrast to many other critics of the Quilt who, she argues, focus on the object status of the Quilt and its symbolic value (201).
represent and express embodied subjectivity, making it more difficult for viewers to neglect bodily experience of the illness that occurs for a specific person in a particular body.

Fig. 5.8. Photographer Unknown, Display of AIDS Memorial Quilt at the National Mall in Washington, D.C., 1996. The AIDS Memorial Quilt Website, <http://www.aidsquilt.org/history.htm>.

Nonetheless, the struggle to “effectively” or “appropriately” represent the identity of those lost to HIV/AIDS is a challenge for those contributing to the Quilt, just as it was for ACT UP and Gran Fury. In particular, the issue of how to negotiate between private and public mourning is an apparent struggle for contributors. Tanner argues that “the panels of the AIDS Quilt often reflect the panel maker’s vacillation between the desire to celebrate the lost subject publicly and the desire to reserve and protect the intimacy of an embodied relationship that the viewer has not shared.”273 Such a tension can produce ambiguity for the viewer around the meaning of the objects included in the panel, thus disrupting an easy or casual interpretation of the identity of the person depicted. Public displays of these private relics often fail to reveal the

273 Tanner 207.
attached meanings, associations, memories, and stories. This restricts access to the full depth of
the object(s) included, and thus the person, him or herself. In this way, the identity and essence
of the person represented is simultaneously revealed and concealed. The AIDS Memorial Quilt,
not unlike the work of ACT UP and Gran Fury, speaks to the ethical and political battle over how
best to represent the personal nature of the HIV/AIDS pandemic.

**HIV/AIDS and Serial Portraiture: Billy Howard and Nicholas Nixon**

Representations are symptoms that visualize even as they conceal what is too dangerous
to articulate openly but too fascinating to repress successfully.
Elizabeth Bronfen, *Over Her Dead Body*, 1992

Particular to much American photography produced by artists responding to the AIDS crisis is a
conflict over how best to represent the *suffering* body of the individual with HIV/AIDS. This has
been an especially controversial issue because such representations create specific social effects --
politically, socially, culturally, and personally -- for those suffering from HIV/AIDS. Indeed, the
struggle to ethically represent the suffering body reveals the limitations of representation and
photography themselves, limitations made all the more stark in relation to the human form. As
Susan Stewart has suggested, “the body itself is necessarily exaggerated as soon as we have an
image of the body, an image which is a projection or objectification of the body into the world.
Thus the problems of imagining the body are symptomatic of the problems in imagining the self
as place, object, and agent at once.” Consequently, serial portraiture of those experiencing
bodily suffering invoke and challenge notions of reality/fiction, agency/passivity, object/subject,
and so forth, bringing forward disputes over the notion of identity and its constitution. The
famous photography of Billy Howard and Nicholas Nixon in response to the HIV/AIDS

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274 Bronfen x.
275 Stewart 132.
pandemic is emblematic of the struggle over the limits of representation in relation to the suffering body. Both of these artists produced the earliest and perhaps the most significant photographic responses to the illness using extremely different representational strategies. While Howard’s work conceals the illness, Nixon’s work reveals and emphasizes the illness and its bodily effects. Billy Howard’s 1989 exhibition, “Epitaphs for the Living: Words and Images in the Time of AIDS,” consists of photos that do not reveal the physical signs of the illness. Such signs remain hidden as a result of Howard’s compositional choices and selection of subjects (see, for example, fig. 5.9). Though his photographs “resist collapsing the identity of all people into a single representation of a skeletal, lesioned Other,” they do so at the expense of acknowledging the individual’s public and personal experience of negotiating the physical signs and symptoms of the illness.276 Ironically, Howard’s photographs seem to erase the illness and its effects on the body in an effort to depict the humanity of those with HIV/AIDS.


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276 Tanner 45.
In contrast, Nicholas Nixon’s 1991 exhibition, “People with AIDS,” employs a completely different representational approach (see, for example, fig. 5.10). Nixon’s works often reduce the depicted to his or her bodily experience of the illness, sometimes to the extent that his or her individuality and humanity is erased. In Nixon’s photographic portraits of the last days of those with HIV/AIDS, the individual is often stripped of his or her clothing, jewellery, possessions, friends, and is often unable to move or compose themselves for the picture. The works appear to mark the transformation from subject to object, trapping the depicted in his or her body.277 This parallels David Crimp’s suggestion that photographic representations of those with AIDS often reduce the sufferer to his or her mortality. He suggests that this is part of an Othering process that produces a taboo against the sexuality of the depicted as much as it is a tool for obscuring the political causes of the illness.278 Similarly, Sander Gilman argues that the visual imagery of disease operates to safely define the Other, to create a stereotype and, in so doing,

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277 Tanner 54-62.
dehumanizes the sufferer. As a result, the portrait of the sufferer and patient is the image of the disease anthropomorphized.\textsuperscript{279} Nixon’s work thus makes HIV/AIDS visible while risking the loss of the individuality of those who suffer from it.

The tension between these two collections of photographs is emblematic of the struggle over how best to picture HIV/AIDS itself. As Tanner argues, “[i]f representations of the dying body reduce people with AIDS to powerlessness and obscure the potential for living with AIDS, photographs which consistently depict people with AIDS as untouched by illness may represent a qualified affirmation that celebrates the subjective presence only by erasing signs of bodily vulnerability.”\textsuperscript{280} This suggests that such photographic representations often reveal a tension between representing disembodied identity and embodied, but anonymous, illness. Indeed, this is a tension characteristic of much art surrounding HIV/AIDS. Interestingly, this parallels the previous chapter’s claim that identity is culturally constructed as disembodied, and that embodied persons are often understood as lacking identity and selfhood. Consequently, these works, whether serial portraiture, activist or memorial art, indicate how necessary it is to address identity issues when confronting the HIV/AIDS epidemic. While a plethora of art projects have attempted to return subjectivity and identity to those affected by the illness, few are able to depict both the individual in his or her uniqueness and the embodied materiality of that person as he or she is affected by the illness, while at the same time referring to the political conditions of the virus. Without creative and resistant representational strategies, artwork about HIV/AIDS

\textsuperscript{278} Douglas Crimp quoted in Tanner 40.
\textsuperscript{279} Sander Gilman quoted in Lupton 73. Tanner suggests that, in light of this, “photographic representations of such subjects must continually invent ways of subverting visual conventions – not only those that code the unmarked body as ‘healthy,’ but those which would transcend the embodied dynamics of subjectivity or reduce the representational subject to an unfamiliar object the subject would choose to disavow” (63).
\textsuperscript{280} Tanner 41.
“cannot help but construct a ‘knowledge’ of the disease that collapses into a series of visual conventions and cultural stereotypes more dangerous than any admission of ignorance.”

281 Tanner 63.
Chapter Six

STITCHES Doll Project: Stitching Identity Together Again

Recuperating Subjectivity: Dolls that Recover Identity

As chapter five suggests, the struggle over how best to represent the tragedy and enormity of the AIDS epidemic has resulted in a persistent representational crisis. Artists and activists alike have struggled to create representations that both reflect the cultural and political magnitude of HIV/AIDS and convey the deeply personal experience of the illness and the physical, social, and political erasure it causes.\(^2^8^2\) As chapter five argues, these representational struggles have often surrounded identity and embodiment, struggles which themselves test the limits of Western conceptions of subjectivity. Against this history, the STITCHES Doll Project has produced a novel way to represent both the body and the unique identity of individuals suffering from HIV/AIDS, while attending to the political circumstances surrounding the pandemic. This chapter focuses on the ways in which the STITCHES Doll Project assists in the recovery of identity for participants in ways that are valuable and transformative.

The STITCHES Doll Project, begun by Kathy Gerus-Darbison (fig. 6.1) and Candice Moench in July 1999, provides an opportunity for women with HIV/AIDS to share their experiences of HIV/AIDS through art production, specifically through the creation of fabric dolls. The Project seeks to act as a “living memorial” for women who suffer from HIV/AIDS and record their stories so that they may be “preserved for future generations to learn from.”\(^2^8^3\) To address the institutional and public neglect of women’s issues and experiences in relation to

\(^{2^8^2}\) This is a particularly poignant struggle for women given the fragmentation, commodification, and objectification of female bodies in Western visual culture. See, for example, Jean Dykstra, “Putting Herself in the Picture: autobiographical images of illness and the body,” Afterimage 23.2 (1995): 16-20. Dykstra argues that in this context, discourses surrounding the body and illness weigh “more heavily on women’s senses of themselves” (17).

HIV/AIDS, Gerus-Darbison and Moench designed and instituted doll-making workshops at various outreach agencies in Detroit, Michigan. As the Project grew, agencies in other cities across the country requested bundles of fabric dolls so they could run their own workshops. Since 2000, these workshops have been held at agencies that provide outreach for HIV+ women who seek support in spaces such as homeless shelters, therapy groups, sexual assault clinics, hospices, and hospitals. The Project now has more than one hundred dolls in its collection.

In these doll-making workshops, HIV+ women are given unadorned fabric dolls and asked to decorate them to reflect their experience of HIV/AIDS. Participants are asked to answer the question: “if my doll could talk, what would she say?” and to include their answer on a “monograph” to be displayed with the doll. Participants are not required to provide any biographical information out of respect for the privacy of the doll-maker. Indeed, it is this privacy and anonymity that makes participation possible for many of the women, especially given the kind of discrimination that HIV+ women face (as chapter three explores). Consequently, many of the dolls are made by anonymous participants, or participants use initials or nicknames to identify either themselves or their dolls. Workshops are often lead by social workers over a period of several weeks, during which the participant is encouraged to see her doll as literally being, or becoming, herself. Importantly, these doll-making workshops facilitate the creation of socially supportive environments for women who may not have much support, enabling HIV+ women to connect with one another. Gerus-Darbison has found that these workshops often create communities that are sustained long after the doll-making ended.

Once the dolls are finished, they are given to the STITCHES centre where they are prepared to go on display. Since its inception, STITCHES has exhibited and toured the dolls and

284 Gerus-Darbison, personal interview.
285 Gerus-Darbison, personal interview.
their monographs across America in conjunction with informational displays and presentations on HIV/AIDS. The dolls have been displayed at a variety of locations, including public schools, academic conferences, international conference on AIDS, and various universities throughout North America, with the intention of educating the public about the disease and the lives of those who live with it (see fig. 6.1 and fig. 6.2). The form of the project is quite simple, but the effects, by many accounts, have been striking. Gerus-Darbison contends that “[t]hese women’s stories will live on, after they are gone, to be sure they are not forgotten. The dolls will be testaments to the struggle of women in our world today. Their dolls will continue to speak for them and educate others about all the intersecting issues that cause harm and oppress women worldwide.”

Fig. 6.1. Patricia O’Blenes, Kathy Gerus-Darbison with Several of the STITCHES Dolls on Display at Her House, April 2009, photography. C and G Newspapers Online, <http://www.candgnews.com/Homepage-Articles/2009/4-1-09/Gerus-Darbison-AIDS-project.asp>.

286 Kathy Gerus-Darbison, “Creative Expression that can change the World: HIV+ Women create dolls to educate others,” Feminist Research Group Graduate Conference (University of Windsor, Windsor, ON) 23 May 2008.
Interestingly, the impetus behind the Project, as well as claims to its efficacy and pedagogical role, commonly operate with a shared logic and rhetoric. The language used to describe the hopes and effects of the Project is strikingly similar across accounts given by participants, workshop leaders, the media, and organizations that host the project. For example, because of the dolls’ perceived ability to increase compassion, overcome discrimination, and create solidarity, doll-making is consistently described as therapeutic, pedagogical, and a form of social activism. This aspect of the Project was explicitly set out by the founders in the Project’s twofold mission:

1) It gives women the opportunity for their “voice” to be heard in a safe, confidential, and educational manner. Many women do not have the luxury of speaking about their HIV status in their everyday lives. They may live in fear of rejection, reprisal or other types of discrimination. With this project, the dolls speak for themselves. 2) The completed dolls become part of a national travelling exhibit and, in that way, educate the general population about the risks of HIV infection. The STITCHES dolls teach knowledge
about and compassion for all people living with HIV infection. The creativity of each individual doll “speaks” to the visitors who come to view them.287

Accounts given by workshop leaders echo the language of this mission statement in interesting ways. Jon Sperry, a behavioural health counsellor who facilitated a STITCHES Doll workshop, wrote that involvement in the Project resulted in female participants “embracing their culture, self confidence, and recovery.”288 Similarly, social worker Candice Carreno, who ran a women’s therapy group in which STICHES dolls were created, argues “[n]ot only did the STITCHES Doll project provide a macro voice of education and awareness, it bonds individuals and creates opportunities for growth and empowerment.”289 Both accounts suggest that the dolls facilitate the development of selfhood and social cohesion through newly discovered pride in oneself and one’s culture. Indeed, many social justice and social change projects, artistic or otherwise, are justified on these very grounds. The question thus becomes: how we interpret and evaluate such claims? Specifically, how exactly does the Project work to increase self-worth and produce socially supportive cultures?

