

Viola Amato

INTERSEX NARRATIVES

Shifts in the Representation of
Intersex Lives in North American
Literature and Popular Culture

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From:

Viola Amato

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Shifts in the Representation of Intersex Lives
in North American Literature and Popular Culture

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This book explores representations of intersex – intersex persons, intersex communities, and intersex as a cultural concept and knowledge category – in contemporary North American literature and popular culture. The study turns its attention to the significant paradigm shift in the narratives on intersex that occurred within early 1990s intersex activism in response to biopolitical regulations of intersex bodies. Focusing on the emergence of recent autobiographical stories and cultural productions like novels and TV series centering around intersex, Viola Amato provides a first systematic analysis of an activism-triggered resignification of intersex.

Viola Amato earned her PhD in North American Literature and Culture from Humboldt University of Berlin. Her research focuses on queer movements, social class, and higher education in neoliberalism.

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Contents

Acknowledgments | 9

1. Introduction | 11

- 1.1 Contextualization: Intersex at the Intersection of Medicalization, Human Rights Issues, and Ethical Debates | 14
- 1.2 Positioning of the Study in North American Intersex Studies | 18
- 1.3 Primary Corpus and Structure of the Study | 23

2. Approaching Intersex: Conceptual and Theoretical Framework | 29

- 2.1 Concepts and Terminology | 30
- 2.2 Intersex as a Contested Category | 33
- 2.3 The In/Visibility of Intersex: Visualization Practices, the Medical Gaze, and the Biopolitical Regulation of Intersex Bodies | 45
- 2.4 The Dilemma of Intelligibility and Strategies of Survival: Intersex between ‘Normalization’ and Resistance | 50

3. The Intersex Movement of the 1990s: Speaking Out Against Medical and Narrative Violence | 55

- 3.1 The Paradigm Shift from Medical Narratives to Narrating Personal Experience | 55
- 3.2 Fragmented Bodies, Fragmented Realities: First-Person Narratives of Intersex Lives, 1994-2002 | 60
 - 3.2.1 ‘Normalizing’ Intersex Bodies: The Medico-Cultural Erasure of Intersex and the Renegotiation of ‘Loathsome Options’ of Recognition | 60
 - 3.2.2 Medical Gaze vs. Visual Self-Invention: The Performativity of Genitals and the Construction of Sexuality | 71
 - 3.2.3 Making Up for the Absence: Redefining Sexual Pleasure and the Challenging of Heteronormative Ideas of Gender and Sexuality | 83
 - 3.2.4 Intersex in the Eyes of Lovers: Overcoming Sexual Trauma and the Eroticizing of the Intersex Body | 90
 - 3.2.5 “Sharing Our Stories, Our Lives, Our Anger”: Ideas of Community and the Collective Rearticulation of Intersex | 96

- 4. Challenging Dominant Narratives From Within: Autobiography as a Critical Reflection on the Paradigm Shift in Intersex Narratives** | 103
- 4.1 Coming Out as Intersex – and What Next? Intersex Autobiographical Writing against the Limits of Representation | 103
- 4.2 Thea Hillman’s “Search for Self in a World Obsessed with Normal”: *Intersex (For Lack of a Better Word)* | 108
- 4.2.1 Storytelling as a Coming Out Process: The Violence of Representation and the Struggle for Recognition | 110
- 4.2.2 “A Password into a Secret Club”: Anxieties about the ‘Different’ Body, the Medicalization of Intersex, and Questions of Non/Conformity | 124
- 4.2.3 Inhabiting Uninhabitable Homes: Intimate Relationships, Sexual Survival, and Queer Subculture as an Alternative World | 140
- 4.2.4 “I’m More Like You than I Am Like Them”: Ideas of Community and Questions of Belonging | 150
- 4.2.5 The “Daily Work of Acceptance,” of Surviving as Intersex | 156
- 5. Reimagining Intersex: Literary Renegotiations of the Dis/Continuities between Hegemonic Narratives and the Recognition of ‘Difference’** | 159
- 5.1 Mainstreaming Intersex I: Novels between Fictional Liberties and the Need for Narrative Closure | 159
- 5.2 From Medical Object to Cultural Phantasma and Back on Track: *Middlesex* and Movements of Escaping/Striving for ‘Normalization’ | 163
- 5.2.1 Callie, a Medical Case Report: The Sexual Disorders and Gender Identity Clinic as a Space of Pathologizing Intersex | 168
- 5.2.2 From Callie to Cal, from Detroit to San Francisco: A Cross-Country and Gender Transition Journey | 182
- 5.2.3 San Francisco: Space of the Freak Show and Mythology | 184
- 5.2.4 Is there a Moral Obligation to Write a Particular Story of Intersex? | 199
- 5.3 How to Make A Life in Your Body When Your Body Feels Uninhabitable: *Annabel* and the Search for Spaces of Recognition | 201
- 5.3.1 The Cultural Parameters of Gender Construction: Medicine, Aesthetics, and Sexual Violence | 204
- 5.3.2 A Parent-Child-Relationship: Lost Daughters and Sons of Nature | 219

- 5.3.3 “Make a Life for Yourself any Way You Want, in any Place”: Thomasina and the Crossing of Spatial and Gender Boundaries | 227
- 5.3.4 “Building a Voice up from the Ruins”: Wally, Annabel, and the Quest for Vocal Self-Determination | 232
- 5.3.5 Does an Intersex Story Have the Obligation to be Subversive? | 236

6. Screening Intersex at Prime Time: Intersex in/as a State of Emergency and Popular Culture’s Un/Acceptable Interventions | 241

