

Embodying Transgenerational Exposure:
Gender/sex/sexuality and experiences of being DES-exposed

Research Report

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Letter to Readers

I was born in 1971. For many of you reading this, you will recognize 1971 as the year in which Arthur Herbst, Howard Ulfelder and David Poskanzer published their ground-breaking article “Adenocarcinoma of the Vagina — Association of Maternal Stilbestrol Therapy with Tumor Appearance in Young Women” in the *New England Journal of Medicine*. The article documented an association between in-utero exposure to diethylstilbestrol, or DES, and vaginal cancer (clear cell adenocarcinoma). The authors wrote:

The time of birth of these patients (1946 to 1951) coincides with the beginning of the widespread use of estrogens in support of high-risk pregnancy. [...] Although the chance of development of these tumors appears to be very small, the results of this study suggest that it is unwise to administer stilbestrol to women early in pregnancy. Furthermore, abnormal bleeding in adolescent girls can no longer be assumed to be due to anovulation, and the possibility of vaginal tumor should be excluded by a physician's examination.

This discovery was critical and has had far reaching implications for how we think about the temporality of the effects of in-utero exposure to toxins, the risks of “synthetic hormones”, and the ways in which pharmaceuticals are regulated, prescribed, and monitored. DES was synthesized in 1938 in England by Charles Dodd and colleagues and initially approved by the US Food and Drug Administration (FDA) in 1941. First used most widely as a means to alleviate what were then considered the “symptoms” of menopause (Bell 2009), following FDA approval in 1947 DES was prescribed to pregnant women for the purpose of preventing a miscarriage (DES Action Timeline). Even though laboratory studies prior to its use in the field of human health offered evidence of diethylstilbestrol's carcinogenic effects (Bell 2009), the market for synthetic estrogens was ripe (Bell 1995). Even though studies in the 1950s (Dieckmann et al. 1953) questioned the efficacy of DES in preventing miscarriage and demonstrated its potential harm, prescription use continued. *DES Daughters: Embodied Knowledge and the Transformation of Women's Health Politics* by Susan Bell (2009), *DES Voices: From Anger to Action* by DES Action USA founder Pat Cody (2008), *Toxic Bodies: Hormone Disruptors and the Legacy of DES* by Nancy Langston (2010), and *Our Stolen Future* by Theo Colburn, Diane Dumanowski, and John Peterson Myers (1996) tell the stories of DES and the social, health and environmental justice movements that are tied to the growing awareness of the effects of DES and more broadly endocrine disruptors from varied perspectives.

I'm a Lecturer in Gender Studies at Mount Holyoke College, where I teach interdisciplinary courses in feminist health and science studies. My scholarship and teaching focus on the areas of health, reproduction, genetics, science and technology regulation, and experiences of gender, sex, and sexuality. I have a PhD in anthropology from York University in Canada (received in 2002), with a focus on medical anthropology and queer ethnography, and I completed a postdoctoral fellowship at Lancaster University in England in a growing field called feminist science studies. In Fall 2016, I received a request from DES Action to help support a symposium they were planning for Spring 2017 to recognize and raise awareness about the

recent transfer of the DES Action USA papers to the Sophia Smith Collection at Smith College (another member of the Five College Consortium). I played a small role in the lead-up to the symposium. Yet, the invitation to collaborate had raised my awareness of what I now think of as “appearances” of DES in a number of recently published academic book chapters and articles. My interest was also piqued by references to “gender issues” as an effect of DES exposure in the drafts of the initial advertising for the symposium. Students from classes that I teach who attended the symposium remarked that the health advocacy efforts and the scientific research related to DES exposure was presented and addressed in a very “binary” framework. The students were referring to the frequent and common use of gendered terms such as DES daughter or DES son by DES-exposed people and members of DES Action and to the ways in which the results of DES-related scientific studies were organized around the “sex” categories of DES-exposed males or females. A few hours later, I found myself in a dinner conversation about the vaginal differences (including vaginal adenosis) experienced by many DES-exposed people. Combined, all of the above contributed to the conceptualization of a project designed to explore the associations that people make between exposure to DES and understandings or experiences of gender, sex, and sexuality.