In almost all accounts of the STITCHES Doll Project, the root of the Project’s capacity to be therapeutic, educational, and socially progressive is situated in the doll’s seeming ability to “represent” the woman, “speak for” her, and “reclaim her voice.” Within this rhetoric, participants’ empowerment is achieved through the doll’s perceived ability to articulate the participant’s identity which, it is contended, has been hidden and destroyed as a result of HIV/AIDS. The mission statement of the STITCHES Doll Project, for example, identifies the role of the dolls as providing visibility to these women and returning them, and their stories, to the social realm. It is here that value of the Project is positioned. In an interview I conducted with

288 Jon Sperry quoted in Kathy Gerus-Darbison, “Workshop Comment Cards collected by Founder Kathy Gerus-Darbison,” e-mail to the author, 26 July 2008.
Gerus-Darbison, she claimed that “[i]t is very empowering for them [participants] to create a doll that speaks for them (my emphasis).”\textsuperscript{290} Similarly, social worker Sarah Serrano claims that the dolls help these “wonderful artists find their voices.”\textsuperscript{291} This interest in recovering the voice of the participant is often elided with recovering identity itself, or with representing the doll-maker’s identity with more accuracy or authenticity. For example, Serrano writes, “[t]he dolls served as creative outlets, tools of empowerment and assertiveness. . . It was wonderful to see them go from making the dolls into a representation of what they wanted to be and the journey for them to realize that the dolls they were making were an actual depiction of who they were deep down inside.”\textsuperscript{292} She implies, in other words, that the dolls enable access to the essence of those who create them, an essence that has been hidden or damaged as a result of HIV/AIDS.

It is Serrano’s explanation above that I would like to take as a place of departure in attempting to understand how these dolls come to have meaning for their creators, and why it is that the dolls have the impact so many claim. Serrano’s assertion suggests that the dolls enable a kind of self re-discovery that allows individuals to articulate that which, up to this point, had been repressed. If the dolls are understood as giving the power of speech to those whose voice has been historically and socially stifled, how exactly does this happen? Similarly, in what way can we understand the claim that the dolls are a “truer” representation -- “an actual depiction” -- of these women? Perhaps most interestingly, can the claim that the Project allows these women an opportunity to reclaim their identity be supported? Such descriptions of the Project are based a presumption of “lack” on the part of the person with HIV/AIDS, specifically a lack of voice, of authentic representation, and of proximity to truthful contact with self and identity. This lack, as has been suggested in previous chapters, is a result of the perceived (and consequently lived)

\textsuperscript{289} Candice Carreno quoted in Gerus-Darbison, “Comment Cards.”
\textsuperscript{290} Gerus-Darbison, personal interview.
\textsuperscript{291} Sarah Serrano quoted in Gerus-Darbison, “Comment Cards.”
relationship between identity and HIV/AIDS within Western culture, specifically the erasure and disintegration of identity both individually and culturally, physically and socially for those with HIV/AIDS. I suggest that the creation of dolls by participants in the STITCHES Doll Project works to compensate for this lack and to recuperate a sense of self, wholeness, and authenticity for participants.

The ways in which the recuperation of self occurs is, however, neither consistent nor uniform. At a minimum, the creation of the dolls provides a space for articulating the loss of identity that occurs with HIV/AIDS, as well as a place to express the desire to recover control over one’s body and identity. In the most effective instances, however, the construction of the dolls assists participants in recovering and reclaiming identity using a variety of strategies. While it is not my suggestion that the dolls operate equivalently for each participant, it is my contention that by critically reflecting on several of the dolls, the ways in which they are decorated and constructed, as well as their accompanying monographs, we can appreciate that their creation often has the effect of assisting in the recovery of identity and that there are persistent strategies for this recovery identifiable across the collection. As Gerus-Darbison indicates, “[t]he actual doll, the way she is clothed or not, the accessories she has attached to her or that accompany her . . . tell a story.” Given this, the following explores several dolls individually, collectively, and in relation to one another, to determine the mechanisms by which identity is recovered by their creators and how these mechanisms work.

292 Sarah Serrano quoted in Gerus-Darbison, “Comment Cards.”
293 Gerus-Darbison, “Creative Expression.” As Gerus-Darbison suggests, “[a] content analysis of the dolls and monographs collected as part of the STITCHES Doll Project reveals that contributions to the project are as varied as the individual doll makers. Women make use of and experience participation in the project in a variety of ways. Some doll makers use their participation in the project to help sort out their feelings about being infected, others want to educate, some send messages or hope, and still others try to make sense of their illness.”
294 Gerus-Darbison, “Creative Expression.”
There are innumerable methods by which a threat to identity may be eschewed, certainly too many to name here, and the presence of illness and death, which poses a particularly profound challenge to a sense of self, requires a variety of strategies for reclaiming and reconstructing a threatened identity. The following focuses on three strategies for recovering identity used by participants in the STITCHES Doll Project. These strategies include the following: the sharing of illness and death, rejecting or refusing illness and death, and experiencing illness and death as a sacrifice. While other strategies are used for re-establishing identity, these three are particularly evident across many of the dolls. Sometimes they intersect and are mutually reinforcing, and oftentimes a doll exhibits one or more strategies simultaneously. The context in which the dolls are made, as well as their subsequent display and use, is also analyzed to consider how these dolls recover identity.

A Note on Interpretation

The following analysis proceeds based on the contention that the work of art in the case of the STITCHES Doll Project is the Project itself, which I understand as a work of community and activist art. Consequently, the production of the dolls, the installation and display of these dolls, as well as the doll collection itself, I consider to constitute different parts of the work. While this chapter proceeds by privileging an analysis of doll creation, and the identity recovery strategies they employ, analysis of these dolls is ultimately re-contextualized within the Project itself, which is the object of study. Consequently, the success of doll-making to recover identity for participants reflects on the efficacy of the Project itself, although this does not constitute the extent of the Project. As reflected in the STITCHES Doll Project mission statement, the Project operates through two primary mechanisms: doll production, and the collecting and displaying of these dolls (as pedagogical tools). Thus, in the next chapter I include a discussion of the
collecting and display practices of the STITCHES Doll Project, and how these practices affect the re-establishment of identity for participants. It is the success and/or failure of these two elements of the Project to assist in the recovery of identity for participants upon which I base my evaluation of the success of the artwork itself, the STITCHES Doll Project.

It should also be made clear that I do no posit identity as stable, or contend that there is “real” or “true” self which participants are able to access through the STITCHES Doll Project. Rather, I am interested in how participants are able to recover the (Western) foundations of identity: mental control over the body and a repression of embodiment, illness, and death (as set out in chapter four). In this sense, my analysis proceeds based on an exploration of identity in relation to mortality rather than an investigation of participants’ capacity to recover identity in relation to nationality, sexuality, etc. While I do not see these two explorations as mutually exclusive (see chapter three), and I do include some discussions of participants capacity to recover other elements of their identity, such as femininity, my focus is the doll-makers ability to recover identity by eschewing embodiment, illness, and death so as to neutralize the threat these pose to the (Western) foundations of identity.

When attempting analysis of these dolls, it is important to note that the recovery of identity is possible with these dolls because of the direct identification the participant has with the doll. Because the doll is discursively constructed by program organizers and workshop leaders as literally being the woman who makes it, participants construct dolls based on who they understand themselves to be. Gerus-Darbison, for example, refers to her doll as “me” in several interviews.295 Because participants see themselves as the dolls, they are able to use the dolls to enact the identity recovery strategies they use, or will use, in their daily lives. That is, the dolls

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295 Gerus-Darbison, personal interview. See also Erin McClary, “A doll that’s worth a thousand words: Local HIV/AIDS outreach program, advocate receives $60K grant,” C and G Newspaper, 20 August 2008.
do not just symbolize recovery strategies, but are one way in which strategies are deployed. This would not be possible if participants were instructed to create dolls that were strictly pedagogical in nature, or were told to create works that would reflect the HIV/AIDS pandemic in general terms, rather than personal ones. Thus, it is important to remember that, in some sense, the dolls and their meanings are already created by the Project designers and workshop leaders through their descriptions of what the Project is about, who it is for, what it is supposed to accomplish, and so forth. This affects how and why the dolls are created and what meanings are attached to them.

Further, as I previously suggested, I treat these dolls and their monographs as texts and not truths, insisting that the dolls indicate and engage with various discourses and practices.\textsuperscript{296} More specifically, I suggest that these dolls are meaningful for producers and viewers insofar as they engage in, and/or resist, visual conventions and their associated meanings. This is the case for the accompanying monographs as well, whose meaning and significance is always constructed through larger discourses, in this case around illness, the body, identity, femininity, and so forth. Interpreting these texts is never straightforward or apolitical, and the use of such conventions as metaphors needs to be explored in relation to these larger systems of meaning. Indeed, as Deborah Lupton suggests, individuals suffering from illness often utilize metaphorical discourse to conceptualize themselves and articulate their thoughts and feelings. Strict attention needs to be paid to what metaphors are used, what discourses they can be connected to, and so on.\textsuperscript{297} Consequently, interpretation of these dolls attempts to consider the dolls and their monographs in relation to larger narratives, discourses, and representational strategies connected to the themes and issues the dolls address.

\textsuperscript{296} See Squire 62.
\textsuperscript{297} Lupton 54-5.
The Sharing of Illness and Death

A strategy for recovering identity that is common to all participants in the STITCHES Doll Project is the sharing of illness and death. The Project is designed to give participants an opportunity to share with an audience the physical, psychological, political, and emotional effects of HIV/AIDS on their lives. This is achieved through the decoration of the doll, the creation of a monograph, and the subsequent display of both publicly. For women who produce dolls within groups or workshops, this sharing can also occur socially among participants without the mediating object of the doll. This “sharing of illness” is a mechanism for identity recovery insofar as it provides an opportunity for the women to articulate themselves as subjects publicly, an articulation achieved through the expression of the experience of HIV/AIDS. This functions “to remove” the illness, a removal which works to reaffirm identity in two ways. First, it forces the women to become reflective objects for themselves, which requires distancing themselves from their illness to achieve reflection. Second, because participants articulate these experiences and immediately give them away (by giving the doll away), they are able to remove the illness from themselves (and its attached threat to identity). Both the articulation of subjectivity and the removal of the illness function to reaffirm a sense of self for participants. The following explains these strategies and explores them in relation to two dolls.

The most fundamental way in which selfhood is affirmed is through the claiming of a self that thinks, feels, and acts. We are said to be present, to exist and to have identity, in so far as we can claim that we are an “I” that has an internal life (thought, emotion, etc.) and express that to another person, imagined or real. Philosopher Emmanuel Levinas argues that we always articulate our experiences to someone, and that this relation is always already more basic than the content of the articulation. Indeed, Levinas maintains that this relation to a someone makes articulation possible, is the grounds upon which it rests, and thus that this relation is the basis of
If this is the case, the subjectivity of participants is made present, is given substance, through their articulation of selfhood as expressed by the dolls. Insofar as many of these women have been unable express their experiences of the illness because of the stigma around HIV/AIDS, the dolls enable a return to a relationship with others by creating a space for these women to articulate “I think,” “I feel,” “I hurt,” and so on. As suggested by Levinas, “(t)he I does not begin in ‘I am I’ but begins in a concrete relationship with the world.” The dolls are able to help recover this relationship and consequently affirm the basis of identity for participants.

This establishment of selfhood is further enhanced when participants create dolls within groups or workshops. Identification with others who are also suffering because of illness, and a sharing of stories about the illness and its effects, can build identity based on mutual experiences of pain and suffering. This can help reverse the effects of the erasure of identity caused by HIV/AIDS and its attendant panic and hysteria. Seana S. Lowe’s analysis of two Denver-based community art projects found that “(w)hile social interaction helped individuals to enhance and expand their definitions of self, the activity of coming together to do art also resulted in the development of collective identity as a type of group membership based on a shared aspect of community life.” As Maxine Greene suggests, “a way of speaking of an expanded community . . . takes shape when diverse people, speaking as who and not what they are, come together in both speech and action to constitute something in common among themselves.” In the case of the STITCHES Doll Project, doll-making workshops enable a sharing of the burden of HIV/AIDS through solidarity building and community development. In this context, participants are able to build positive identifications because of, not in spite of, HIV/AIDS. This is reflected in many of the participants’ testimonials, which emphasize the transformative power of the dolls and the sense of community they foster.