- 6.1 Mainstreaming Intersex II: Medical Drama Series between Entertaining and Educating the Masses | 241
- 6.2 *Chicago Hope*’s Parental Dilemma, or: Production Notes on a Baby in “The Parent Rap” | 246
- 6.3 Deceiving Gender: Intersex Femininity as a “Masquerade,” or: the Violence of (Mis)Representation in *Emergency Room* | 259
- 6.4 Deceiving Gender, Revisited: Intersex Femininity is only “Skin Deep,” or: *House*’s Case of Intersex Misogyny | 270
- 6.5 *Grey’s Anatomy*’s Ethical Doctors and Resistant Teenager, or: Renegotiating ‘Normalcy’ in “Begin the Begin” | 285

7. “We Exist, We Are Human, We Are Everywhere among You”: A Conclusion | 295

Bibliography | 305

1. Introduction

‘Intersex’ has always been a contested category, and hence providing a definition of the term and the concept is a challenging task. Intersex activist Michelle O’Brien contends that when speaking or writing about intersex, “the first thing that has to be understood is that the definition of intersex has changed and has become increasingly policed by people with medical, activist and academic careers” (O’Brien 2009). Morgan Holmes, intersex activist and scholar, likewise argues that “intersex is not one but many sites of contested being [that] is hailed by specific and competing interests, and is a sign constantly under erasure, whose significance always carries the trace of an agenda from somewhere else” (Holmes 2009: 2). The shifting processes of signification and resignification of ‘intersex’ that have occurred throughout the centuries, but most considerably in the last two decades, need to be taken into account and are indispensable for an adequate understanding of intersex. Yet in order for intersex individuals and (an) intersex collective(s) to become recognizable, to be socioculturally acknowledged, and to act as a political agent, intersex organizations have developed a working definition of intersex. The Organization Intersex International (OII)¹ provides the following definition that is currently in use and widely accepted by global intersex activists, NGOs, and generally by other medical and political agents involved in intersex debates (although their own respective definitions of intersex may differ): “*Intersex people are born with physical, hormonal or genetic features that are neither wholly female nor wholly male; or a combination of female and male; or neither female nor male*” (OII Australia 2013).² Implied in this definition is the acknowledgment that various forms of intersex exist, hence intersex is to be understood as comprising a spectrum of

1 The Organization Intersex International (OII) is currently the largest global network of intersex organizations with branches in a dozen countries on five continents.

2 OII Australia references other international definitions of intersex formulated by the World Health Organization, the Office of the UN High Commissioner for Human Rights, and the Council of Europe (OII Australia 2013).

diverse variations in sex characteristics, rather than constituting a single category. For the purposes of my project, I adopt this working definition of intersex and the terminology promoted by the OII, being aware of the reductiveness of that definition and the historico-cultural contingency of the term.³

While intersex refers to specific aspects of the sexed body, intersex cannot be understood outside the performativity of gender and the interrelation between a person's sense of gendered self and sexed embodiment. Judith Butler, whose concept of gender performativity has played a significant role in understanding the constitution of gendered and sexed realities, contends that "'gender' includes the way in which we subjectively experience, contextualize, and communicate our biology," whereby the extent to which "primary sexual characteristics signify gender more directly" varies individually (Butler, in an interview with Williams 2014). This sense of gendered self and embodiment is to be understood as referring to "an innate and subjective experience of having a body [...] with primary sex characteristics" (Williams 2014). OII activists Curtis E. Hinkle and Hida Vioria rectify the common misconception about intersex, that intersex is not about gender: "Intersex is not just about our bodies but also about how we perceive ourselves within those bodies and gender identity is a crucial part of everyone's identity. To erase the importance of gender to the individual intersex person is to reduce that person to only the physical aspects of their body, neglecting the more important part of the equation, their own perception of that body and themselves, as opposed to how others perceive them" (Hinkle and Vioria 2012). The conditions of the intelligibility of intersex are contingent on the interrelatedness of perceptions of sexed corporeality and sense of gendered self and (normative) cultural notions of gender and sex. Since gender implies a subjective and situational experience of one's sexed corporeality, experiences of intersex individuals necessarily differ from non-intersex persons' experiences with their bodies (while experiences also vary among intersex persons): "Intersex is an experience, it is an experience of being different; that difference is in part to do with having genitals that are different, of having a sex that is not quite the same as other men and women," and may or may not involve a range of experiences, desires and issues concerning one's individual sense of self, sexed corporeality, and

3 I use the term intersex 'variation' rather than intersex 'condition,' as the latter implies a bodily 'defect' which is ostensibly medically 'manageable.' In 2006, the term 'Disorders of Sex Development' (DSD) was introduced to replace 'intersex' by former members of the Intersex Society of North America (ISNA) and representatives of the medical establishment. I reject the use of DSD to refer to intersex individuals for the same reasons pointed out by several activists of OII, for instance Tony Briffa, that DSD stigmatizes intersex persons, and that the "very term [DSD] turns intersex variations into diseases requiring medical intervention, and being a 'disorder' inherently puts the medical profession in the leading position as experts over intersex people" (Briffa 2014).

sexuality (O'Brien 2009). Intersex intelligibility consequently necessitates different or alternative cultural, linguistic conditions than those currently available.