Supported by funding from DES Action and Mount Holyoke College, between September 2017 and 2018 a number of undergraduate research assistants and I undertook research in the newly deposited archive of DES Action USA at the Sophia Smith Collection at Smith College and I conducted 25 one to two hour long interviews with people who self-identify as DES-exposed. These interviews were like open-ended conversations focusing on the connections interviewees make between being DES-exposed and their understandings and experiences of gender, sex, and sexuality. The invitations for participation in the interviews did not specify criteria for participation based on any particular gender identity or sexual orientation. However, in conversation with DES Action while designing the project, a decision was made to make strong efforts in both our archival research and interview-based research to be attentive to and to reach out to a number of communities whose experiences are not very visible or known in the history of the DES health movement, including: a) transgender DES-exposed people; b) people who were assigned male at birth, many of whom identify as DES Sons or transwomen who were exposed to DES; and c) people who identify as both DES-exposed and lesbian, bisexual, or gay. The interview conversations were with a group of DES-exposed people, ages 57 to 70 (plus one 85 year old woman who was prescribed DES when pregnant), whose experiences and understandings of gender, sex, and sexuality transcended the borders of gender or sexual identity categories. Reading our demographic chart one could say the following:

19 interviewees identify with the sex/gender they were assigned at birth (cisgender)

6 interviewees identify as transgender (one transman, 5 transwomen)

5 interviewees identify as lesbian

2 interviewees identify as bisexual

10 interviewees identify as heterosexual

8 did not specify a sexual orientation

However, this breakdown requires engaging with the meanings that each of these terms hold for interviewees. What are the differences between identification with a sex/gender/sexual orientation versus behaviour or desire? How should one record identifications and experiences over time? What “counts” as being cisgender or transgender? Some interviewees self-identified as “heterosexual” when asked about “sexuality/sexual orientation”, but their interview narrative focused primarily on stories of same-sex behaviour or desire. Other interviewees did not specify a sexual orientation and one learns through the stories about their experiences. As time goes on, we plan to explicate the meanings of these intricate and complex identifications and belonging for health-relevant activism and research.

What is notable is that the majority of the interviewees are white, with one interviewee self-identifying as Jewish and one interviewee self-identifying as Portugese. In many ways, this racial/ethnic composition may not be unexpected given the racial disparities in healthcare access and the promotion of prenatal care to white women during the period of exposure. Class status, over a lifetime, was much more varied with a number of the interviewees having experienced different class status at different points in their lives.

When we first began talking about this project, I don’t think any of us - myself, Karen Calechman (DES Action Community Manager and Mount Holyoke College alum), and Su Robotti (DES Action and Med Shadow Executive Director) - could have imagined where it would lead. At the core of most of my research is a commitment to queer feminist and multi-sited ethnographic methodologies, which invite me to consistently question scientific and social norms, to explore the ways in which they are invested with authority and also questioned, and to follow the “leads” that emerge through the research and analysis. The analysis and writing related to such a project often happens over a long period of time. I constantly struggle with wanting to share all of the ideas that are emerging and wanting to avoid having these ideas be taken as “fact”. In an attempt to counter the deferral of “results” to a point when the project could be said to be complete, student research assistants and I contributed to Voice, the newsletter of DES Action, throughout 2018, DES Action’s 40th anniversary year. I also presented some of the themes that were emerging in the analysis of a subset of interview narratives at a Mount Holyoke College reunion in May 2018, which was live-streamed as a Facebook Live.¹

I am extremely grateful to have had the possibility to immerse myself in the details of DES Action USA at the Sophia Smith Collection. Each time I re-listen to an interview or re-read an interview transcript, I am warmed by the willingness of the interviewees in this project to share their experiences, many of which are extremely personal, troubling, sad, and also clear demonstrations of profound resilience. One of the interviewees noted:

I learned through my life that things don't just... happen [laughs]. They journey. [Pause. Crying] It's good to have companions on the journey. And I wish I had known [pause] other companions on this journey, besides my sister, 40 years ago. [Crying] I really do. I don't know if it would have made a difference in terms of the... sadness, but it, um...but I believe that we are created to be in community... that would have been one that would have made a difference...

¹ The video can be viewed at: <https://desaction.org/members-area/video-interviews/>

I recognize that putting voices onto paper, creating conversations between people who will most likely never meet, can not make up for the experience of isolation that a number of interviewees voiced. It is not the same as creating a community space (in person or online) for people to engage with each other directly. A number of interviewees cited their involvement with chapters of DES Action as influential in how they understand the ways in which their DES-exposure is embedded in their life narratives. DES Action continues to work to maintain the visibility of people affected by DES and offer support and support groups for those affected. I do hope that by working with stories about the ways in which DES has intensely permeated the everydayness of life at various points over the course of people's lives, I can offer impulses for conversations that may or may not have taken place...yet. I expect that the conversations that arise might, just as our project has, push against and transcend the borders of what might be thought about as DES-specific topics.