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299 See Levinas 33-48.
300 Seana S. Lowe, “Creating Community: Art for Community Development,” *Journal of Contemporary Ethnography* 29.3 (June 2000): 377
the dolls. For example, Carole Huttoe’s doll, entitled *There is Life After AIDS*, expresses in her monograph, “(s)isters in this struggle / Hold your heads high! / We are beautiful / We are somebody / We will survive.”

This kind of solidarity building enables participants to share the weight of the HIV/AIDS and see the illness as an *opportunity* for community development.

The expression of selfhood enabled by the dolls not only affirms the identity of participants but also operates to remove illness and death (and thus the threat they pose). At the most basic level, to create a doll and monograph, the participant must become a reflective object for herself, separating herself from herself, and thus making herself external to herself. As Maurice Merleau-Ponty suggests, “experience of one’s own body runs counter to the reflective procedure which detaches subject and object from each other, and which gives us only thought about the body, or the body as an idea, and not the experience of the body or the body in reality.”

Merleau-Ponty’s claim here is that embodied experience is not identical to reflection on that experience, and that reflection always requires taking up a position whereby one becomes an object for oneself. One necessarily distances oneself from oneself to achieve reflection or analysis on thought, emotions, experiences, and so forth. Consequently, there is a twofold move: the construction of the doll articulates identity, and thus grounds a sense of self, while simultaneously requiring that the doll maker become an object for herself, thus distancing herself from her experiences of HIV/AIDS, illness, and its associations with death. As a result, identity is affirmed and illness and death are distanced.

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301 Maxine Greene quoted in Lowe 377.
303 Merleau-Ponty quoted in Tanner 8.
304 I am not suggesting that illness is not an important part of identity for many, or that it shouldn’t be. Rather, I am claiming that illness poses a threat to the Western conception of identity as existing solely for those who achieve mental or intellectual control over their bodies. I would suggest that, insofar as illness challenges the separation between body and mind at both a personal and cultural level, it is often perceived and experienced as a threat to selfhood.
These reflections on illness and death are distanced even further through the act of physically sending the dolls off for display. Because each doll is identified as the woman who creates it, the participant projects her illness and experiences of HIV/AIDS onto the doll, which is then removed from the self. It is perhaps for this reason that so many agencies who host STITCHES Doll Project workshops host “goodbye parties” for the dolls. At these goodbye parties, each participant is able celebrate the construction of her doll while mourning the loss of her as she is given over to the STITCHES centre for public display. Such goodbye parties reaffirm the anthropomorphizing of these dolls, reiterating the fact that these dolls are the women who created them. Indeed, the dolls are regularly referred to as “the girls” by those involved in the STITCHES Doll Project. What is lost, however, is not the woman/doll, but HIV/AIDS and participants’ experiences of it. While such a loss may be painful, and hence necessitate a sorrowful goodbye, this is a primary mechanism by which the women are able to reject the illness and hence re-establish themselves as subjects.

This twofold articulation of subjectivity and removal of illness and death is evident within the doll collection. To narrow my focus, I look specifically at one of the most significant ways in which presence is made visible in the doll collection: the expression of the self-estrangement and erasure of self experienced as a result of HIV/AIDS and its social, cultural, and political meanings. To articulate the loss of self is, ironically, one of the most powerful strategies for recovering that self, because the search for self, the desire to fight self-estrangement, is exclusively a human task, a task a “someone” undertakes. Insofar as these dolls express this

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305 Gerus-Darbison, “Creative Expression.”
307 See Juha Varto quoted in Mika Hannula, “River Low, Mountain High: Contextualizing Artistic Research,” Lier & Boog 18.1 (February 2004): 77. Varto writes, “[t]hings happen to me and I myself am happening, but there is no way to step outside, to place oneself further off; to see more clearly, to be wiser.
search and sense of self-estrangement, participants are able to recover a sense of self through the articulation of those feelings. To investigate these mechanisms at work, I begin with a visual and textual analysis of two dolls, created by participants Jacqueline Pacheco and Tina Case respectively, to explore how they negotiate identity and HIV/AIDS, including how they navigate the cultural narratives that accompany the illness. Subsequently, I explain how this constitutes a sharing of the illness that recovers identity.


Jacqueline Pacheco’s doll (fig. 6.3), *Pac Woman*, is illustrative of the loss of identity characteristic of HIV/AIDS, and the desire to reconcile that loss. In comparison to almost all of the dolls in the collection, this one stands out for its unique construction and strange use of I can only exist, in the way typical of human beings: in the middle, putting things in place, foundering”
materials. Unlike all of the other dolls, this doll’s face is almost fully covered by a black mask, her eyes barely visible. Small human figures, arms outstretched, cover her chest, while small happy-face buttons, several upside down, follow the hem of her short black costume. She stands straight, arms at her side, without shoes. Her monograph reads,

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Feeling little people inside my body
eating me up!!
Ugly
Sad Wild
Crazy
Cannot find myself
Searching
Destroy

HIV bandit lady.
The good is to help others around the world.
Safe sex.
People around the world, take care
of yourselves.308
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This monograph expresses Pacheco’s experience of hiding from herself and others. Pacheco describes herself as the “HIV bandit lady,” which is reflected in her black mask which implicates her in the crime of her illness. The mask also suggests that feels she must conceal her illness from others to survive. Indeed, this is a reflection of how individuals with HIV/AIDS have been constructed in scientific and popular discourse as the virus itself; dirty and dangerous. Many suffering from the illness have been known to shut themselves up in their houses because “they were sure others were able to see their contamination.”309 Pacheco’s doll reflects the cultural belief that the virus is visible just by looking at the surface of her body, and that she needs to protect herself against the eyes of those who would find her out, the connotation being that such a

(77).
309 Squire 62.
discovery would result in disciplinary action. As Susan Sontag suggests, there is an inevitable move from the cultural demonization of HIV/AIDS and characterizations of it as an alien “Other,” to the attribution of fault to the patient, regardless of whether the patient is thought of as a victim. Consequently, the impetus behind the “hiding” exhibited by Pacheco’s doll is an attempt to maintain a sense of self, a sense of dignity and safety, by removing the illness from her identity in the social sphere. If Pacheco can hide the disease socially, she is able to maintain a “normal” identity in social and cultural spheres. Consequently, the doll gives voice to a strategy of identity maintenance that she is deploying in the social sphere.

In light of this, we can read the use of military imagery and vocabulary in Pacheco’s doll and attendant monograph as an attempt to engage a battle; a battle that, in Pacheco’s eyes, ultimately seeks to separate her from her illness. Sontag argues that this kind of imagery is often present in descriptions of HIV/AIDS, including autobiographical accounts, and this is exemplified in the warfare imagery that is used in several of the other doll’s descriptions as well. For example, Diane Jimenez’s monograph explains that she feels “like an Indian at war / War within myself.” Similarly, a doll entitled Fancy, made by an unknown participant, describes HIV/AIDS as having “invaded my space/body,” while S.M.’s monograph for her doll, Hope, reads “you now hold me in bondage / Where it impossible to escape / You now rule my body / Like a political dictator / and I long for freedom.” Such imagery clearly invokes notions of warfare and battle, situations in which the maker searches for control over her body and her self both physically and socially. While Pacheco’s doll’s body is populated by other faces and figures, the monograph suggests that these “little people” are agents of destruction within her

310 Sontag 99.
311 Sontag 95-8.
body, making it difficult to “find herself.” It seems that the disintegration of identity and self, in Pacheco’s case, is internal. This parallels Sontag’s suggestion that AIDS descriptions often involve notions not only of pollution, but invasion from the inside.\(^\text{314}\) It is this internal threat which has to be hidden externally so that Pacheco’s identity might be maintained and saved from destruction.


Tina Case’s doll (fig. 6.4), *Me*, poignantly expresses the loss of identity typical of HIV/AIDS. Her monograph reads,

I heard someone say something and I knew it wasn't right because it was very ungodly. Full of anger and dislike, but it was really shocking to look in the mirror and see that the foul mouth person was staring at me. I saw a man today whose walk was way off track


\(^{314}\) Sontag quoted in Lupton 58.
because he choose the darkness instead of following the light, but when I turned around I found there was no one else. So it made me realize I was looking at myself. While standing on the riverbank my mind was in a daze. So I threw a rock in the water because I wanted to see some waves. I glanced at my reflection as the waves rolled by and it was there, that I noticed my problems started, with me, myself, and I.³¹⁵

Case’s doll, not unlike Pacheco’s doll, clearly conveys the self-estrangement that has occurred for her and is linked with HIV/AIDS. There is a repetition of the act of coming into contact with herself through sound, sight, and vision, but being unable to recognize herself. She experiences herself as either no one, or as someone else, until she acknowledges, at the end of her passage, that she has been hiding from herself and problems that are, ultimately, her own. This journey she describes revolves around a search for self and identity, and the ways in which identity is lost to her. Case’s doll enables an articulation of this search for identity, and thus reveals her to be present and human insofar as she is searching for herself, a search which she is then able to share with others.

But how, exactly, does this constitute sharing the illness, and how does this ground both participants’ sense of self? In the case of Pacheco, the creation of the doll clearly positions her as an agent and thus a subject. She fights her illness consciously, and she develops strategies to maintain her identity socially, both strategies the doll expresses. Similarly, the doll conveys her experience of physical and social erosion caused by the illness. The ability to articulate disintegration of self is, as was previously suggested, an effective strategy for asserting identity because only a self, a subject, can lose a sense of self or subjectivity and mourn that loss. This articulation of loss is thus, ironically, quite grounding. This is also true of Case’s doll, whose search for self is an all-too-human endeavour. Thus, these dolls assert the participant’s

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subjectivity and exhibit and perform strategies for removing the illness, all of which operate to affirm the participant’s sense of self.

The Rejection or Refusal of Illness and Death

A rejection or refusal of death and illness is also a common strategy for dealing with HIV/AIDS, as it is for many terminal illnesses. Psychologists often read the rejection or refusal of the illness and/or death as a stage of denial that patients typically go through and ultimately overcome. However, Corrine Squire’s extensive 1995 interviews with people infected by HIV suggest that panic around the illness, and such attendant strategies as the rejection of the illness, continue long after diagnosis and are often recurrent.316 Rejection or refusal of the virus may take various forms, including refusal to believe one has the illness, refusal to believe that the illness is a ‘problem’ in any sense, refusal to engage in discussions about the illness with others, refusal to believe that there is such an illness, and so forth. Several of the individuals Squire interviewed utilized strategies to reject or refuse the illness, including a refusal to speak to friends or family, even if they would be sympathetic, or a refusal to associate with others with HIV. Other interviewees explained that they refused to structure their lives around the illness at all and declined to make decisions about actions or goals based on their seropositivity.317 We can read such refusals as indicators of a desire to reject the illness itself and a hope to re-establish, or maintain, a lifestyle and a sense of self that was present prior to the illness.

316 Squire 62-3.
317 Squire 63-4.
These forms of rejection are also uniquely present in several of the dolls made through the STITCHES Doll Project. Consider T. J. B.’s doll (fig. 6.5), *T-Bird*, which was made by a woman who lives at Rivington House, a healthcare facility for persons living with HIV/AIDS in New York City.\textsuperscript{318} Her monograph reads,

> What the hell am I doing here?
> I am in a wheelchair and I want to get out!
> I want to walk. I used to walk.
> I don’t like the wheelchair because I feel very confined.
> What the hell am I doing here??\textsuperscript{319}

This monograph clearly emphasizes that this STITCHES participant refuses to identify with her illness and with her body in its current state. She asks, repeatedly, “What am I doing here?”


distancing herself from her present condition and refusing to acknowledge the events that lead up
to it. Indeed, her statement suggests that she is genuinely surprised at her condition. Such
surprise is paralleled by a few of the individuals who participated in Squire’s study as well.
Indeed, Squire found that several interviewees “carried their deliberate forgetting far enough to be
amazed at times to remember their seropositivity.”320 It also appears T.B.J. refuses to identify
with her environment, the healthcare centre at which she lives, and its attendant culture and
support; another strategy for distancing herself from the virus and its effects. Through the
repetition of “I” throughout her artist statement, T.B.J. invokes her identity as separate from the
illness, its effects, and the care that she receives because of it; the definitive message of her
monograph emphasizes that this is not her, this is not her life. She clearly feels trapped by her
illness, unable to walk and remove herself from her present situation, but simultaneously refuses
to blame herself for the condition and the anger and pain it has caused her. This resistance to
blame is in itself a rejection of the rhetoric and discourse around HIV/AIDS, particularly in
regards to women.