Why is the theme of intersex so relevant at this very moment? In her introduction to *Critical Intersex*, a collection of essays scrutinizing the paradigms of contemporary intersex identity politics and clinical practices published in 2009, editor Morgan Holmes asks whether we have arrived at a 'post-intersex' moment by now, when the concept of 'intersex' as signifying bodies that are neither distinctly male nor female has become obsolete (Holmes 2009: 1). Current debates on intersex issues as human rights issues prove otherwise: The ethical relevance of ending the so-called medical 'normalizing' treatment of infants and children born with an intersex variation still has the highest priority on intersex activists' agenda on a global scale. Furthermore, current discussions in North America concerning legal regulations of (non-conformative) genders (registration of gender at birth), sexualities (access to marriage, adoption and social benefits for 'same-sex' couples), and embodiment (transgender rights, disability rights, reproductive rights) indicate ongoing issues of contestation about heteronormativity and (white, heterosexual, cis) male supremacy. Intersex exists at the intersection of varying and several of these concerns, which allows one to consider intersex as a critical intervention in normative forms of sexed and gendered modes of being: "Intersex [is] a powerful term whose historical, social and political import remains *critical* as a tool for interrogating heteronormative and bionormative presuppositions about proper embodiment," Holmes argues (Holmes 2009: 7). Intersex also implicates a level of self-reflexivity about its own efficacy and legitimacy: "Intersex also remains a *critical* site for our interrogation of the limits of its ability to speak of and to the experiences of self of those so labelled, and a *critical* site for the examination of scholarship on intersexuality" (Holmes 2009: 7). Intersex is so relevant, especially at this moment, because it signifies both the limitations of the conditions of intelligibility for non-normative sexed and gendered realities as well as their contestation, disruption and resignification.

Intersex Narratives explores representations of 'intersex' – more specifically, of intersex persons, intersex communities, and intersex as a cultural concept and epistemological category – in North American literature and visual culture from 1993 to 2014. The project starts from the observation that a significant paradigm shift in the narratives about and their representations of 'intersex' took place at the beginning of the 1990s, which resulted in specific cultural productions that have emerged in response to the need for new narratives on intersex. Prior to the organizing of intersex activism, which started on a larger scale with the founding of the Intersex Society of North America (ISNA) in 1993, the discourses on intersex were almost exclusively set within the medical context, which have constructed 'the' intersex body as a pathological body. This medical discourse on intersex, which has been prevalent since the late 19th century, has evolved into a hegemonic narrative with the

(epistemological) power and efficacy of a metanarrative or master narrative.⁴ Individual intersex voices have been systematically erased by and within this hegemonic discourse. In the early 1990s, intersex individuals have begun to reclaim the definitory power over their bodies and their sense of self, which prompted the production of ‘alternative’ intersex narratives and thereby processes of the resignification of ‘intersex.’ The production of various ‘other’ intersex narratives primarily involves texts in which intersex activists formulate their criticism of medical practices, demands for human rights and self-determination for intersex people, and accounts of actual experiences of intersex individuals. Soon, literary and visual cultural representations of intersex emerged as a reaction to the paradigm shift of intersex discourses, and to the ethical questions that arose from the new discourses. The trajectory of the several narratives on intersex cannot be understood in a (strictly) chronological order, but as simultaneously progressing and inter-referential movements, as continuing processes of (re)affirmation, challenging and resignification.

Profound academic research on the shifting paradigms of contemporary intersex narratives and on the literary and cultural works that have been produced in response to these shifts is still lacking to date, both in North American literary and cultural studies and in gender studies. This book seeks to close this research gap by providing a cultural analysis of the resignification of intersex through the cultural production of fictional and non-fictional intersex narratives within the last twenty years, thereby focusing on the interrelatedness of hegemonic intersex discourses and ‘counter-narratives.’ It interrogates the strategies of resistance against the dominant discourses on intersex and moments of productive incoherence within these narratives, which potentially provide the conditions of intelligibility for (their) intersex subjects.

1.1 CONTEXTUALIZATION: INTERSEX AT THE INTERSECTION OF MEDICALIZATION, HUMAN RIGHTS ISSUES, AND ETHICAL DEBATES

From the end of the 19th century on until recently, discourses on intersex were dominated by the medical science and psychology. Physicians and psychiatrists were – and still are to a considerable extent – the principal actors in defining and managing ‘non-normative’ or ‘ambiguously’ sexed bodies; thus, intersex variations have

4 In postmodern theory the terms ‘master narrative’ or ‘metanarrative’ refer to an abstract narrative that is considered as a comprehensive, totalizing explanation of historical knowledge and experiences by relying on a transhistorical and universal truth, and to be justifying the legitimacy of a culture’s authoritarian power (Lyotard 1984: xxiiiif).

subsequently been classified as pathological ‘conditions’ that need to be medically ‘managed’ and ‘cured.’ The paradigm shift of intersex discourses at the beginning of the 1990s effected a de-medicalization of intersex to some extent; yet in a more recent (minor) paradigm shift, the North American medical establishment and medical associations such as the American Academy of Pediatrics reclassified intersex variations as ‘disorders of sex development’ (DSD) in their *Consensus Statement on Management of Intersex Disorders* (2006), providing the basis for the regulation of the medical management of intersex (the contested reclassifications of ‘intersex’ will be further discussed in chapter two).

From the beginning intersex activism was concerned with promoting human rights policies and practice for all intersex people, “particularly the right to self-determination and bodily integrity” (OII USA 2012). One of the most critical issues activists address is the medically unnecessary surgical alteration of intersex infants’ genitalia and the cultural premises on which medical intervention is based. Over the past years, intersex organizations and activists have made significant progress in advancing the human rights cause for intersex individuals, culminating to date in the United Nations’ acknowledgment of non-consensual medical ‘normalization’ treatment of intersex persons as human rights violations (*Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, Juan E. Méndez, 2013*). Already in 2005, the Human Rights Commission of the City and County of San Francisco (HRC) published *A Human Rights Investigation into the Medical ‘Normalization’ of Intersex People*, a report of the public hearing by the HRC and the city and county of San Francisco which was held in May 2004. The San Francisco HRC has been working on important issues regarding intersex since 1998, together with intersex people, in an effort to address civil rights abuses. The hearing’s key issue were the ‘normalizing’ medical interventions being performed on intersex infants. In September 2011, the world’s first International Intersex Forum, an annual event organized, and later supported, by the International Lesbian, Gay, Bisexual, Trans and Intersex Association (ILGA), took place in Brussels, assembling 24 activists from 17 intersex organizations from all over the world. Its goal is to work towards ending the discrimination against intersex people and to promote the right of bodily integrity and self-determination.