The initial funding from DES Action to carry out this project opened up possibilities for undergraduate Gender Studies students at Mount Holyoke College to gain first-hand research experience on a project in its initial stages. Since then, I've been able to integrate undergraduate research assistants and summer research interns in multiple stages of analysis, including focused exploration of various themes that emerged from the interviews. We found that many of the interviews could be classified as containing stories about experiences primarily - but not exclusively - related to: 1) reproductive health; 2) sexual health; and 3) transgender health. Some of the on-going topics we are exploring are:

- 1) Perceptions of risk associated with the unintended or consensual use of synthetic and/or bioidentical hormones;
- 2) Hormone balancing, wellness, and risk;
- 3) Historical uses of diethylstilbestrol in the "treatment" of intersex and gay people;
- 4) Non-reproduction related exposure to DES in low-income and/or racialized communities;
- 5) Experiences of sexuality, bodies, and aging;
- 4) Retrospective and life narratives of infertility and pregnancy loss;
- 6) Intergenerational and explanatory narratives of intersex and transgender embodiments; and
- 7) Conceptual disparities in reproductive and environmental justice.

As mentioned above, one of the first presentations of this work occurred during a reunion at Mount Holyoke College, attended by many who belong to the cohort of what I now think of as the "potentially exposed." This was also live-streamed as a Facebook Live. I've also presented the work at a student-led seminar, a faculty seminar, a first year biology class, and most recently at the annual meeting of the American Anthropological Association. As I became increasingly engrossed in the questions that were emerging from this project, I found myself developing a new course "Feminist Engagements with Hormones," which I am teaching for the first time this semester.

Over the past year and a half, I have received a number of inquiries about the project and expressions of interest in participating in further research. As noted just above, the possibilities for continuing research are there. With students and members of DES-exposed communities, I hope to further explore the themes above and to put the outcomes of this work into wider circulation.

With gratitude to all who have shared their experiences with me and my students and to all who navigate the effects of DES exposure and the uncertainties about what those effects may be,

Jacquelyne Luce

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Preface

The report that follows is an initial outcome of a project entitled: *Embodying Transgenerational Exposure: Gender/Sex/Sexuality and Experiences of Being DES-exposed*. This report engages with themes that emerged in relation to a focus on DES exposure and queer (LGTBQ) sexualities, gender non-conformity and transness.² As described in more detail below, this project emerged from a political-theoretical investment in LGBTQI³ health and a recognition that DES-exposed LGBTQI people have not been visible within DES-related health advocacy and educational material and activities. For a confluence of reasons, LGBTQI DES-exposed people might have particular healthcare and information needs. However, it became clear that articulating specific needs for health care or health information related to being a DES-exposed LGBTQI person was not central to the interviewees' stories about living at the interface of these identities.

Publicly circulating articles, blogs, books, and videos make reference to the possible ways in which DES exposure can shape both gender identity and sexual orientation. I was aware of the questions surrounding what I now think of as “chemically induced” queerness or transness from the outset of this project, but I didn't have a sense of how deep, prevalent, or meaningful this concept might be among a generation of people who were “potentially exposed” to DES and identifying with sexual desires or gender identities that challenge normative expectations of heterosexuality or assigned-at-birth sex/gender correlations.

Through the interviews, I came to realise that some interviewees viewed this project as holding the potential to perhaps shed light on the question of whether or not DES can cause transness or queerness. Other interviewees were sharing their story from the position of having experienced unacknowledged harm or damage through DES-exposure. A number of transgender interviewees and heterosexual-identifying interviewees who experienced same-sex/same-gender desires, located “gender dysphoria”, “gender incongruence” or “homosexual desires” in line with other medically acknowledged pathological effects of DES exposure, such as cancer, reproductive and genital tract anomalies, and fertility or pregnancy complications. Popular, scientific, mainstream, and counter-cultural knowledge and understandings of gender, sex, and sexual orientation have shifted many times throughout history and cultural contexts. Feminist scholars have long questioned arguments that seek biological and genetic explanations for gender, sex, and sexual orientation “differences” (see Terry 1995, 1999; Jordan-Young 2010). This scholarship highlights the contexts—of social norms of heterosexuality, femininity and masculinity, race, ethnicity and ability, as well as the social, medical, and institutional discrimination against women, lesbian, gay, bisexual and transgender people, and racial and ethnic minorities—within which the scientific research on “difference” has been conceptualized and conducted. While I don't share the perspective that DES exposure can *determine* or *cause* part of one's sense of self that is as complex as gender identity or sexual orientation, I recognise that I wonder how bodily and social experiences associated with DES exposure might influence one's understandings, experiences, and desires

² I use “transness” in this context as an umbrella term that includes identifications and experiences such as: transgender, transexual, cross-dresser, genderqueer, gender non-conforming and non-binary.

³ LGBTQI = Lesbian, gay, bisexual, transgender, queer, intersex

related to gender/sex identity and sexuality. I, too, am thinking through possibilities effect by association and “relational biologies”⁴ (Luce 1999).