The physical construction of T.B.J.’s doll is an interesting contrast and reflection of the
feelings expressed in her monograph. The doll stands quite stiff and straight, her arms straight at
her side and her face staring blankly at the viewer. While many of the other dolls are elaborately
decorated, particularly in feminine ways, T.B.J.’s doll is rather plain and unadorned. She even
lacks a mouth and nose, a lack that is, interestingly, reflected in many of the other dolls whose
monographs express depression, anxiety, and apathy in regards to the virus. While other
participants who are also confined to wheelchairs often constructed their dolls to reflect this
reality, T.B.J.’s doll stands straight up. Nevertheless, she lacks shoes or any other objects that
would indicate her being “out in the world” in any sense. Consider this in contrast to another doll

320 Squire 64.
that expresses similar sentiments, *DeeDee* (fig. 6.6), created by an unknown maker who also lives at Rivington House. Her monograph reads, “I wish to live outside the nursing home. I want my own place but I take so much meds every day. I’d like to get up and go but I can’t.”321 While both women clearly indicate a desire for physical, and hence personal, agency, *DeeDee*’s physical construction reflects this in a way that T.B.J.’s doll does not. *DeeDee* wears shoes, a dress, a purse, and a hat in matching colours, as well as a broach and earrings, almost as if she were about to embark on a shopping expedition. Her limbs are arranged in a more active position, her hair and clothing are bright, and she generally appears more engaged, ready, and active that T.B.J.’s doll.


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The contrast between the monograph and the physical construction of T.B.J’s doll might be read to suggest a rejection of her current lifestyle and illness (through, for example, her refusal to put her doll in a wheelchair), as well as a refusal to project her wishes and hopes onto her doll (through, as is the case with many of the dolls, the elaborate construction of costumes that indicate agency, femininity, beauty, and so forth, elements the participants often feel they lack). Because the STITCHES Doll Project is often enacted as an opportunity for participants to express their anxiety and fear, hopes and dreams, we might read this refusal to live out her desired life through her doll as, in part, a rejection of the Project itself. This, in turn, can be read as a further rejection of the illness. To admit to the validity and helpfulness of the STITCHES Doll Project is to admit to her illness and its effects on her, requiring an acceptance that this is her life and a part of her identity which, I would suggest, T.B.J. would like to avoid.

B. Wilson’s doll (fig. 6.7), *African Queen*, is an interesting instance of refusing HIV/AIDS and its associated culture and discourse, and might be read in a similar way to T.B.J.’s doll. Where the monograph would normally appear, it reads, “When asked what her doll would say if she could talk, Wilson replied ‘Nothing’. And yet, the physical construction of the doll speaks volumes. The doll holds a unique stance, one of her arms proudly jutting out from her hip and the other held up in a defiant position. The doll’s title, *African Queen*, reflects a pride in both Blackness and femininity, and, when read in relation to the body language of the doll, clearly indicates a political position. While her face is left blank, without mouth or nose, perhaps reflecting her refusal to speak, the doll takes up a position of resistance. Perhaps her refusal to speak about her illness and its effects indicates a desire for self-sufficiency and self-containment. This refusal can be read, not unlike T.B.J.’s doll, as a rejection of the illness, a degrading and eroding force physically and culturally, as well as of the STITCHES Doll Project, which seeks to engage participants in discussion about the effects of the illness. Ultimately, it seems, Wilson’s doll is resistant to the stigma associated with HIV/AIDS and Wilson refuses to engage in a discussion about it. In an interesting contrast to many of the participants who share their experiences with the audience, and affirm identity in this process, Wilson gains her sense of pride, independence, and self by refusing to do so.

We might also link this refusal to speak about her experiences of HIV/AIDS to a rejection of racist discourses surrounding the illness. For example, as Evelynn Hammonds points out, “[a]nthropologist E.J. Sobo argues that community-level HIV/AIDS risk denial among African-Americans is part of a self-protective strategy adopted in the face of racist finger-

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pointing and blame laying; therefore, risk denial is essential for maintaining group pride.”

Sobo’s suggestion here is that African-American communities use strategies of denial and refusal to counteract racist discourses surrounding HIV/AIDS and reaffirm a sense of self. We might read Wilson’s refusal to speak as a refusal to engage with, or respond to, these racist discourses, as well as a strategy for surviving in a culture that characterizes her as inherently dirty and dangerous because of her race. Indeed, the STITCHES Doll Project itself, when viewed in relation to, and enacted within, this racist culture might be viewed and/or experienced as an opportunity for Black women and other racial minorities to “come clean” about their “sins” publicly. While this is likely not the intention of the founders or the workshop leaders, the confessional form of the Project forces individuals into a position where they can be morally evaluated. It seems possible that, in such a racist culture, this is a dangerous position for individuals who are not white and are subject to racist understandings of their contraction of HIV. We might read Wilson’s refusal to speak as a refusal to be socially and morally evaluated in a cultural climate that is fundamentally hostile to her.

However, we might also ask why both women made dolls at all if they, even in part, wanted to reject the STITCHES Doll Project and the opportunity to express their sentiments about HIV/AIDS. While we can only speculate as to why they chose to participate, I would suggest that the dolls provided an opportunity to articulate that rejection in a way that refusal to participate in the Project would not. The deliberate choice to say “Nothing” about HIV/AIDS, as

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323 Hammonds 119. Hammonds goes on to explain that “Sobo’s analysis focuses on the narratives that poor inner-city African-American women construct about risks. She identifies two important ones. The first she calls the ‘wisdom narrative’ where African-American women try to maintain their ability to identify ‘clean’ (i.e. disease free) and upstanding male partners. The second is the ‘monogamy narrative’ in which African-American women describe an idealized, monogamous, heterosexual union which they use to deny the infidelity of their partners and promote their own self-esteem. These narratives indicate that risk for HIV/AIDS for African-American women is constructed within the context of African-American culture. Rather than risk denial, these poor African-American women are trying to construct an image of themselves in relation to their male partners that allows them some agency and self-esteem while locating
a woman who is both severely affected by the illness and a committed member of HIV/AIDS activist groups, is quite a powerful choice. Such a choice, however, needs to be made visible for it to have the kind of power it is intended to have. Consequently, participation in the Project and the creation of a doll that refuses to speak is necessary for Wilson to assert her power by exemplifying her ability to choose to speak or not. This operates to reestablish a sense of self and agency. Similarly, T.B.J.’s refusal to accept her illness, its effects, her environment, and the STITCHES Doll Project, allows her to distance herself from the illness and thus assert her power in determining who she is. Both dolls indicate how acts of refusal and rejection can be integral strategies for reasserting a sense of self and a sense of identity. By constructing these dolls, participants are able to put strategies of refusal and rejection into action.

Experiencing Illness and Death as Sacrifice

Another method to remove the threat to identity HIV/AIDS poses is through experiencing illness and death as sacrifice. Individuals may frame their illness as a sacrifice so that others can learn from them, so that others can be spared, or as a sacrifice to God’s plan. In each case, individuals transpose the illness into a larger narrative and position their own illness as a meaningful part of system greater than themselves. In the case of the STITCHES Doll Project collection, participants who used this strategy often reinterpreted their contraction of HIV/AIDS as a sacrifice for humanity, including their immediate family or humanity at large, or as a sacrifice to God’s plan or will. This strategy is an informative contrast to the previous two tactics for re-establishing identity. Both sharing the illness, and rejecting or refusing it, operate by eliminating and removing the threat HIV/AIDS poses to identity. In the case of experiencing illness and

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themselves within the dominant category of woman. To use Gloria Anzaluda’s term, they are ‘making face,’ constructing identities” (119-20).

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death as sacrifice, participants still experience HIV/AIDS as a threat to identity, but only insofar as it threatens a cultural construction of identity as individualistic and consisting in an achievement of mental control over the body. In other words, those who understand their illness as a sacrifice locate identity as being founded in a social or metaphysical relationship rather than in the maintenance of a self-sufficient, solipsistic self. This cultural construction of selfhood is rejected in preference for a framework that positions identity as a function of one’s relationships with others, not one’s control over self. As a result, participants who utilize this strategy often end up embracing the illness on the basis that it grounds this alternative account of identity by placing one in a meaningful social or religious relationship. Consequently, the initial experience of HIV/AIDS as a threat to selfhood is replaced by an understanding of the illness as, ultimately, valuable and positive. The following explores several dolls and the way they affirm identity by interpreting the illness as a sacrifice for others or for God. I go on to explore how this relates to gender performance and suggest that part of the appeal for such a sacrifice may be wrapped up with notions of femininity and its associations with martyrdom.

**Illness as Sacrifice for Humanity**

Experiencing one’s illness as a sacrifice for the rest of humanity, or for one’s family, is a common strategy both within, and external to, the STITCHES Doll Project. Often participants in the Project express that their contraction of the illness will enable others to learn from them and consequently to lead their lives with both care and passion. Gerus-Darbison has found that “(s)o many women speak about the desire to educate and spare others the suffering and shame they have gone through.”325 Within this framework, the dolls are viewed as pedagogical tools that

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325 Gerus-Darbison, “Creative Expression.”
provide participants with an opportunity to share their stories and wisdom in a context that is less threatening than face-to-face encounters. In both cases, some individuals take this understanding a step further, suggesting that their contraction of the illness ensures that others won’t have it, as if she were directly replacing someone who would have contracted HIV/AIDS. The dolls can function as public concretizations of this sacrificial process by enabling participants to overtly name the (ethical and/or religious) significance of their illness. By understanding themselves as martyrs, individuals who use this strategy are able to make sense of their illness, give it meaning, and thus re-establish their life as meaningful.


Terri Wolters’ doll (fig. 6.8), *Angel Unaware*, and its attached monograph, poignantly express how understanding one’s illness as a sacrifice for others can function to ground identity.
and meaning for a person with HIV/AIDS. Unique to the collection, Wolters’ doll understands her illness as both a sacrifice to others and to God simultaneously. Wolters’ monograph reads,

She shows the Christian life
I had always lived.
If my ex-husband (a minister)
and I had never divorced,
I would never have this illness.
But I would rather I had this
and be an example to others.
And, so my 3 sons will always
take precautions.326

This doll’s monograph expresses Wolter’s unique understanding of her illness in relation to both her family and God. Through the use of “had” in the second line, her monograph implies that she was, but is no longer, a good Christian, and she suggests that this change was a causal agent in her contraction of HIV/AIDS. Her mention of her husband’s position as a minister makes this “straying” from the Christian faith even more stark. This religious tone is reflected in the doll itself, depicted as an angel with a simple smile and no adornment beyond the cross next to her heart. She is clad in simple black and white, in reference to her faith, and long feminine curls fall on her shoulders. She holds her hands together in front of her and looks straight out at the viewer with innocence and peace, a peace which is, the title implies, a function of her ignorance. The angel’s lack of awareness presumably refers to the participant’s ignorance about the risks of HIV/AIDS and the fate that awaited her when she divorced her husband.

In this context, she states that she would rather have the illness than not, insofar as her experience will help others, specifically her three sons. Interestingly, framing her illness in this way allows Wolters the sense that, as a result of the disease, she is recuperating her faith by sacrificing herself for others, not unlike Jesus. The thought appears to be that through martyring

herself, Wolters is able to, ultimately, save her sons. This understanding, however, involves a strange twist of logic insofar as it presumes that her sons couldn’t or wouldn’t have taken precautions if she had not contracted the illness. This is based on the (mistaken) presumption that people need to witness suffering to avoid risk-taking behaviour, which is certainly not always the case. Indeed, most HIV/AIDS awareness programs are based on the premise that individuals can avoid such behaviour by learning about it, and that witnessing its effects is not a necessity. Wolters’ ability to avoid this logic, however, testifies to her need to make sense of her illness within this framework and give the illness, and hence herself, meaning and substance. Through the doll, Wolters is able to publicly attach religious meaning to her illness, and thus to herself and her actions, enabling her to recover a sense of self by positioning herself as part of a larger religious and sacrificial project that she enacts through HIV/AIDS.