Work focused on ensuring human rights for intersex individuals on an international scale includes the German Ethics Council’s (Deutscher Ethikrat) expert report on the situation of intersex people in Germany in 2012, which had as its goal the reprocessing and improvement of the political, medical and judicial conditions for intersex people; the study “Human rights between the sexes” published by Dan Christian Ghattas of OII Germany, together with the Heinrich Böll Foundation (2013), which investigates the human rights status of intersex people in 12 countries around the world; and the Australian Senate’s report, “Involuntary or coerced sterilisation of intersex people in Australia” (published in 2013), which “raises major

concerns about medical ethics and the human rights of intersex people in Australia” (Carpenter 2013). In May 2014 the Council of Europe Commissioner for Human Rights has released the statement, “A boy or a girl or a person – intersex people lack recognition in Europe,” which presents the difficulties, legal issues, and human rights violations, such as medical ‘normalizing’ treatment, which intersex people face (Muižnieks 2014). The ongoing struggles and work that is still to be done regarding the human rights situation of intersex people demonstrate that non-consensual and (in most cases) unnecessary cosmetic genital surgeries on intersex infants continue to be performed in many countries – and that this violation of human rights has serious implications for all people, not only for those who are intersex.

Current ethical debates do not only involve the attempted medical ‘normalization’ practices, including (non-consensual or forced) genital surgery, hormone treatment, and sterilization, but a multitude of related issues resulting from the medicalization of intersex. Among the recent points of contention is the question of the legal status for intersex (or trans, or gender nonconforming) individuals, especially concerning the gender entry on identity documents, which effects further legal issues such as eligibility for marriage, child adoption, as well as access to health care, jobs, housing, social benefits, etc. A recurring controversy concerns the classification of gender nonconformity (including intersex people) as a ‘mental disorder’ in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM), published by the American Psychiatric Association (APA). Intersex activists reject the inclusion of intersex into the DSM because the “classification of ‘gender dysphoria’ [is] problematic in the way it relates to intersex people who reject an arbitrarily assigned gender,” and its perpetuation of the pathologization of intersex as ‘disorders of sex development’ (OII Australia 2012).

A major intersex-related theme of public interest is the issue of Olympic and professional sports sex testing. The most prominent case in recent sports history that gained wide international media attention in 2009 was the case of Caster Semenya, the former world-champion South African runner whose intersex variation has caused a stir far beyond the realm of athletics. The ‘Semenya case’ made intersex visible not only in sports but in society at large and opened up a public debate about intersex. The issue of sex testing of elite athletes is far-reaching and has tremendous consequences not only for individual athletes but touches on gender issues in sports on a more fundamental level. The International Olympic Committee’s (IOC) and the International Association of Athletics Federations’ (IAAF) new policies of sex testing that were reinstalled in 2011 (more than a decade after the IOC and the IAAF abandoned mandatory sex testing for all athletes), in response to Caster Semenya’s ‘case,’ have been sharply criticized by experts such as medical anthropologist Katrina Karkazis and her colleagues, who argue that the proposed policies are scientifically and ethically questionable. In their article “Out of Bounds? A Critique of the New Policies on Hyperandrogenism in Elite Female Athletes,” published in *The American*

Journal of Bioethics (2012), they argue that the IAAF/IOC's new policies of sex testing are really a form of reinforcing gender policing in elite sports: "We cannot think about the Caster Semenya case or evaluate these new policies without careful attention to common assumptions about gender and its relationship to bodies. [...] 'Gender verification policies' in elite sports are meant to distinguish competitors on the basis of sex-linked biology – that is, *sex* rather than *gender*" (Karkazis et al 2012: 5).

The history of IAAF/IOC sex testing exposes a double standard with regard to genders, as in the beginning only female athletes were subjected to sex testing, ostensibly "because concerns about 'fraud' and 'fairness' have centered on the possibility that males could unfairly outperform females" – a practice that, according to Karkazis et al, really translates as an "[a]nxiety about women competitors' femininity" (Karkazis et al 2012: 6). They question the new policies' "claim that atypically high levels of endogenous testosterone in women (caused by various medical conditions) create an unfair advantage and must be regulated" (Karkazis et al 2012: 3), pointing out the cultural and political implications related to the IAAF/IOC's practices. The current policies in elite sports perpetuate normative cultural ideas and the scrutinizing and regulating of gendered bodies, specifically of bodies that vary from normative femininity: "We need to move beyond policing biologically natural bodies and the resultant exceptional scrutiny of extraordinary women" (Karkazis et al 2012: 14). The authors of the study "Out of Bounds?" have already pointed out that the policies of sex testing "require female athletes to undergo treatment that may not be medically necessary and may, in fact, be medically and socially harmful, in order to compete" (Karkazis et al 2012: 13). Rebecca M. Jordan-Young et al report in their study "Sex, health, and athletes," published in *BMJ* (2014), on recent cases of several women athletes who have been forced to undergo 'partial clitorectomies' and 'gonadectomies' to be/come eligible for competing in the Olympic games (Jordan-Young et al 2014).

The most recent ethical debate revolves around the genetic selection against intersex traits through the procedures of assisted reproductive technology such as preimplantation genetic diagnosis and other forms of testing. This issue has lately gained in urgency, since "diagnosis and testing are already possible for numerous intersex traits, such as Androgen Insensitivity Syndrome (AIS), Congenital Adrenal Hyperplasia (CAH), and sex chromosome differences such as 47,XXY and 45,X0" (Carpenter 2014). The de-selection of intersex pre-embryos or embryos perpetuates the physical and cultural erasure of intersex individuals, which is already in effect through the intended medical 'normalizing' of intersex subjects and the forced sterilization of intersex persons.