The narratives of trans and queer people who also identify with and as members of the DES-exposed community are complex. Their narratives do not map onto a straight-forward understanding of gender or sexual orientation as “biological”. The interviewees also do not uniformly equate transness/queerness with/as pathology with transness/queerness as a negative identity. The interviewees offer insight into the ways in which knowledge from different experiences, academic disciplines or clinical fields, and generations inform the meanings we give to gender, sex, and sexuality and the very questions we ask and deem askable. Why and how did DES exposure emerge as an explanatory narrative of queerness and transness? Which knowledge foundations are these arguments based on? Who is considered to be holding “authoritative knowledge” in this matter? By following the trajectories of interviewees’ narratives we can learn about the institutions and power structures within which normative and non-normative/counter normative experiences of the body and desire are produced, maintained, and challenged. The analysis of the interview narratives, alongside the publicly circulating hypotheses mentioned above, offer possibilities to explore the broader issues of why we ask the questions we ask about the origins of sex or gender. They highlight the conversations of scientific and social sense-making which generate prescriptive containers of femininity and masculinity - and also transness or non-binariness - that we very often find ourselves in, trying to get access to, or trying so hard to escape.

⁴ I started thinking about the idea of “relational biologies” while working with lesbian and bisexual women who were trying or had tried to become pregnant. Many of the women’s stories highlighted the ways in which they experienced their “biologies” - their bodily possibilities for pregnancy - as relationally defined; as defined by their intimate partnerships, their relationships with potential sperm donors, their relationships to queer positive health providers or their relationships to knowledge about assisted reproduction.

Introduction

Diethylstilbestrol, or DES, was synthesized in 1938, and prescribed to millions of pregnant people, predominantly between 1938 and 1971. DES is a chemical with estrogenic properties. In its developmental stages, there were speculations about its many potential uses (Bell 1995). DES was initially approved for use in menopausal women and, after 1947, was prescribed much more widely to “prevent miscarriage, premature labor and related complications of pregnancy” (NIH National Cancer Institute). Even prior to FDA approval, studies showed carcinogenic effects of DES on animals in laboratory studies (Langston 2014). Despite these findings, and then emerging evidence that DES was ineffective at preventing the pregnancy complications for which it was being prescribed, DES continued to be prescribed until 1971 when a link was made between prenatal exposure to DES and clear cell adenocarcinoma, a cancer of the cervix and vagina. In 1971, the FDA notified physicians that DES should no longer be prescribed to pregnant women. DES remained available. DES has also been widely used within the animal and agricultural domains (Langston 2014:30) and veterinary medicine (Haraway 2016).

Researchers have studied DES in relation to reproductive health issues (e.g. cancers of the reproductive tract and fertility issues), pharmaceutical regulation, and environmental health. Scholars and activists have documented the DES movement, and especially the work of DES Action and the DES Cancer Network, showing it to be a powerful and transformative example of an embodied health movement, within the broader context of the women’s health movement (Morello-Frosch 2006; Bell 2009; Cody 2008). The collective action of “DES daughters”, as the girls and women affected by prenatal exposure came to be known, drew attention to numerous gaps in the process of regulating novel pharmaceuticals and demonstrated a critical need to include sex and gender (most often used interchangeably) as critical variables in scientific and medical research.

*Embodying Transgenerational Exposure: Gender/sex/sexuality and Experiences of Being DES-exposed*⁵ was designed as a qualitative research project to address a much less understood, narrated and investigated set of questions. While there have been intermittent references in the public sphere and, in particular, on internet- based media, to the possible relationship between DES exposure and gender/sex identification, expression and embodiment, these questions have not been substantively addressed in activist and educational work or academic scholarship. The project was carried out by the principal investigator, Jacquelyne Luce, together with Mount Holyoke College and Hampshire College undergraduate research assistants and summer research interns (hereafter referred to with “we”).

⁵ The project was originally conceptualized and funded for a year (September 2017 - 2018). With additional support from Mount Holyoke College in the form of a Faculty Research Assistance Support Grant and summer research internship (LYNK) funding, the initial project has expanded significantly. The material reported on here is based on the research conducted during that first year, supplemented by further analyses beyond that time-frame.

Employing a rich interdisciplinary toolkit of concepts and research approaches from gender/feminist studies, feminist science studies, anthropology of the body, and reproductive justice (see for example Franklin 1995; Marcus 1995, Luce 2010), we explored associations that are made between exposure to DES and embodied experiences of gender, sex and sexuality in various social, temporal, medical and scientific contexts. In particular, we aimed to facilitate a detailed exploratory investigation of associations made between DES exposure and gender, sex and sexuality in terms of identity, expression and embodiment. In conversation with DES Action organizers during the initial research design phase, it was clear that there is a severe lack of knowledge about the experiences and education or health needs of LGBTQI people who were exposed to DES. The LGBTQI community has been historically marginalised from DES-related research and from various education and advocacy efforts, but also from accessing appropriate health care and health information more generally. Our approach to the archival material, and our invitation for project participants, was designed to be open and inclusive, so that we could explore the potential relationships between DES and gender/sex/sexuality across a broad range of identifications. While our ongoing work on the project is exploring a broad range of themes raised by participants in the interviews and the material we encountered in the archives, this report focuses specifically on some of the themes that emerged through the interviews with LGBTQI individuals and/or that explicitly address questions of gender/sexuality non-conformity.