Marlena McLendon’s doll (fig. 6.9), *Mother*, also reveals how this participant positions her identity as a function of her sacrificial relationship with others, though she does not frame this sacrifice religiously. In the space where her monograph should be, it reads, “(w)hen asked what her doll would say, she said, ‘Protect’.” The simplicity and earnestness of this statement is reflected in the doll itself, which sits straight-faced and largely unadorned, reflecting the gravity of the task of protection. Her arms wrap affectionately around the baby in her lap, swathed in blankets. Not dissimilar from Wolters, McLendon uses the creation of the doll as an opportunity to position her illness as significant in relation to other. McLendon’s instruction to “protect,” when analyzed in relation to the title of the doll, *Mother*, implies that mothers need to protect their children from the illness. Insofar as doll-making is an opportunity for women to express their own experience of the illness, McLendon’s choice to focus on others instead of herself reveals that she is willing to give up her stories, and thus herself, in the face of the lives and needs of others. Insofar as this is perhaps one of the only opportunities McLendon has, or will take up, to speak about her illness publicly and in a safe context, this is quite a sacrifice. In short, she sacrifices an explanation of her own woes for the opportunity to warn mothers about the need to protect their children. Because she sacrifices her story and thus her identity, McLendon implies that her illness and its effects are meaningful insofar as they can help others who can learn from her. It is here that her identity is grounded, in her relationships with others. Her articulation of this relationship is, in some ways, even more pronounced in her case than Wolters’ because McLendon refuses to reveal any details of her experience of illness and instead focuses entirely on sending a message to others.

**Illness as Sacrifice for God / Spirituality**

Some women, including some participants in the STITCHES Doll Project, understand their illness as a sacrifice to God’s plan; God, him or herself; or spirituality in general. For example, the conception that HIV is contracted “when God calls” is a common risk factor as well as a barrier to healthcare services, for Asian Pacific Islander women.\(^{328}\) Similarly, Squire’s interviews with individuals with HIV/AIDS revealed that some interviewees “described a journey towards ‘owning the virus’, or a spiritual enlightenment that rendered HIV irrelevant.”\(^{329}\) Interpretations of the illness as a form of religious sacrifice are common in the doll collection. S.M.’s monograph, for example, reads, “[a]nd I hope that I am on a journey / And when my destination arrives / God will call my name / And I will be waiting so patiently.”\(^{330}\) Such conceptions of HIV/AIDS as being part of a spiritual path or the result of God’s will enable individuals with HIV/AIDS to give their illness meaning and reestablish themselves, and their identity, in relation to that meaning. A majority of the dolls in the STITCHES doll collection, at a minimum, reference God, God’s plan, or the need for faith. Patrice Junell Joseph’s doll, *Success Story* (fig. 6.10), is an excellent example of situating all meaning around the illness, one’s life, and one’s identity in relation to God. Joseph’s monograph reads, “I haven't given up the fight. God has all power. Jesus has the strength, courage and wisdom that I'll inherit since I've given up my will and am seeking God's will for my life.”\(^{331}\) This monograph expresses value, agency, and selfhood as an emanation of God’s will, and thus neutralizes the threat to self that HIV/AIDS poses by viewing it as inconsequential in comparison to the workings of the divine.

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\(^{329}\) Squire 64.


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Other participants in the STITCHES Doll Project employ exceedingly creative strategies for understanding their illness in relation to a metaphysical or spiritual belief system. Deb Runions’ untitled doll (fig. 6.11) is one of these. Though her monograph is lengthy, it is worth including here because of its wealth of meanings. It reads,

She walks on a path winding and full of changes but wide enough to accommodate friends.

The girl has no knowledge of strangers – only magicians. She carries the world in her hand; he holds mysteries in his pocket. Sometimes they journey alone, sometimes together.

Her cup of security is priceless – encrusted with the jewels of family, washed in the silver and gold of friends. They are her Holy Grail.

The key of wisdom she wears around her neck resting near her heart for it is the Key to Heaven and the kingdom is within.

Water of grace, the girl bears it in pots fashioned from the healing clay of mercy; she submerges herself in the black depths of mystery and walks on that ocean’s bottom, maintaining her life by breathing the air of forgiveness innate to the Creator’s womb.

She meets the bear of romance with respect. Pulling berries from her pocket, she offers a gift. Standing bear sings her the song of power and they part.

The Cobra lays coiled in the center of her path. She kneels humbly before it, honoring the mystery and power it possesses. The serpent strikes her heart, but only lightly grazes her skin as though anointing her with a kiss.

The wall of death is high and deep, but transparent. She sees into the world beyond and is not afraid. Laughing, she drops the cloth of flesh and dons the feather fabric preferred by Spirit. Without restriction her soul flies.

Following the monograph, Runions states that her message is “AIDS is here to heal – not just those of us who have the infection but American society as a whole.”


Immediately, the doll and its monograph stand out from the collection because of their unique positioning of HIV/AIDS as valuable, transformative, and ultimately the beginning, rather than the end, of meaning. Interestingly, the monograph does not reference the illness at all, and “the girl” referred to in the monograph approaches death not with fear but with exuberance and joy. Throughout her “journey,” she is an agent in the world and respects what she meets, refusing to destroy it. HIV/AIDS, in this narrative, is subsumed into a journey of life and is a facilitator of a variety of powerful and meaningful experiences. The experience of the illness and death are not rejected but embraced by Runions, and seen as beautiful. Her identity is enriched by the experience of the illness because she refuses to seek control over her body, mind, or the world at large. Indeed, the doll itself is overwhelmed by objects from the natural world, particularly feathers, which cover her body. Little clusters of fruit are attached to her feet, and a black ribbon winds its way around her legs. She is naked but for these feathers and mementos. The doll’s body ultimately becomes part of these objects, part of the external world, and she gives up jurisdiction and control over it. By refusing to construct the body of the doll in a way that makes her human form particularly visible, Runions shows a clear preference for understanding the human body and human life as part of a larger natural and spiritual world. The identity of the doll and participant are ultimately grounded through their relationships with these worlds. This understanding of identity as not requiring self-control and maintenance allows Runions to neutralize the threat to identity HIV/AIDS poses, a threat that is so potent for others.

*Martyrdom and Femininity*

Martyrdom and sacrifice are gendered, particularly in relation to the HIV/AIDS epidemic in the United States. Femininity in the U.S., and specifically in the context of the HIV/AIDS pandemic, is deeply linked with the expectation that women be caregivers and sacrifice their physical,
emotional, and vocational needs for their family and children. Katie Hogan’s text, *Women Take Care*, explores how the cultural construction of women as caretakers, combined with the construction of HIV/AIDS as a male disease, has resulted in a culture in which women’s fundamental position is to take care of others. Hogan suggests that this often puts women in a place where they are encouraged to be the “moral compass, to encourage others to respond to the afflicted with compassion, and to care for the physically ill.”334 Because gender performance is so wrapped up with identity, and identity is under erasure when individuals are afflicted by HIV/AIDS, one way women in the HIV/AIDS crisis reclaim their identity is by performing gender with (more) commitment and efficacy. This is to say, women are able to more firmly establish their identity if they determinedly establish their femininity, which is, in Western culture, wrapped up with maternal sacrifice. Indeed, taking up the role of mother, especially a sacrificial mother, is a very successful strategy for affirming femininity and thus identity. As Joy Barlow suggests, “[a] woman may regard becoming a mother as an important aspect of how she sees herself and her future, reinforced by societal influence; motherhood may enhance self-esteem or may be culturally expected.”335

334 Hogan 20.
335 Joy Barlow, “Social Issues: An Overview,” in *Working with Women and AIDS: Medical, Social, and Counseling Issues*, eds. Judy Bury, Val Morrison, and Sheena McLachlan (London and New York: Routledge, 1992) 25. Barlow argues that “(i)t is not unusual for a person infected by HIV and AIDS and his/her partner to have an overwhelming desire to leave behind some creation, and a child symbolizes this need” (25). Indeed, we might read the dolls themselves as symbolic children.
Such a reclaiming of femininity, through motherhood, sacrifice, or both, is important, given the degree to which HIV/AIDS can erode the physical and social markers of femininity. As Barlow suggests, women with HIV/AIDS may not wish to mix socially because they feel too upset or embarrassed about their physical appearance. Women may be affected by this more than men. The social proscriptions and myths about women’s appearance and physical condition may cause many aspects of women’s bodies, well or ill, to become sources of discomfort, pain or sorrow for them.336

The erosion of femininity characteristic of HIV/AIDS in this cultural context is reflected in many of the dolls. Many dolls either express the women’s estrangement from their femininity, sexuality, and body, or are assembled in (stereotypically) feminine ways. Indeed, dolls that are not especially feminine are the exception in the STITCHES Doll Project collection. Consider, for

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336 Barlow 25.
example, Susan K. Brasel’s doll (fig. 6.12), *Pink Lady*, which is extremely feminine in nature. The doll’s costume is delicate and detailed in various shades of pink, and is adorned with frills, bows, sparkles, and rosebuds. The doll wears pink lipstick and tiny pink pearl earrings, as well as little pink slippers. Her delicate hat sits on top of curly blonde hair. The only indication of HIV/AIDS or illness is the small cane she holds and the AIDS symbol carefully wrapped around one of her wrists. While Brasel’s doll stands out for its exceptionally feminine construction, markers of femininity are common among the dolls, including the representations of delicate faces and features, the addition of jewellery, as well as the use of pink, bows, flowers, feathers, dresses, and long hair. Such visual constructions often stand in contrast to the attached monographs which regularly refer to the physical erosion caused by the illness. For example, a doll titled *Fancy*, made by an unknown participant, has a monograph that reads, “[m]y name is ‘Fancy’. At least that is the way I used to feel when I was getting ready for a night out on the town with my friends. Now, since this miserable virus has invaded my space/body, feeling and looking ‘fancy’ is the least of my concerns. All I feel now is old, used up, useless, and ugly.” Such expressions are quite common among STITCHES Dolls’ monographs.

Without a doubt, these dolls express that the erosion of femininity is inextricably bound up with the erosion of identity, and that the recovery of one is often bound up with the recovery of the other. As a result, dolls are often constructed in overtly feminine ways in an effort to recover identity. We might read the construction of the illness as a sacrifice for others in a similar way. If women with HIV/AIDS are able to reaffirm their femininity by positioning themselves as martyrs, particularly in a maternal sense, then they are able to achieve an appropriate social performance of femininity, and thus to reestablish a (feminine) selfhood that

has been under erasure. While it is important to avoid homogenizing how these women come to view their illness as sacrifice, and how this relates to their relationship with their gender(s), it is useful to point out that one impetus behind performing martyrdom is the reestablishment of gender, and thus identity.

These strategies for re-establishing identity, though inventive and often effective, are also partial and prone to erosion. While this chapter has focused on the ways in which doll production can successfully re-establish identity, doll production does not occur in a vacuum and participants do not (wholly) control the discourses and contexts that doll-making occurs within. Participants must negotiate cultural discourses and codes surrounding art and craft production, discourses that affect how they (and others) perceive the creation of their doll, and thus how they use doll-making to recover identity. Further, these codes and discourses shift as the dolls shift contexts, specifically as they shift from the location of production to that of the doll collection and display. The next chapter explores how these cultural codes, discourses, and institutions affect the meaning and value of the dolls, and the relationship this has to participants’ capacity to reestablish identity. I specifically focus on the ways in which identity can be eroded for participants as a result of the Project’s design and relationships to discourses and codes surrounding artistic and visual culture.

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Chapter Seven
Dropping the Thread: Creation and Reception Issues

Dolls That Erode Identity

Whoever is committed to questioning the representational determinants of AIDS . . . will have to go on to ask . . . to what extent that demystificatory gesture itself, however progressively conceived, plays unwittingly into the same public spectacle that it sets out to critique.

Gabrielle Griffin Representations of HIV and AIDS: Visibility Blues, 2001

As Gabrielle Griffin suggests, “representation is both about cultural (re)production and imaging, and about the desire to create a presence, to achieve visibility and recognition, to participate, including in public debates and fora.” As has been explored in chapter five and six, this has been particularly true for art responding to the HIV/AIDS pandemic in the United States. Chapter six explored the ways in which participants in the STITCHES Doll Project sought to achieve presence and affirm selfhood through the creation of dolls that reflected their experiences of HIV/AIDS. I argued that there were a number of strategies used by participants to recover identity, and that these strategies were often intricate, complex, and, ultimately, successful. In contrast, this chapter investigates some of the Project’s attributes that function to destabilize and dissolve the sense of self that the Project aims to shore up for participants. Specifically, I argue that there are three ways that the Project’s design produces creation and reception issues; issues that can operate to erode identity development. While designed to recuperate identity, it runs the risk of taming the illness through the dehumanization of participants, of homogenizing and simplifying participants’ identities and experiences, and of facilitating a loss of power and agency for participants as a result of display and collecting practices. Each of these risks is generated by

340 Griffin 54
the discursive construction of the dolls as metonyms for the women who created them. While elements of the Project may challenge and erode identity for participants, it is not my suggestion that this is uniformly the case, or that these issues affect all participants in the same way. Nevertheless, I argue that certain dimensions of the Project may stunt identity-development for participants and, in some cases, exacerbate identity loss. It is my suggestion that this exacerbated loss of self is, for the most part, painful and problematic for those who experience it.