In the light of the severe human rights violations intersex individuals are subjected to, the ethical implications of intersex representations in literature and (popular) culture cannot be ignored. My research does not take place in a historical,

cultural, political and ideological ‘vacuum,’ but is located within a specific system of thought, within a regulatory system in which normative notions of gender and the sexed body are perpetuated. Hence I position my project with due regard to the ethical debates surrounding intersex; this implies that I seek to avoid the perpetuation of disrespectful (academic) representation, usage of hurtful terminology, and the objectification of and epistemological violence against intersex individuals, acknowledging that this attempt necessarily has its limitations in an academic context.

1.2 POSITIONING OF THE STUDY IN NORTH AMERICAN INTERSEX STUDIES

The biomedicalization of intersex that has taken place since the late 19th century to the present day has recently been criticized by intersex activists and scholars alike. The early 1990s, when questions of the performativity of gender and its relation to sex differences became the state of the art of academic research, have witnessed the (relatively sudden) emergence of (theoretical) works that primarily focus on and argue against the current medical management of intersex and its underlying cultural premises. The (mostly) academic texts are interrogations of the classification of gender and sex nonconforming subjects at distinct historico-cultural moments, ranging from the 17th century to the present day. The most influential works on the histories of intersex include Alice D. Dreger’s groundbreaking work *Hermaphrodites and the Medical Invention of Sex* (1998) and Elizabeth Reis’ *Bodies in Doubt: An American History of Intersex* (2009), while works such as Suzanne Kessler’s *Lessons from the Intersexed* (1998) and Anne Fausto-Sterling’s *Sexing the Body* (2000) focus specifically on the more contemporary processes of the biomedicalization of intersex and their underlying cultural conditions. Works that negotiate more specifically the resignification of intersex as an identity category, representations of intersex, and the interrelations of different cultural narratives include *Intersex in the Age of Ethics* edited by Dreger (1999), Sharon E. Preves’ study *Intersex and Identity: The Contested Self* (2003), and Morgan Holmes’ *Intersex: A Perilous Difference* (2008). *Critical Intersex* (2009, edited by Morgan Holmes) is a collection of critical essays that interrogate the dominant paradigms of contemporary research and activism focused on intersex issues.

Works on the histories of intersex, such as Dreger’s and Reis’ studies, are motivated by the desire to collect and reprocess the clinical case histories of intersex individuals, or of ‘hermaphroditism,’ a term often used at the outset of intersex

research.⁵ The bulk of the works is informed by medical reports and court documents, dating back as far as the 17th century, and covers ‘extraordinary’ cases of variations in sex anatomy. Reis’ *Bodies in Doubt* investigates the history of sex nonconformative bodies from early America to the present, tracing the development of the category of intersex from being subjected to the (definitory) power of legal and clerical authorities to that of medical authorities. Alice Dreger’s book *Hermaphrodites and the Medical Invention of Sex* investigates a history of the relationship between intersex individuals and medical and scientific authorities in the late 19th and early 20th centuries. Both works seek to provide a critique of the dominant normative mechanisms at work in the construction of ‘ambiguously’ sexed bodies by arguing that the intersex body raises questions about *all* bodies and challenges normative notions of distinct sex and gender categories (Dreger 1998: 6). The books’ narratives, while they seem to claim some form of authority in redefining intersex by asserting that there is only *one* specific and linear history of intersex, challenge the idea of a coherent intersex history through their own strategies: The works’ references to other historical narratives, testimonies and autobiographies from intersex individuals and medical records that are supposed to additionally underpin their arguments simultaneously undermine the representations of a univocal, universally valid history of intersex. The fact that this history is made up of a number of (mostly) written records which appear to be fragmentary, contradictory and only loosely connected marks the ambiguity, fragmentation and inconsistency as constitutive of the history/histories of intersex.

Research on intersex that interrogates the construction of intersex as a biomedical(ized) category turns its focus to the cultural premises that inform processes of biomedicalization, pointing to the interrelatedness between normative ideas of gender and the cultural construction of the sexed body. Suzanne Kessler’s *Lessons from the Intersexed* (1998), Anne Fausto-Sterling’s *Sexing the Body* (2000) and a multiplicity of other texts, most prominently written by Cheryl Chase (“‘Cultural Practice’ Or ‘Reconstructive Surgery?’: U.S. Genital Cutting, the Intersex Movement, and Media Double Standards,” 2002b), Morgan Holmes (“Queer Cut Bodies,” 2000), and Katrina Roen (“Clinical Intervention and Embodied Subjectivity,” 2009), postulate specific forms of ‘intersex embodiment,’ a gendered and sexed reality which is a result of an individual’s lived experience of having a body that does not conform to cultural/medical standards of male and female, which makes them subject to processes of ‘normalization’ – whether this experience

5 The term ‘hermaphrodite,’ which historically denotes individuals with differences in sex characteristics, has become outdated by now and its usage is generally rejected by intersex people and organizations. Some intersex persons choose the term to refer to themselves, however. For a discussion of the contemporary usage of the term ‘hermaphrodite,’ see Viloria 2013.

involves actual medical intervention or not. The texts' criticism of the hegemonic medical narrative refers, perhaps inevitably, to medical parameters in order to develop an understanding of the concept of intersex. The implications of these theoretical claims are not unproblematic; hence they will be scrutinized in more detail in chapter two. Yet these texts and theories that conceptualize intersex as a biomedical category are quite influential and have produced a very specific intersex narrative that has shaped and continues to shape the cultural imaginary of intersex in its present state.