There are a few key complexities to this project that we would like to draw attention to:

- 1) It is very difficult to confirm one's exposure to DES. When notifications about the link between DES and clear cell adenocarcinoma were published and circulated in 1971, DES had already been taken by pregnant women for over 20 years, the peak period of prescription in the United States being during the late 1940s, 1950s, and 1960s (Bell 1995). More widespread public health campaigns, many spearheaded by DES Action with various partners, took place during the 1980s and 1990s (DES Timeline). Many people born during the time period in which DES was prescribed were never able to confirm whether they had been exposed and/or at what dosage and gestational age due to the inaccessibility of medical records and/or the death of people (who are predominantly understood to have identified as women) who had taken DES and given birth to exposed offspring. The DES Follow-up Study⁶, which has been ongoing since 1992, includes approximately 21,000 individuals. This group brings together a number of other research cohorts whose exposure to DES has been confirmed. Follow up research based on members of these cohorts with confirmed exposure is understood to enhance the scientific validity of that research. For the purposes of this research, interview participants were not required to provide documentation of exposure. Taking an anthropological approach, informed by the field of science studies, the project focused on the experiences and perceptions of people who *understand themselves to be DES-exposed*. The project includes exploration of *why* interview participants understand themselves to be DES-exposed. Knowledge about the potential of having been exposed to DES has changed significantly with the Internet, as has the

⁶ <https://www.desfollowupstudy.org/index.asp>

circulation of ideas about what types of effects DES exposure might have.

The interviewees understood themselves to be DES-exposed for a variety of reasons. Some of the interviewees' mothers had informed them that they had taken DES while pregnant. Some interviewees experienced difficulties getting pregnant or contributing to a pregnancy and were then informed by a clinician that they had most likely been exposed to DES in utero. Some interviewees, in particular those who are transgender, encountered speculations about an association between DES exposure and gender/sex variance and, given other factors surrounding their birth, concluded that they had likely been exposed to DES. This last subset of interviewees may be the least likely to have any way of confirming DES exposure due to a lack of access to medical records and/or the advancing age or death of the parent who gave birth to them.

- 2) Non-normative genders and sexualities, although increasingly visible in social life, are still considered “deviant” from the normative gender/sex binary of women/men and normative expectations of heterosexuality. Discrimination against LGBTQI people remains high. Many of the interviewees came of age during a time when transsexual or transgender behavior and homosexuality were pathologized both formally (in the DSM for example) and in social spheres. While a great degree of scientific research has sought a biological basis for differences of sex, gender and sexual orientation, a “cause” for homosexuality or transgender identity has not been identified and much of the science in this area has been rigorously challenged (see for example Terry 1999; Jordan-Young 2010; Karkasis 2008). Such research is most often based on the premise that homosexual and/or transgender desires, embodiments, and senses of self are a form of deviancy in relation to a heterosexual and cisgender norm.
- 3) The interviewees in this study self-identified as white and, at the time of the interview, as working, middle, or upper-middle class. One scientific researcher working on DES-related projects commented informally that the predominantly white constituency of the DES-exposed community is possibly a reflection of racial disparities in accessing reproductive health care, and especially prenatal care, during the period in question.
- 4) While we achieved a good distribution of birth/exposure years amongst the interviewees, we have not interviewed any third generation DES-exposed people (people genetically related to individuals who were exposed in utero). Given some of the comments contributed by interviewees, there may be a disparity in knowledge about exposure among the “third generation.”

As an exploratory ethnographic project, the interviewee narratives are indicative, rather than representative, of the associations people who believe themselves to be DES-exposed make between their exposure and their understandings and experiences of sex, gender, and sexuality. Given the complexities outlined above, it is important to understand the interviews as offering us insight into various experiences and embodiments, the power of medical diagnoses

as a route to self and social acceptance, emerging understandings of environmental and epigenetic imprints on our bodies, and articulations of potential community belonging.

Generating Knowledge: Public information, Archival Records and Interviews

Between October 1, 2017 and August 31, 2018 we engaged in three primary forms of generating knowledge (or data collection): 1) archival research with the DES Action records at the Sophia Smith Collection, Smith College; 2) qualitative interviews conducted with: a) LGBTQI, gender non-conforming, and gender transgressive DES-exposed individuals; b) cisgender DES-exposed individuals; and c) individuals who had been or are involved in the DES educational and activist movement; and 3) collection of public sphere representations, including print publications and Internet-based social media discussions. The Institutional Review Board at Mount Holyoke College granted approval of the project in September 2017. Please note that all interviewees and individuals named in the archives have been anonymized in order to protect their privacy and the privacy of potential future generations.