**Taming the Beast: Dolls that Tame and Dehumanize**

I first viewed several of the dolls from the STITCHES Doll Project collection at the University of Windsor’s Feminist Research Group Graduate Conference in May of 2008. It was, by far, the most popular display. Throughout the weekend, Ms. Gerus-Darbison’s display table was constantly populated by attendees who were enthralled by the dolls and wanted to engage with them, including myself. With all of the interesting feminist research on display that weekend, why were the dolls so exciting for so many of us? What kept bringing us back?

I would suggest that much of the interest the Project received that weekend was a result of the aesthetic appeal of the dolls, and how that appeal functioned for the viewer. This appeal is in part drawn from how the dolls function to tame HIV/AIDS, and the bodies who carry it, bodies that have been constructed as threatening, dirty, defiled, abject and deviant. This taming of the defiled may be one of the reasons viewers are so fascinated by the dolls, especially because this taming puts viewers in a distinctly powerful, voyeuristic position. Insofar as the dolls are understood as being these women, those viewing the dolls are able to get close to sites of pollution and abjection without risking face-to-face contact with those who actually suffer from the illness. Such proximity can satisfy the voyeuristic urge to witness death and disease while

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341 Griffin 4.
maintaining ostensible distance and safety. Indeed, because the dolls are seen to embody their creator, the display of the dolls allows viewers to metaphorically explore the diseased bodies of these women without fear of reproach, discipline, or contraction of illness. Insofar as the dolls, and hence women, are made passive and vulnerable through this display process, the threat these bodies pose because of their illness is made visible, controllable, and thus is, in part, neutralized. The passivity of the dolls/women is further strengthened by the dolls’ miniature size, allowing the viewer not only visual power but physical dominance. This affords the viewer an imaginary conquering of these bodies and their illness, as well as a sense that one is accomplishing this conquering by merely looking. As a result, bodies that are experienced as culturally threatening are made visible, miniature, silent, passive, and tame through the display of the STITCHES dolls.

The process of giving up one’s doll for display is itself an act that participants may experience as eroding of agency and control, and thus of identity. While chapter six explored how the act of giving the doll away can function to remove illness and death for the participant, it is also the case that, if participants attach a strong sense of self to the doll, the act of giving it up could function to undo the identity development the Project initially facilitated. Specifically, if the participant firmly embodies her identity development in the doll, the act of giving it up for interpretation and scrutiny may make the participant feel powerless and as though they are on display. This is a distinct possibility insofar as identity in the West is often concretized through the collection of objects and possessions. Indeed, C .B. Macpherson argues that the emergence of the self as owner, ideally surrounded by accumulated goods, emerged in the West as early as the seventeenth century. As James Clifford suggests, “[s]ome sort of ‘gathering’ around the self and the group – the assemblage of a material ‘world,’ the marking-off of a subjective domain that is not ‘other’ – is probably universal . . . In the west, however, collecting has long been a strategy
for the deployment of a possessive self, culture, and authenticity.”  As both Macpherson and Clifford point out, the desire to hold on to objects that one understands as central to selfhood is both common and culturally expected in the West. Consequently, participants in the Project may elide their identity with the doll itself and thus feel a strong desire to keep it. As a result, the giving away of the doll may be experienced as an event that is both painful and eroding of identity.

In many cases, the viewer is also given access to the “dirty secrets” of participants, enabling a further potential for examination. As was suggested in chapter six, the confessional form of the Project forces participants into a position where they are encouraged to share their secrets, secrets that can then be morally evaluated by viewers. This puts viewers in a powerful position insofar as they can inspect the dolls/women without fear that they will be asked to account for themselves and their position in the pandemic. Emmanuel Levinas condemns artwork as unethical on this basis, arguing that artworks cannot take the viewer hostage, cannot ask the viewer to account for herself, in the way that a face-to-face relationship can. Central to this conceptualization is the fundamental passivity of the artwork, of which he writes, “[t]he [art] work does not defend itself against the Other’s Sinngebung, and exposes the will that produced it to contestation and unrecognition; it lends itself to the designs of a foreign will and allows itself to be appropriated.”

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342 C. B. Macpherson quoted in Clifford 217.
343 Clifford 218.
344 While this may be true, it is also not necessarily the case that this secret-sharing is problematic for participants. See, for example, Kate Bisset and Jennifer Gray, “Feelings and needs of women who are HIV positive,” in Working with Women and AIDS: Medical, Social, and Counseling Issues, eds. Judy Bury, Val Morrison, and Sheena McLachlan (London and New York: Routledge, 1992) 125-34. As Bisset and Gray suggest, “for most people, sharing the secret [of having HIV/AIDS] can bring immense relief and they can move from a powerless and fragmented position to a more consolidated whole self from where they are able to make changes” (131).
345 Levinas 227.
colonization, which, he fears, can replace the ethical relation, or be mistaken for it.346 This, I believe, is something worth worrying about with regards to the STITCHES Doll Project. In the case of the STITCHES Doll Project, viewing and inspecting the (passive) dolls replaces a face-to-face conversation that could occur between participants and viewers. Insofar as the dolls are thought to “speak for” these women, there is a sense in which participants’ actual voices are, ultimately, redundant. In this context, face-to-face contact and discussion about the personal and political reality of HIV/AIDS is made superfluous. Indeed, Susan Stewart makes a similar claim with regards to the modern Western museum, in which, she argues, “an illusion of a relation between things takes the place of a social relation.”347 Consequently, the design of the STITCHES Doll Project may inhibit or preclude face-to-face relationships and conversations, substitute participants’ with their dolls, and thus allow viewers to explore the bodies of these women without having to acknowledge their humanity. This is a dehumanizing process for creators and can operate to stunt identity-development processes.

The docility and vulnerability of these dolls is, in part, a function of how dolls themselves are understood culturally. In the West, dolls are conventionally understood as objects of comfort, objects which display and teach gender norms, objects for play, or objects to be collected. Female dolls, which make up the vast majority of dolls in the West, are almost exclusively pretty, feminine, and child-like. Participants in the STITCHES Doll Project are undoubtedly faced with this cultural understanding of the meaning, function, and aesthetic of dolls. As a result, there is pressure on participants to create dolls that are feminine and juvenile, a pressure that is further entrenched because of the need to reclaim femininity in light of the physical destruction HIV/AIDS causes (as explored at the end of chapter six). The expectation that dolls need to be

346 Levinas 227-8.
347 Stewart quoted in Clifford 220.
both simple and uplifting might account for a large sector of the dolls whose monographs consist of statements like: “Life is Good!” or “Getting an HIV test is a win-win situation.” Similarly, almost all the dolls exhibit no visible signs of illness, and if they were stripped of their context and monographs, could easily pass as conventional, feminine dolls without particular significance. Such statements and methods of decoration are implicated within larger cultural discourses around both dolls and contagious, sexually-transmitted diseases. Unquestionably, constructing dolls and monographs in this way requires a variety of repressions that enable the participant to create a product that is enjoyable for the viewer and (perhaps) herself. If participants simplify and distort their experiences out of the desire to conform to societal expectations around dolls, consciously or unconsciously, this results in the creation of objects that do not actually speak for the participant or about her experience of HIV/AIDS. This has two results. It tames the illness for the viewer, and thus fails to convey the experiential and political reality of HIV/AIDS. Second, it prevents the participant from using the doll to reaffirm a sense of self.

Dolls that Homogenize and Simplify

As much as the STITCHES Doll Project can and does develop socially supportive environments for women with HIV/AIDS, it may also be a site where individual experiences of the disease are given up or sacrificed to accommodate a group understanding of the illness. This process is particularly common in groups which have been stigmatized and oppressed, such as those with

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349 See Douglas Crimp quoted in Dykstra 19. Crimp points out that “the discursive systems of the institutions in which artworks circulate have an enormous effect on how those artworks are understood” (19).
HIV/AIDS, and can result in identity formation that is precarious or harmful for group members. As Jean Dykstra suggests,

Cultural imperialism develops when the dominant culture defines some group as “other” and the members of that group become imprisoned in their own bodies that are defined as ugly, dirty, defiled, shamed, impure, contaminated or sick. Members of the marked group then internalize the attitudes of the dominant culture, while simultaneously maintaining a positive identification with others in their group, forming a double consciousness that leads to a fragile, shifting subjectivity.350

Insofar as the STITCHES Doll Project facilitates social communities based on shared experiences of illness, suffering, and oppression, and encourages participants in these communities to share their stories in identical ways (i.e. through doll creation), it runs the risk of missing or disciplining divergent accounts of the illness, as well as homogenizing these women’s experiences and lives. Because these groups are formed around the experience of illness, social identity may also become predicated upon illness such that participants begin to define themselves through their HIV status. As a result, individuals who are less ill may be seen as less valuable community members and subsequently experience social exclusion. This suggests that Project workshops may require a variety of repressions and exclusions to achieve unity, solidarity, and homogeneity among participants. Biddy Martin and Chandra Talpade Mohanty claim that such repressions are endemic to being “at home” with others, and that the search for home is always “challenged by the realization that ‘unity’ – interpersonal as well as political – is necessarily fragmentary, . . . it is not based on ‘sameness,’ and there is no perfect fit.”351 Indeed, they point out there is a tension between the desire for sameness and synchronicity, and “the realization of the repressions and violence that make home, harmony, sameness imaginable, and that enforce it.”352 Thus, the

350 Dykstra 23.
352 Martin and Mohanty 310.
STITCHES Doll Project might be criticized on the basis that it forces a shared experience for participants, and that this constitutes a kind of violence. Further, it is worth noting that even if a healthy community is achieved through the Project, community is never a perfect solution for the panic around HIV/AIDS, as Corinne Squire discovered in her interviews with HIV+ individuals.353

Doll-construction also requires a simplification of selfhood that may be experienced as problematic. Participants are forced to choose one of several versions of themselves to concretize through the doll, a choice that can be extremely difficult, especially if the participant sees the doll as a projection of who she wants to be in the future. Participants have to navigate past selves, private identities, political experiences, contradictory feelings, and hopes for the future, to determine how to construct the doll. Inevitably, any construction will leave parts of oneself out, and for some creators what is left out may significantly impede her ability to reaffirm a strong sense of selfhood. Indeed, this might be a reason to offer participants the opportunity to make more than one doll. Similarly, because the fabric dolls that are supplied are all identical, they cannot accommodate artists who want to create dolls with a different physique, or feel that the dolls do not reflect their own perception of their body. While the dolls do differ racially, it is often the case that Black women receive white dolls or vice versa, so there appears to be no particular allocation of dolls based on race. Though we cannot presume that this is necessarily an issue for participants, it is certainly a possibility that both of these aspects of the Project’s design make it more difficult for participants to identify with their dolls, and thus to use them to reestablish identity.

353 Squire 63.
Losing Control, Losing Power: The Doll Collection

The way in which collecting and collections function culturally and historically is not politically neutral or innocent, but is “tied up with nationalist politics, with restrictive law, and with contested encodings of past and future.”\textsuperscript{354} Collecting practices in the West are often, if not always, wrapped up with the desire for cultural development, immortality, and a place in history.\textsuperscript{355} To explain contemporary collecting practices, James Clifford has produced a diagram, which he has titled the “art-culture system” to account for the classification and meaning attributed to objects as they circulate within collections and human culture (fig. 7.1). Within this system, there exists four distinct “semantic zones” in which objects fall: (1) the zone of authentic masterpieces (specific to the art museum and market), (2) the zone of authentic artifacts (specific to history, folklore, ethnography, material culture, and craft), (3) the zone of inauthentic masterpieces (specific to fakes, inventions, ready-mades, and anti-art), and (4) the zone of inauthentic artifacts (specific to tourist art, commodities, curio collections, and utilities).\textsuperscript{356} Clifford argues that objects are attributed varying levels of authenticity and value depending on their position within this matrix, and that objects may move between and within zones depending on shifts in cultural and societal values and assumptions.\textsuperscript{357} Clifford suggests that, as objects move between zones, the value, meaning, and authenticity attributed to them shifts. This parallels Ruth B. Phillips and Christopher B. Steiner’s claim that “an object circulating the networks of world art exchange lies not in the properties of the object itself but in the very process of

\textsuperscript{354} Richard Handler quoted in Clifford 218.
\textsuperscript{355} See Clifford 216-30.
\textsuperscript{356} Clifford 223-4.
\textsuperscript{357} Clifford 223-4.
137
collection, which inscribes, at the moment of acquisition, the character and qualities that are associated with the object in both individual and collective memories."