Until the late 20th century, intersex first-person narratives were all but absent from the corpus of historical records of intersex 'cases' that were published or otherwise publicly articulated. One famous exception are the memoirs of Herculine Barbin (1838–1868), which were later republished and commented on by Michel Foucault (1980) and served as a relevant source for (mainly) academic works on intersex. Apart from the very few first-person accounts of intersex people, and apart from a couple of legal documents recording court decisions about the legal status of persons with 'indeterminate' gender, the corpus of historical intersex narratives is made up of primarily one type of narrative, i.e. scientific reports by medical authorities, which consequently produced a hegemonic discourse on intersex.⁶ At the beginning of the 1990s, however, when intersex individuals gradually began to establish organizations, along with political activism came an increase in personal accounts of life stories in which the narrators sought to come to terms with their intersex corporeality and their often negative past experiences with the pathologization of their bodies. The scope within which these first-person accounts were published was rather limited, as they were printed primarily in organizations' magazines and newsletters, and consequently reached only a very small and exclusive audience. It was nevertheless a first step towards breaking the silence about intersex and ending the invisibility of intersex individuals within society.

The themes of the stories are closely intertwined with the efforts to challenge the medical practice of genital mutilation performed on infants born with 'indeterminate' genitalia. Thus, while the individual narratives are motivated by the need to fight against the medical establishment's authority over their bodies and for the right of bodily integrity and self-determination, they at the same time iterate the medical discourse and the hierarchical power relations inherent in it. *Intersex in the Age of Ethics* edited by Dreger (1999), Sharon E. Preves' study *Intersex and Identity: The Contested Self* (2003), and Morgan Holmes' *Intersex: A Perilous Difference* (2008), among others, are works that take up this paradigm shift in intersex narratives and pay particular attention to the value of narratives about intersex individuals' experiences that consists in the challenge and deconstruction of hegemonic medical

6 I delineate the corpus of historical intersex narratives as including narratives about real people, thus I exclude the mythological narratives about 'hermaphrodites' here.

narratives, and hence contribute to a resignification of intersex as a self-affirmative concept.

While the hegemonic medical narratives have recently been criticized and challenged by intersex activists and scholars, academic research on the paradigms of contemporary intersex (identity) politics is still scarce to date. *Critical Intersex* (edited by Morgan Holmes 2009) is a compilation of essays from international scholars that “challenge[...] the primarily North American and liberal humanist paradigm of intersex identity politics and clinical practices by explicitly adopting ‘queer interventions’ to further discussion on an ontological phenomenon that can never be reduced to a pure, embodied state, nor to a simple cultural rendering in which ‘intersex’ is whatever we want it to be” (Holmes 2009: 2), and hence marks a crucial shift in intersex scholarship. As the collection intervenes not only in current medical practices and research, but also in the “hegemonized identity politic [sic] of liberal activism” (Holmes 2009: 5), it turns the focus on the ‘alternative’ discourses on intersex that have been produced since the 1990s. The self-critical approach of *Critical Intersex* displaces the current debates on intersex to a level of self-reflexivity about the intersex movement’s own practices and its reproduction of hegemonic claims on intersex.

Due to the recency of the fictional and non-fictional literary and cultural narratives that focus on intersex experience, profound academic research on the cultural corpus of intersex works in North America is still lacking. This book is dedicated to this hitherto neglected type of narrative production that renders a resignification of intersex in the cultural imaginary possible. The academic negotiations of intersex have been taking place in the life sciences, gender studies, queer studies, and the emergent and still not clearly delineated branch of intersex studies, and, to a lesser extent, in North American literary and cultural studies. A research project about the shifting paradigms of intersex narratives in the North American context hence is necessarily an interdisciplinary project. For my analysis I draw on the contributions of gender, queer and trans studies for a new understanding of normative/non-normative genders and sexed embodiment, and on the contributions of literary and cultural studies regarding in particular the study of (textual/discursive) practices of individuals belonging to a marginalized group as constructing (a self-affirmative) selfhood, that challenges hegemonic accounts the author/speaker is subjected to. I hence position my work at the intersection of North American literature and culture studies and queer/gender studies. Issues of gender and/or sexual nonconformity have been discussed in North American literature and visual culture, including representations of ‘female masculinity’ (J. Jack Halberstam, *Female Masculinity* 1998), male homosexuality (Vito Russo, *The Celluloid Closet: Homosexuality in the Movies* 1981), and lesbian sexuality (Mary Ann Doane, *The Desire to Desire: The Woman’s Film of the 1940s* 1987; Terry Castle, *The Apparitional Lesbian: Female Homosexuality and Modern Culture* 1993; Teresa de

Lauretis, *The Practice of Love: Lesbian Sexuality and Perverse Desire* 1994; Patricia White, *Uninvited: Classical Hollywood Cinema and Lesbian Representability* 1999) in film and television, and of transgender or genderqueer subjects in literature (Eveline Kilian, *GeschlechtSverkehrt. Theoretische und literarische Perspektiven des gender-bending* 2004).

Yet, significantly, a thorough analysis of literary and visual cultural representations of intersex individuals and intersex themes is absent from this research area. I position my project roughly in the tradition of these works, aiming at a critical interrogation of the cultural mechanisms that produce the conditions of intersex intelligibility in the cultural imaginary. The fictional and non-fictional narratives about intersex experiences that have emerged within the past two decades in the North American context by now make up a small but fine corpus of narratives that necessitates a profound examination at this distinct historico-cultural moment, a task that my book willingly attends to. I argue that these specific intersex narratives have emerged not only as a critique of the hegemonic medical narratives but as a response to more general concerns of contemporary issues of gender nonconformity, sexed corporeality, human rights debates, and ethical debates on the constitution of humanness and citizenship, or cultural identity (who counts as human, as a person, as a citizen? Who can be a subject, i.e. both subjected to cultural/social mechanisms and a subject in the sense of an active maker and user of culture [de Lauretis 1986: 10]?). I read intersex subjects as sites of contestation over 'proper' or normative embodiment, over normative gender identifications, and over humanness; therefore my analysis starts from the assumption of the cultural significance of intersex as indicating shifting paradigms of the conceptualization of normative/queer embodiment. I argue that accounts of intersex subjects challenge and deconstruct hegemonic narratives of sexed embodiment and their underlying cultural notions of corporeality, gender and sexuality, and produce alternative concepts of thinking about and understanding sexed bodily difference which are effected through, and in turn effect, processes of the resignification of intersex. My book's contribution to the field of North American studies can hence be understood as a negotiation of not only the paradigm shift in the narratives about and their representations of 'intersex,' but as a renegotiation of the conditions of intelligibility for subjects whose gendered and/or sexed realities are located outside or at the margins of recognizability, and thus representability, in the North American cultural imaginary.