Websites and Social Media

We have developed a collection of articles, blogs, and videos that are dedicated to DES-related issues and/or that feature DES-related content which circulate on the internet and various social media platforms. We have been particularly interested in identifying posts and re-posts of statements articulating an association between DES exposure and either transgender or intersex identity.

DES Action Archives

From January through August of 2018, the research team was immersed in archival research. The DES Action USA records were recently acquired by the Sophia Smith Collection of Women's History at Smith College in Northampton, Massachusetts. The collection was processed by archivist Jen Bolmarcich and a comprehensive finding aid is available online.⁷ The collection consists of nine series, comprising 23 boxes of material.

We employed an ethnographic approach to the archival material, keeping an open mind to what may or may not be relevant to this project as it develops over a longer duration of time. We were particularly interested in how the archival material might shed light on the ways in which topics related specifically to gender, sex or sexuality were mentioned, taken up, or shelved throughout

⁷ <https://findingaids.smith.edu/repositories/2/resources/996>

the history of this exemplary health movement. We began the archival research being particularly attentive to any mention of communities which seemed to have been marginal to the actions undertaken and knowledge that was circulating: men who had been exposed to DES; transgender or gender nonconforming individuals who had been exposed to DES; and people of color who had been exposed to DES.

A folder entitled, "Minutes and reports, 2001-02," which archivist Jen Bolmarcich describes as containing "a significant discussion of reports and potential research concerning DES effects on gender identity and sexual orientation among DES Daughters and Sons" acted as a starting point for our research. Following the initial research, an assessment of the amount of material, and a review of the collection as a whole, we prioritized completing Series I: Administration and Series II: Membership and Financial Materials, which corresponds to boxes 1 through 5, within the timeline of this particular project.

The Administration series offers a sense of some of the issues that were addressed in board meetings, the ways in which some issues were seen as pressing, etc. Series II: Membership and Financial Materials offers some insight into the types of membership drives that were held and the questions that potential members and members submitted to DES Action USA. For each folder/box, we took notes on the content, with photos of the material accompanying our comments. Furthermore, we conducted unstructured "free writes" following each session in the archives in order to capture the ideas that were sparked during that session. This process has been helpful in generating preliminary ideas about the role of DES Action USA in raising public and clinical awareness about DES material. Comments, as well as what can be thought of as "representational absences" - that which we notice not due to its presence but due to a growing awareness of its absence - offered initial ideas about the ways in which the visibility of various effects of DES were tied to pre-existing clinical knowledge, legal action, and collaboration potential. The significance of some of these records is becoming more apparent in combination with our ongoing analyses of the interview data.

Interviews

Qualitative narrative interviews offer the possibility for people to tell their stories and to highlight thoughts, experiences and ideas that are important to them. An interview guide offered a foundation for the interviews, which took on a conversational format and tone. Both interviewees and the researcher asked questions and pursued areas of interest that arose during the interview. An on-going process of reflecting on the content of each interview, facilitated the integration of various topics in interviews with other interviewees, as well as a return to interviews already conducted.

In total, Jacquelyne Luce conducted 25 interviews between January and August 2018 with people born between 1948 and 1970. April Albrecht was able to join in on a couple of these during her summer 2018 research internship before her senior year. All interviewees were self-selected. Information about the project and the possibility to volunteer to participate in an

interview was shared via an article in Voice, the DES Action newsletter, as well as in a letter passed on directly to people with whom an active staff member of DES Action had previously spoken about the project. Invitations to participate in an interview were also sent to current staff and former board members of DES Action. The project was described in an email blast sent out by DES Action and featured in a Facebook Live event in May 2018. The research team contributed regularly to DES Voice, raising additional awareness about the project. Potential interviewees indicated their interest in participating by email, letter or phone call to the Principal Investigator or by completing an initial expression of interest form that was submitted online.

At the outset of the project, we planned to interview people who belonged to three categories, recognizing that the categories are not mutually exclusive: 1) DES-exposed individuals who wished to talk about how they perceive any relationship between DES exposure and their understandings or experiences of gender, sex and sexuality; 2) people who were/are active in DES activism; and 3) DES researchers. Upon assessing the direction that the project was taking, in April 2018 we decided to focus on interviews with people in the first two categories. Thus, any DES researchers who are reading this report, we hope that you might be willing to talk with us as this project continues in its many iterations!

We did not aim to achieve a randomized or representative sample of interviewees, but - although we had anticipated conducting a total of 10 to 16 interviews - in the end we interviewed everyone who volunteered to participate within the project period.⁸ This turned out to be important as the distance that participants had from direct current involvement or interaction with DES Action increased over the course of the project as information about the project reached people through various channels. The majority of the interviews were conducted by phone, some were via video conferencing, and one was in person.