Given that objects can move between the semantic zones that Clifford describes, and that such classifications operate to determine the meaning and value of these objects, as Phillips and Steiner explain, the question becomes: where is the STITCHES doll collection positioned in the

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“art-culture system,” and how does this positioning determine the meaning and value of its contents? I would argue that the doll collection is most obviously placed in zone (2), that of the authentic artifact. Zone 2 includes within its purview objects that are typical of the cultural collectivity that produced them, including anthropological, “ethnic,” or ethnographic objects, as well as objects classified as folk art and craft. Given the Project’s design, implementation, and discursive construction, the STITCHES doll collection is best understood within this zone, as a form of folk art or craft. The following explores how the STITCHES Doll Project’s position in the realm of folk art and craft affects its meaning and value. Specifically, I address how this classification and context affect understandings of the doll-makers, and how does this in turn affects participants’ ability to re-establish identity.

The category of “folk” either signifies “people imagined in to be preindustrial survivals, or, when one is not talking about Europe, the cultural practices of the Other . . . that have not been mass marketed.” Specific to conceptions of the folk are notions of “everyday life,” “genuine culture,” “craft culture,” and “community.” As Charles Keil suggests, “[u]nlike ‘primitive,’ ‘folk’ has only a positive, friendly meaning. The folk are not the oppressed whose revolution is long overdue, but the Quaint-not-quite-like-us, the Pleasant peasant, the Almost-like-me-and-you.” The authenticity and special status attributed to the folk by the bourgeoisie is a function of their perceived opposition to class society, specifically “modern industrial state-capitalist civilization.” As Phillips and Steiner suggest, “accompanying industrialization is the desire for

359 However, I would also suggest that the Project, or particular objects produced within it, may move into zone 1, that of the authentic masterpiece, depending upon the context in which it is placed, the ways in which it is discursively framed, and other mediating factors.
360 Clifford 223-4.
363 Keil 265.
364 Keil 264.
the local and the handmade.”

Interest in the folk thus in part stems from a deep nostalgia for the past and a longing for an escape from the modern. As Daniel Miller suggests, one of the most typical attempts to account for, understand, and/or reject (fractured) modernity, as well as provide the foundation for modern art’s forward historical movement, is the tendency “to look backwards to the image of a world lost, to the idea that there was once an integrated, cohesive, social totality which can be located historically.” Myths surrounding the folk embody this nostalgia for a time before commercial influence, a time that is imagined to be simpler, more cohesive, and more authentic.

The STITCHES Doll Project exhibits many elements typical of what is understood as folk art and folk culture. First and foremost, the Project’s workshops are deeply reminiscent of folk culture, especially feminine folk culture, including the sewing bee, crafting collectives, and quilt making. Indeed, Gerus-Darbison specifically compares the creation of dolls to quilt-making. Similarly, folk cultures are imagined to exhibit a preference for community over the individual, and in so doing reject the notion of the individual “artistic genius.” The apparent anonymity of the producers of cultural and artistic objects in folk culture is paralleled in the STITCHES Doll Project insofar as participants’ names and biographical information are often unrecorded. Similarly, the material culture of the Project also positions it within the history of folk art and craft production. This is done through the Project’s emphasis on the handmade quality of the dolls, specifically through its invocation of the notion of hand stitching in the

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365 See also Phillips and Steiner 10. Phillips and Steiner argue that “[s]uspicious of mass manufacturing and mass marketing and the desire to retrieve the authenticity belonging to the rare and the singular lost through the new modes of production . . . go back to the eighteenth century and have permeated . . . many domains of consumption from then until now” (12).
368 Kelley 427-9.
369 Gerus-Darbison, personal interview.
Similarly, the nomenclature used by Project founders and workshop leaders, such as “plain rag dolls,” also situates the material culture of the Project within the folk art realm. Indeed the choice to have participants create “rag dolls” as opposed to another type of doll, such as a porcelain, clay, or paper doll, indicates a real alignment with a lineage of feminine folk art and craft. The STITCHES Doll website re-emphasizes this connection by offering various craft objects for sale, such as cigar boxes, to provide financial support for the Project. These craft objects are described as “ONE OF A KIND, individually hand painted items,” a description clearly placing the Project within the realm of folk art and craft.

Insofar as the collecting of anthropological objects, including the collecting of folk art, enables “an imagined access to a world of difference,” part of the value of these objects is predicated on their perceived ability to enhance the owner’s knowledge, power, and wealth. The value of these objects is crucially linked to the belief that folk cultures are on the precipice of demise, and hence that access to these cultures and their cultural production is threatened. As Phillips and Steiner suggest, “[f]rom the earliest times of contact and colonialism to the present day, the worlds in which ‘ethnic’ arts are produced are said to have been teetering on the brink of extinction.” Fear around the looming death of creators and cultures has produced a collecting culture in which there is a real desperation to “collect before it is too late.” However, as Virginia Dominguez suggests, we can ask: “[t]oo late for what?” Dominguez argues that the

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370 This is particularly notable given the fact that the fabric dolls participants are provided with to decorate are actually mass produced and not handmade. This contradiction reveals the founders desire to situate this Project within the folk art and craft realm despite elements of the Project that are not consistent with this classification.


372 Phillips and Steiner 3.

373 Phillips and Steiner 19. Indeed, as Phillips and Steiner suggest, “[p]roducers, middlemen, and consumers have all capitalized in their own ways on this myth of imminent demise and on the frenzied act of collecting engendered by the fear of extinction” (19).

374 Douglas Cole quoted in Clifford 234.

375 Virginia Dominguez quoted in Clifford 234.
urgency around such collecting practices is a function of the belief that the loss of these objects
would mean losing the ability to preserve “our own historicity.” She argues that this belief
involves a twofold displacement in which

Objects are collected no longer because of their intrinsic value but as metonyms for
the people who produced them. And the people who produced them are the objects
of examination not because of their intrinsic value but because of their perceived
contribution to our understanding of our own historical trajectory. It is a certain view of
‘man’ and a certain view of ‘history’ that makes this double displacement possible.

Dominquez contention here is that within discourses surrounding the collection of
anthropological objects, the object comes to stand for the (disappearing) culture of origin, a
culture which is valuable insofar as it provides Western culture an opportunity to reflect upon its
identity, history, and future.

This understanding of collecting practices is significant in relation to the STITCHES Doll
Project because the rhetoric around the dolls echoes this need to preserve these objects/women
before time runs out. As was explored at the beginning of chapter six, the founders emphasize
that the Project will ultimately immortalize these women’s lives and experiences for the benefit of
future generations. Kathy Gerus-Darbison, for example, states that she developed the Project
with Candice Moench because they “did not want these women to die and their stories to die with
them. The dolls allow these women to live on and touch others.” This understanding of the
Project positions the value of the dolls as the result of their standing in for, and immortalizing,
these women. Indeed, we see that this is the very process to which Dominguez refers. Within
this framework, the women deserve to be immortalized because of their capacity to facilitate
reflection upon the larger political and social reality of HIV/AIDS, specifically how the
HIV/AIDS pandemic relates to our cultural identity and trajectory. Consequently, within this

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376 Dominguez quoted in Clifford 234.
context, the value of the dolls/women is a function of their relevance to a larger project of cultural development, not a function of unique and intrinsic value. While it is not my suggestion that the founders of the Project don’t believe these women to be unique and valuable, positioning the dolls as part of a pedagogical and sacrificial project that aims to concretize cultural identity can function to erase the individual uniqueness and value of the dolls, as well as the women who created them.

The act of collecting itself also functions to erase an object’s original social value and relation. If a collection “contains what ‘deserves’ to be kept, remembered, and treasured,” an object’s value and meaning is in part bestowed as a result of its inclusion in a collection. The degree to which the value or meaning of an object is a function of its being part of a collection presumably varies depending upon the object and context. Nevertheless, if this is the case, we might suggest that the inclusion of an object in a collection can actually operate to remove original social value by positioning it as valuable because it is in the collection, and consequently locating its value in relation to the other objects in the collection. Indeed, Susan Buck-Morss’ essay, “A Global Counter Culture?,” makes a similar argument in relation to art itself. She suggests that art has traditionally been framed epistemologically (i.e. what is art? what counts as good art? how do we value art?), but since Marcel Duchamp’s infamous urinal, the contemporary artworld has largely framed art ontologically (i.e. art is what artists do). In so doing, art becomes essentially powerless and meaningless insofar as “museums and other institutions of the artworld really do not care what they [artists] do . . . so long as it is done within the authorized,

377 Dominguez quoted in Clifford 234.
378 Gerus-Darbison, personal interview.
379 Clifford 231.
380 See Phillips and Steiner 19.
381 Buck-Morss 66-8.
Frederic Jameson makes a similar argument, pointing out that “there is very little in either the form or content of contemporary art that contemporary society finds intolerable or scandalous.” Dominguez, Buck-Morss, and Jameson all point to the fact that art is increasingly defined as art by virtue of its inclusion in artistic institutions or collections, and that this inclusion functions to powerfully redefine the object and its value.

Insofar as the STITCHES dolls value is in part predicated upon their inclusion in a collection of cultural and pedagogical importance, the dolls are evaluated and appreciated in relation to one another. Indeed, chapter six uses this very framework to evaluate individual dolls’ value and meaning through comparison and contrast. Such a methodology operates on the presumption of similarity between the objects in a collection, however minimal. While this methodology was useful for revealing strategies for identity development used by doll-makers, it simultaneously operated to establish the dolls as comparable and similar in nature. However, the dolls similarity and comparability is assumed by virtue of their inclusion in a single collection. Thus their inclusion in the collection is the condition for believing in some (basic) similarities, not vice versa. This reveals that collections, in this case and others, can function to elide objects with each other, positioning the objects’ value as relational in an effort to consolidate a historical or philosophical construction of cultural identity. This replaces the original social relation and value of the object, which is located in the context of production. For individual doll creators, such a process can operate to reverse the reestablishment of identity that the creation side of the Project may have facilitated by sacrificing the originality and singularity of each doll for the ostensibly greater, and more valuable, project of collecting.

382 Buck-Morss 68.
383 Jameson 124.
Further, the act of collecting anthropological objects in the West can operate to discredit and historicize the present insofar as such collections commonly operate through a nostalgia for a more authentic past. Within this framework, the value of an object is a function of its contact with, and/or embodiment of, the distant or the extinct. As Clifford suggests, “the value of Shaker crafts reflects the fact that Shaker society no longer exists: the stock is limited.”\textsuperscript{385} The same might be said of the STITCHES Doll collection; the value of the dolls is, in part, predicated on the death of the creators and/or their contact with mortality. The dolls are all the more precious, precarious, and valuable because they are the mark of something or someone whose existence is threatened. Indeed, this may be one of the reasons that the date of the death is displayed along with the monograph for those participants who have died – it forces loss to the fore. Why is contact with the past so culturally valuable? Stewart argues that particular objects from the past come to serve as traces of authentic experience under an exchange economy, and that the need for such objects is critical in such contexts because experience is increasingly mediated and abstracted.\textsuperscript{386} This is, perhaps, one of the reasons for Cole’s desperate encouragement of collecting practices; collections enable contact with authenticity, authenticity itself being valuable insofar as it is perceived as increasingly more rare in contemporary society.\textsuperscript{387}

The STITCHES Doll Project collection must be understood in relation to such discourses. If collections of cultural objects are valuable and important insofar as their contents are understood as historic markers of (distant) authenticity, to function successfully as a collection, the STITCHES Doll Project must, to some degree, historicize doll-makers and their work to achieve the perception of authenticity. Should this contact with the authentic, the historic, the

\textsuperscript{385} Clifford 223.  
\textsuperscript{386} Stewart 132-5.  
\textsuperscript{387} See also Bendix 7. Bendix argues that authenticity is also sought out because to authenticate a subject is to legitimate it, and to do so can in turn legitimate the authenticator, thus increasing the authenticator’s cultural capital (7).
lost, or the irrecoverable be unachievable for the dolls, their cultural value is likely to decrease. As Stewart suggests, “[w]e do not need or desire souvenirs of events that are repeatable.”388 It is perhaps for this reason that the rhetoric around the STITCHES Doll Project often emphasizes its singularity, its relationship with human culture and history, and participants’ looming deaths. Through such idiom, the STITCHES Doll Project justifies the significance and value of the doll collection. This process, however, can prove problematic for participants because it dissolves their work and identity into a collective cultural endeavor, while simultaneously threatening to place them in the past rather than the present. Politically, this is dangerous insofar as it positions HIV/AIDS, and those who live with it, as historic. Such a move makes political concern and action regarding HIV/AIDS appear needless, which is particularly dangerous because of the interconstitutive nature of representation and the real. As Peggy Phelan suggests, “the real is positioned both before and after its representation; and representation becomes a moment for the reproduction of the real.”389 If this is the case, then it is possible that the creation of the STITCHES Doll Project collection, in its navigation of cultural norms around collecting, actually historicizes and de-politicizes HIV/AIDS and those who suffer from it. This can significantly stunt the Project’s ability to help recover identity for participants insofar as it requires sacrificing the local, the particular, the personal, the incongruent, the present, and the political for the production of cultural identity and human history.