1.3 PRIMARY CORPUS AND STRUCTURE OF THE STUDY

The fact that the number of contemporary North American literary and popular cultural negotiations of intersex is to date rather limited can be interpreted as resulting from the relative invisibility of intersex individuals (not only) within North American culture. However, that does not reduce the complexity of the existing works and their representations of intersex persons and themes. Despite the limited quantity of the works, they come in a variety of narrative forms: novels, short stories, autobiographies, essays, articles, television series, films, documentaries, docu-fiction, photographs, comics, and others. Yet, the corpus of this book is not made up of an arbitrary compilation of seemingly unrelated texts, neither does it claim completeness. Rather, the selection is based on the interrelations among specific texts and the transference of knowledge about intersex between them. Of particular interest are the influences of autobiographical intersex accounts on mainstream popular cultural negotiations, and how these are in turn reprocessed by intersex authors. The texts selected allow for a comprehension of the paradigm shifts of intersex narratives. The processes of iteration cannot be understood chronologically, but need to be considered as correlative; it is apparent that the reproduction of knowledge about intersex has a circular and cross-referential quality. The principal line of argument is that these narratives are constituted through processes of reiteration, whereby specific discourses, motifs, strategies, and narrative plots are reiterated by and within the different narratives under consideration, which both produces particular representations of intersex subjects and at the same time opens the intersex subject up to the possibility of its destabilization and resignification (cf. Butler 1993: 10).

The book consists of five main parts – one theory chapter and four analytical chapters – in addition to the introduction (chapter one) and conclusion (chapter seven). The second chapter elaborates the conceptual and theoretical framework for my analysis. This includes a clarification of my usage of terminology, specifically terms such as identity, subject vs. individual, sex and gender. The chapter continues with a discussion on intersex as a contested category, claimed by specific and competing interests of several groups, including the medical establishment, intersex organizations and activists, scholars of gender and queer studies, and others. Further, this section discusses Foucault's theories on control mechanisms and his concept of the medical gaze, which crucially help to comprehend the power relations between intersex subjects and medical authorities, and the constitution of intersex embodiment through and against visualization practices. The central theoretical framework used for my analysis is Judith Butler's theory of intelligibility, specifically her text "Doing Justice to Someone. Sex Reassignment and Allegories of Transsexuality" (2001). In the remainder of the chapter I will outline the usefulness of applying this concept to my analysis of intersex narratives, point out the limits of

the theory, and interrogate what the texts themselves can accomplish in terms of a new paradigm of intersex (narratives) through processes of reiteration and resignification.

Chapter three comprises an analysis of short first-person accounts of intersex experience. Intersex voices were silent, or rather silenced, for the most part in the history of and within historical discourses on intersex. While the hegemonic medical intersex narratives seem to foreclose a positive reclaiming of intersex subjecthood and intersex intelligibility, the first-person accounts of intersex individuals have the potential, “as personal sense-making strategies,” to resist and subvert the dominant narratives (Bamberg 2005: 288). Thus, I seek to identify strategies of resistance or deconstructive moments within these narratives of intersex experience. The narrating of selves and personal experiences not only benefits the individual in that it allows them to develop a sense of mastery over their lives and their bodies and to reclaim the “right to determine the legal and linguistic terms of their embodied lives” (Butler, in Williams 2014) in a way different from that forced upon them by authorities. Butler argues that it is possible to resist or reject one’s initial sex and gender assignment (that are given to us by others), but for our ‘self-assigned’ sex and gender to become intelligible we need “a world of others, linguistic practices, social institutions, and political imaginaries in order to move forward to claim precisely those categories we require, and to reject those that work against us” (Butler, in Williams 2014).

I argue that these narratives under consideration provide, while perhaps in a restricted way, such a cultural context, or space, from which to develop ‘alternative’ concepts of sexed and gendered modes of being, and to figure out the conditions required for different forms of intersex recognizability and intelligibility. These narratives hence can serve as points of reference for a cultural intersex collective. The Intersex Society of North America (ISNA) provided the superordinate narrative context in which many of the early first-person accounts of intersex individuals were embedded. Many of these narratives were published in ISNA’s newsletter *Hermaphrodites with Attitude* between 1994 and 2005, and in the special issue of *Chrysalis*, ‘*Intersex Awakening*’ (1997/1998). The main focus of these early personal accounts is the criticizing and challenging of the way narrators’ intersex variation was or is handled by medical practitioners and within society. Thus, medical themes and issues related to the consequences of medical ‘normalization’ procedures such as genital surgery and hormone treatment clearly dominate and structure these accounts. At the same time, the narratives convey a general tendency towards the formation of a new collective intersex identity which is based on shared experiences with the medicalization of their infant or child bodies.

Chapter four provides a discussion of intersex writer and activist Thea Hillman’s autobiography *Intersex (For Lack of a Better Word)* (2008). Narratives of intersex experience written by intersex authors which exceed the length of essays or short stories are still rare to date. Hillman’s autobiography has received wider recognition

on its release not only within the intersex communities but also within more mainstream popular culture, which is certainly due to the author being a prominent figure and having been a spokesperson of ISNA. *Intersex* addresses very personal and intimate aspects of and experiences with the author's intersex corporeality, in particular themes of sexed embodiment, gender identification, sexual practices, and her relationship to family, lovers and friends. Her autobiography marks a significant departure from earlier intersex accounts in that she openly discusses issues which are considered off-limits in intersex discourses (both public and within intersex communities) by many other intersex individuals and activists. Her narrative moreover critically engages in discussions about intersex activism, the intersex communities and their relations to other communities of gender and/or sexuality nonconforming people, such as the queer scenes; hence creating moments of self-reflexivity about her own positioning within current intersex discourses and cultural spaces.