One of the trickiest things about this project has been the “messiness” of the demographic categories that stories are often aligned with. We were interested in people’s understandings and experiences of sex, gender, and sexuality. As part of the interview process, participants were asked about their self-identification with categories of gender identity, sex that was assigned at birth. However, we explored sexuality and sexual orientation through the stories that were shared. Four interviews were conducted with cisgender, straight DES-exposed women who explicitly identified as being formally active within the DES movement. These interviews were semi-structured, exploring perspectives on DES Action’s structure, history, and contemporary potential alongside topics and clarification questions that were emerging from the on-going analysis of the other interviews. One interview was conducted with a cisgender, straight woman who had taken diethylstilbestrol while pregnant. The other 20 interviews were with people who understood themselves to have been exposed to DES in utero. Nine of these interviews were with people who explicitly identified as LGBTQI; 5 other interviews with either cis or straight identifying participants were deemed extremely relevant to the “queering” of

⁸ An additional 13 people have expressed interest in participating in this project following the completion of the initial interviews. We hope to be able to continue the work and express gratitude for your interest.

understandings of gender, sex and sexuality. The remaining interviews are significant due to the interpretations that interviewees offered about the associations they make between being DES-exposed and their experiences as a woman, man, sexual being, and so forth. These interviews were predominantly with cisgender women who had experienced the effects of DES exposure and connections to their sense of self (gender/sex/sexuality). These interviews offer tremendous insight into notions of femininity and hypersexuality, early assisted reproduction, ideas about hormones, conversations between those exposed in utero and those who are of the third generation, and so forth.

Emerging Ideas: What are we Learning?

The on-going analyses of the archival material, interviews, and public representations trace the appearance, emergence and submersion/subversion of sex/gender/sexuality in the records of DES Action and, in many ways, the DES movement. We are exploring the different ways in which people perceive and make sense of potential connections between DES exposure and their understandings and/or experiences of sex/gender/sexuality. We've worked with the data throughout the project, enabling the project as a whole to be shaped by the work we have already done and both our own and interviewees' responses to it. The following is an introduction to themes that emerged in the preliminary analysis and that we are exploring in analysis and further research.

The Interrelation of Trans/Intersex Embodiment and Identities

Dana Beyer, a transgender activist and politician, has publicly made a connection between having been exposed to DES in utero and her development of a transgender sense of self (Beyer in Rudacille 2006; Beyer 2008). Interestingly, while the connection between her transgender identity and her DES exposure has been articulated often, she has also more infrequently identified as intersex.⁹ In a number of the interviews, however, some interviewees who identify as transgender, also discuss being intersex. Some do so in a theoretically speculative manner in which they talk about the possibility of a convergence between transgender and intersex embodiment. Others differentiate the form of intersex they embody from what is meant by, in their words, "classical intersex". These interviewees use the term intersex to capture the ways in which their sense of gender relates to ideas of being "bisexual" or an integration of two sexes.

In our initial reading of the DES Action archival material, the concept of "intersex" does not

⁹ Differences in genital structure or fertility experienced by DES-exposed individuals, such as hypospadias, cryptorchidism (undescended testes), and low sperm motility are also considered characteristics of intersex embodiment.

appear. Our preliminary review of intersex activist or support organizations does not identify DES exposure as a topic within their public facing material. However, diethylstilbestrol (Stilbestrol) is recorded as being used within treatment protocols to “manage” intersex patients (Gill-Peterson 2018). We have begun to look into these various intersections between DES and sex/gender non-conforming individuals and communities more closely. Our ongoing research will review the documents we collected from the archives to look more closely for references to intersex embodiment and we hope to have the opportunity to examine the use of diethylstilbestrol in various fields of endocrinology practice of the 1940s and 1950s that lie outside the frame of “women’s” or “reproductive” health.

DES Daughters/DES Sons: Implications and Questions Surrounding the Terminology

One of the questions that we have grappled with is whether or not the terminology of DES Daughters and DES Sons needs to be expanded in order to specifically address the needs of transgender and gender nonconforming individuals who were exposed to DES. During a symposium organized by DES Action and held at Mount Holyoke College in Spring 2017, two student members of the audience stated that they found the language being used represents a binary understanding of sex/gender. The students suggested that this framework could limit the visibility of transgender and gender nonconforming peoples’ experiences of being DES-exposed. We asked interviewees about their perspectives on the language that is used. In contrast to the students who voiced the questions, most interviewees do not see a need to expand the terminology. DES-exposed transwomen, for example, articulated an understanding of themselves as DES Sons, a term they defined as males who had been exposed to DES. The interviewees understood themselves to have been male at the time of exposure and, thus, regardless of gender identity later in life, to be the subject of information and research related to DES Sons. However, their perspectives on this ease of moving between identity categories was destabilised when they were asked to consider how they might identify if participating in scientific/medical research themselves.¹⁰ We ask: How might examining data - biological samples and lifestyle data - that has already been coded as “male” or “female” have implications for knowledge about the long term effects of DES across access of difference?