388 Stewart 135.
Chapter Eight: Conclusion

Navigating Discourses, Negotiating Identity

It's just a disease, not a curse, not a punishment, not an embarrassment. . . . We are not being invaded. The body is not a battlefield. The ill are neither unavoidable causalities nor the enemy.

Susan Sontag, *AIDS and Its Metaphors*, 1989390

Philosopher Emmanuel Levinas writes, “violence does not consist so much in injuring and annihilating persons as in interrupting their continuity, making them play roles in which they no longer recognize themselves, making them betray not only commitments but their own substance, making them carry out actions that destroy every possibility for action.”391 This understanding of violence is perhaps nowhere more applicable than in relation to the HIV/AIDS pandemic in the United States. The cultural panic and hysteria around this illness has placed those with the illness in positions where they no longer recognize themselves as human; where they are forced to live in secrecy about their disease to maintain social relationships; where self-hatred and disgust can lead to drug-use, criminal activity, and social isolation; where they are threatened with assault and abuse because of their HIV status. This constitutes violence and speaks to the urgent need for political, social, and cultural action to address HIV/AIDS and the multitude of issues it raises and is implicated in.

What is so unique about the cultural phenomenon of HIV/AIDS is its capacity to make visible oppressive systems of thought, problematic discourses, repressed fears and identities, existential angst, and the methods by which we constitute ourselves as subjects, as whole, as valuable. As a result, programs and projects that seek to address HIV/AIDS inevitably confront

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389 Peggy Phelan quoted in Griffin 7.
390 Sontag 183.
391 Levinas 21.
divisions between public/private, self/Other, and agency/passivity, as well as discourses surrounding public interest, healthcare practices, national identity, moral culpability, Western possessive individualism, contamination and illness, sexuality and ethics, and so forth. In this way, HIV/AIDS has the revolutionary potential of making visible and urgent some of the issues and dilemmas that prohibit the creation of ethical communities and relationships interpersonally and internationally. It is within this framework that we might now appreciate doll-maker Deb Runions claim that “AIDS is here to heal – not just those of us who have the infection but American society as a whole.”

This thesis has explored how Western understandings of the meaning of HIV/AIDS, combined with its physical, emotional, social, and psychological effects, have violently challenged and eroded a sense of self for those who contract the illness. I have argued that because identity in the West is predicated upon self-control, self-containment, self-sufficiency, mental control, and a rejection of embodiment, illness, and death, HIV/AIDS has been experienced at both a personal and cultural level as corrosive of identity. This has caused socio-cultural and political panic around the illness, panic that significantly contributes to the pain and fear already experienced by those who have the illness. In response to such pain, the STITCHES Doll Project provides an opportunity for HIV+ women to use a variety of strategies to re-establish their identity. I have argued that strategies such as sharing the illness or displacing it, when enacted through the STITCHES Doll Project, can successfully assist in re-affirming identity for participants. As a result of this exploration, I would suggest that one of the reasons to believe in the value of community and activist art is its capacity to assist in the building of social, cultural, and personal identities. A strong sense of identity allows individuals to see themselves as agents

in their own lives, and consequently take responsibility for themselves, their actions, and the world around them. It has been suggested that community art must “find the means to stimulate people to find themselves and find their own futures.”393 This is precisely what the STITCHES Doll Project aims to do, and succeeds in doing.

Nevertheless, the Project’s success at individual, social, political, and pedagogical levels is tempered by the challenges posed by cultural codes, discourses, institutions, and practices. Of specific interest in my thesis is the Project’s negotiation of contemporary understandings, practices, and institutions of art and visual culture in the West. This is of interest in relation to the concerns outlined in chapter one, namely the current worry about whether art, specifically activist and community art, has the capacity to make genuine social and political change in a globalized, media-saturated, capitalist context. Theorists such as Susan Buck-Morss, Suzi Gablik, Frederic James, Susan Stewart, and Kenneth Coutts-Smith have worried that because contemporary art is defined by its autonomy and self-sufficiency within the rhetoric of “art for art’s sake,” the social, political, and ethical contexts, meanings, and potentials of the work of art are eradicated almost entirely by virtue of its inclusion in the artworld and gallery system.394 Coutts-Smith argues that within this framework, “the whole of known culture is placed in terms of neutral and negative institutional equality, divorced from function, divorced from meaning, divorced from human use, divorced from any social dimension whatsoever.”395 Such a divorce from utility depoliticizes artistic practice and renders artists “impotent within the larger public sphere.”396 Barbara Herrenstein Smith similarly contends,

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393 Barbara Santos quoted in Adams and Goldbard 22.
394 See, for example, Clifford 215-52.
395 Coutts-Smith 29.
396 Buck-Morss 69. See also Gablik 74. Gablik makes a similar argument, suggesting “[a]utonomy, we now see, has condemned art to social impotence by turning it into just another class of objects for marketing and consumption” (74).
The recurrent impulse and effort to define aesthetic value by contradistinction to all forms of utility or as a negation of all other nameable sources of interest or forms of value – hedonic, practical, sentimental, ornamental, historical, ideological, and so forth – is, in effect, to define it out of existence; for when all such utilities, interests, and other particular sources of value have been subtracted, nothing remains. \(^{397}\)

The question thus becomes whether and/or how the STITCHES Doll Project successfully negotiates such discourses, among others, and whether that negotiation enables the Project to achieve its goals.

Rather than evaluate whether or not the Project as a whole can be deemed “successful” at negotiating these systems in desired or emancipatory ways, my research has proceeded on the presumption that it is more fruitful to explore the ways in which the Project both participates in and challenges discourses and norms that undermine its goals. In her interviews with individuals with HIV/AIDS, Corrine Squire similarly found that personal narratives surrounding the illness both opposed and affirmed cultural discourses about the disease that were harmful to the interviewees. She likewise argues, “[i]t is not helpful, I think, to try to resolve these narratives’ contradictions. Instead a psychologist approaching HIV through narrative would want simply to explore how these double meanings worked together to maintain AIDS panic at the same time as enabling a hopeful, healthy life often largely dissociated from AIDS.” \(^{398}\) In line with this approach, my research has sought to explore how negotiation of these cultural codes, norms and practices helps to both re-build, as well as un-do, identity for participants. Though the Project’s capacity to re-establish identity is always partially failing and partially succeeding, this does not imply its inefficacy necessarily. Indeed, the partiality of identity-recovery mechanisms may be a reason to believe in the value of the Project. Stewart, for example, maintains that the souvenir functions and has value because of its partiality, because it can never completely recuperate the


\(^{398}\) Squire 66.
experience it stands for, and it is this very cultivation of distance between the present moment and a treasured memory that grounds the value of the souvenir (by fielding the possibility of desire).\textsuperscript{399} The STITCHES Doll Project might be read in a similar way. Part of the value and interest of these objects is their capacity to fail at the recovery of identity, to fail at recuperating a time before HIV/AIDS and its physical, emotional, social, and psychological affects. Insofar as they fail in this way, they come to stand in for the lost and the irrecoverable, and are thus imbued with value.

At the level of the participant, I have argued that each individual has to navigate both the (troubling) social, cultural, and political understandings of HIV/AIDS, as well as the Project’s design and discourses, and the risks and potentials inherent in these. My research has pointed to the unique ways in which individuals use their agency to negotiate these codes and re-establish a sense of self.\textsuperscript{400} Nevertheless, as chapter seven makes explicit, the Project’s design puts it in jeopardy of reversing this process of identity-building by distancing and taming the illness, dehumanizing participants, homogenizing and simplifying identities and experiences, and historicizing and depoliticizing the dolls through collecting practices. Consequently, each participant’s success at negotiating the codes and discourses surrounding both the disease, and the Project itself, determines her capacity to utilize doll-making to build and maintain a strong sense of self in a culture that defines her as dangerous, ugly, immoral, and dirty. As Kate Bisset and Jennifer Gray suggest, “while some [women with HIV/AIDS] are paralyzed by fear, uncertainty and anxiety, a few can use the situation as a catalyst to help them focus on priorities in their

\begin{footnotesize}
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\item \textsuperscript{399} See Stewart 132-51.
\item \textsuperscript{400} See Dykstra 19. Dykstra argues that agency can be expressed through individual “interpretation of disease and illness, and by representing our embodiment in ways that may reject the social interpretation of our body” (19).
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lives.401 However, the capacity or opportunity to negotiate these codes in liberating ways is not equally accessible or straightforward for all participants. It is crucial not to overlook the ways in which navigation of these codes is more available to some women, particularly privileged women. To this end, chapter three attempted to sketch out some of the ways that various forms of oppression collude to make HIV/AIDS more prevalent, painful, taboo, and oppressive for particular populations.

Negotiation of these codes at the level of the Project as whole also proved problematic in several ways as well. As chapter seven demonstrated, some dimensions of the Project impede its ability to build valuable and ethical social and political communities. Some of these impediments have to do with the structure of the program itself (e.g. the materials women are given to express their experiences, how workshops are run, etc.), while others have to do with how the Project negotiates cultural codes, institutions, and discourses (e.g. its negotiation of cultural codes around dolls or collecting practices). It is the latter that is of particular concern insofar as the ability to change the structure of the Project itself (e.g. by enabling participants to create many dolls or create their doll from scratch) is much less complicated than attempting to successfully negotiate display practices or the cultural meanings of collections. While my research focused on the problems these cultural codes and discourses pose for the participant in relation to identity-building, future research might explore how these codes affect other dimensions of the Project. For example, future investigations might consider how the Project’s negotiation of these codes affects its pedagogical role, or how the Project might function to encourage governmental reliance on cultural projects that bear the burden of social programming, programming in which

401 Bisset and Gray 133. See also Gerus-Darbison, “Creative Expression.” Gerus-Darbison makes a similar point in regards to the STITCHES Doll Project itself. She argues, “[a] content analysis of the dolls and monographs collected as part of the STITCHES Doll Project reveals that contributions to the project are as varied as the individual doll makers. Women make use of and experience participation in the project in a variety of ways.”
neoliberal governments refuse to invest. Such concerns have been, largely, outside of the purview of my research, but are relevant to evaluating whether the STITCHES Doll Project is a successful instance of community and activist art, and thus relevant to considering whether there is reason to believe in the value of such artworks.


Understanding the value and meaning of these dolls is complicated and multi-faceted. My research has attempted to show one way of reading the value of the dolls (i.e. in relation to identity-building processes), but future research might investigate dolls that do not particularly lend themselves to this framework. I would like to close by addressing two such dolls, two of my

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402 See specifically George Yudice, *The Expediency of Culture: Uses of Culture in the Global Era*.
favourites. The first was made by an unknown participant and titled Tiffany (fig. 8.1). Her monograph reads, “[b]ecause of the mental state of this artist she was unable to express her own feelings about living with HIV/AIDS. She simply said ‘Hello.’” Given the physical condition of this participant, it is difficult to evaluate whether the STITCHES Doll Project helped her reestablish a sense of self. But her choice to say “Hello,” to reach out to us, is startling. There is a nakedness about this greeting in this context that, I would argue, grabs the viewer and requires her response. There is a real humanity in such a gesture, a calling to the Other, that makes this doll deeply compelling.

Deborah’s untitled doll (fig. 8.2) embodies this same capacity to startle the viewer, though in this case it is achieved through the doll’s physical construction. Deborah’s doll is stripped of individuality, decoration, and even humanity; her arms and legs wind around each other in a desperate attempt to close in on herself. While her nakedness makes her vulnerable to scrutiny (moral and otherwise), it is the doll’s awareness of this vulnerability, enacted through the body folding in on itself, that makes her deeply sympathetic. This act of self-protection incriminates the viewer insofar as it struggles against the viewer’s visual dissection and challenges his or her position as a (potentially passive) witness to the horror of HIV/AIDS. The viewer is, ultimately, confronted with the humanity and pain of those with HIV/AIDS. I would suggest that beyond its capacity to reverse oppressive systems of thought, beyond its ability to help participants reassert identity, the STITCHES Doll Project is valuable because it reminds us of our humanity, our vulnerability, and our need of each other. This is, I believe, a persuasive reason to believe in the power and potentiality of community and activist art.
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