Chapter five focuses on the analysis of two novels, Jeffrey Eugenides' *Middlesex* (2002) and Kathleen Winter's *Annabel* (2008). Both novels focus on their respective intersex protagonists' childhood and adolescence, beginning with their births in the 1960s, unfolding their trajectories that involve struggles with their birth gender assignments, dealing with the threat of or actual medicalization of their bodies, and their eventual (attempted) emancipation from the confines of the restrictive contexts which regulate their sexed embodiment and gender. *Middlesex* and *Annabel* share a particular understanding of what it means, or can mean, to be born and to live with an intersex variation, of how the category of intersex has been produced by specific hegemonic discourses, and of the problematic implications of this production. The two novels are to date the only book-length fictional narratives in the North American context, which are commercial enough to attract a larger readership. This circumstance is however only one factor in my decision to add the two novels to my corpus. Apart from the fact that the scarcity of these sorts of texts on intersex bestows upon *Middlesex* and *Annabel* a literary hegemony of intersex representations to some degree, the significant temporal gap between the two publications allows for an analysis of the interdependencies of non-fictional texts of intersex experiences and current activist accomplishments in medical, legal and political matters, and fictional cultural imaginations of the category of intersex at distinct historico-cultural moments. I discuss the representations of intersex protagonists and intersex-related themes in the two works in due consideration of the potential contributions and limitations of fictional texts when it comes to contemporary cultural negotiations of intersex. Fictional narratives can offer, in contrast to non-fictional and/or autobiographical narratives, a more flexible spectrum of possibility for the reimagination of intersex lives, as they are not restricted by the realities intersex people face. Nevertheless, literary representations of intersex necessitate a critical and self-reflexive stance towards existing discourses and narratives on intersex, both

non-fictional and fictional. I seek to interrogate how the novels' reiterations of specific intersex narratives and discourses, of particular motifs, narrative strategies, and plots reaffirm hegemonic narratives on intersex and at the same time open 'intersex' up to processes of destabilization.

The sixth and last analytical chapter is dedicated to the interrogation of intersex representations in visual popular culture, namely in four medical television series. I discuss the mainstreaming of intersex themes and the problematic aspects and potential benefits of bringing intersex to the attention of a mainstream audience, mediated by medical drama fiction and focalized through intersex individuals as 'patients' or, rather, subjects of medical treatment and procedures of medicalization. The fact that the theme of intersex is not only featured in all major popular medical series, but almost exclusively in *medical* series, signifies the close relatedness and association of intersex with medical issues. However, this can also be read as cultural negotiations of not only the medicalization of intersex but of the criticism of and ethical questions arising from medical practices. The latter argument is closely connected to the question whether a (commercial and extremely popular) television program has an educational 'mandate,' or the responsibility to inform the public about intersex themes, which inevitably raises issues of accuracy and fair representation.

Four of the most popular American medical drama television series each have featured one episode dealing with the theme of intersex: *Chicago Hope* (1996), *Emergency Room* (1998), *House* (2006), and *Grey's Anatomy* (2006). The *Chicago Hope* episode "The Parent Rap" is the only episode in the selection that focuses on the birth of an infant with indeterminate gender, and on the parents' difficulties in deciding how to deal with their child's intersex variation; a scenario that is supposed to represent a 'classical' situation of an 'intersex birth.'⁷ The other three episodes, "Masquerade" (*Emergency Room*), "Skin Deep" (*House*), and "Begin the Begin" (*Grey's Anatomy*) respectively feature a storyline about a teenager who was assigned female at birth and has been raised as a girl, but in whom undescended testicles are discovered during adolescence. Despite the similar initial situation, the series'

7 The American medical drama television series *Emily Owens, M.D.*, which was running for one season from 2012-2013 before it was cancelled due to low viewer ratings, features one episode about a baby whose intersex variation is discovered a few months after its birth ("Emily and... the Question of Faith," season one, episode 6, originally aired November 27, 2012 on The CW Television Network). While this episode is definitely interesting for an analysis of how current ethical debates are negotiated in a fictional popular visual cultural production, especially in the light of the time span of almost two decades between the *Chicago Hope* and the *Emily Owens, M.D.* episodes, my study concentrates for now on the more commercially successful television series, which have attracted an extremely large audience.

approaches to the issue in terms of narrative strategies, visualization, plot development and, specifically, the iteration of particular discourses and medical ethical questions vary considerably. This section of my book interrogates how the narrative shifts in intersex representation and current debates on intersex themes intersect with fictional popular culture formats' negotiation of intersex themes and discourses, and the intricate ways in which cross-referential and intertextual processes reaffirm, criticize, or challenge hegemonic narratives on intersex. My analysis will demonstrate that temporality is not the only factor that determines the mutual influences between narratives, but that other interests and concerns can be equally relevant.

The study concludes with the summing up and evaluation of my findings regarding the shifting paradigms of intersex narratives within the last two decades. I assess the significance and the validity of the results of my analysis of how intersex, as a contested category, has been undergoing processes of signification and resignification, which have occurred through chronological, achronological or circular, cross-referential, interdependent, and both predictable and spontaneous movements. I try to answer the question of whether we can ever arrive at a 'post-intersex' moment, and what the different narratives and discourses on intersex have to do with it. I conclude my thesis with reflections on survival, intersex futurity, and intersex as intervention.