We are also beginning to explore how our knowledge and understandings of people’s experiences might shift if we bring early research on DES, endocrine disruptors, and intersex embodiment into conversation with each other. “Endocrine disruptor” as a concept was first coined in 1991 in the context of a Wingspread Conference organized by Theo Colborn, who then co-authored *Our Stolen Future* (Colborn, Dumanoski, and Myers 1996). Thus, the first 20 years of research on the effects of DES was conducted outside of this paradigm, yet was perhaps more closely integrated with the emerging environmental justice work that we understand. We have begun to map the movement of knowledge and actors (scientists, clinicians, and activists) at the interface of DES-related research and research on endocrine disrupting chemicals more broadly.

¹⁰ see Luce, J. and April Albrecht 2018.

Articulations of “queer tendencies” and biological impossibilities

A number of interviewees offered very nuanced reasonings as to why they understand DES to be closely associated with their being transgender. Other interviewees did not articulate the mechanisms of sexual differentiation by which a type of causal effect could be plausible, but rather drew on sources regarding the potential association that they considered to be reliable.¹¹

Interviewees narrated DES as responsible for their life experiences in very different ways and to very different degrees. Some of the most striking, and also most disturbing, stories were told by people who had experienced a lifetime of feeling morally, socially and sexually “deviant”. They told stories about suppressing their desires and controlling any possibilities of behavior that they considered potentially deviant from a heterosexual norm. One interviewee, who identifies as a heterosexual woman, explained that people who are lesbian, gay or bisexual from conception are “naturally” so. In contrast, she views her same-sex desires as being induced by exposure to DES, rendering them “unnatural.” (This is interesting in relation to colloquial discourse on “sexual chemistry.”) In this framework, heterosexuality becomes a marker of success; a sign that one has overcome, or fought against, pathology.

Interviewees who identified as LGBTQI expressed that they had at some point wondered about the potential connection between their identity and DES exposure. However, not everyone expressed the potential connection as a negative one. There seemed to be a clear distinction between interviewees who have struggled significantly with queer desires or a transgender sense of self throughout their life and those who embrace queerness or transness as an integral and positive dimension of their identity.

This theme also relates to a number of stories shared by cisgender women who experienced fertility difficulties and/or who came to understand their bodies as “atypically” or “not quite” female. For these interviewees, DES exposure had rendered it biologically impossible to become pregnant or extremely difficult to carry a fetus to full term. Interviewees told emotionally powerful stories about their experiences of infertility and/or cancer and the ways in which not being able to have a child through their body reconfigured their sense of gender and sexuality in varied ways.

In order to explore this theme further, we are revisiting all of the interviews in order to think through the ways in which narratives of struggle in relation to queer or transgender experiences are integrated in the larger stories about the social context of interviewees’ lives, as well as in academic histories of queer and transgender rights and recognition. We are also exploring the

¹¹ DES Voice has, for example, published an article that refutes causal relations between DES exposure and same-sex desires (see Pat Cody’s review of a scientific article reporting on the outcomes of a “Survey on Psychosexual Characteristics of DES Daughters and Sons” in issue #96 Spring 2003) and a more speculative article regarding the potential association between DES exposure and gender dysphoria (see Transgenderism and DES: Is There a Link? in issue #149 in Summer 2016).

ways in which some aspects of DES-related activism or education - based for many decades on the harm done to women's reproductive bodies - may inadvertently contribute to a rhetoric of queerness or transgender identity as DES-induced damage or harm.

DES as a prototypical “gender-bending” endocrine disrupting chemical

The lived experience of when, why and how interviewees came to identify as DES-exposed holds an important place within their narratives about how DES is related to their experiences and understandings of sex, gender, and sexuality. All of the ciswomen who were interviewed found out about their DES exposure in their teens and early 20s and/or when experiencing fertility or pregnancy related complications. Two transgender interviewees (one transman and one transwoman) had been aware of their DES exposure since a similar time frame. However, a number of the transgender interviewees in this study came to identify as DES-exposed in their mid-fifties and sixties. They learned about DES having been prescribed to people who were pregnant in the same time period within which they were born while seeking to understand their experiences of gender dysphoria and/or identification as transgender. Their search for information, aided by the Internet, occurred following more widespread understandings of the environmental and “gender-bending” effects of endocrine disrupting chemicals (EDCs) and publicly available stories told about DES as a cause of transgender identity.

Interviewees told us about research they had read about that offered them an understanding of the “naturalness” of transgender animal behavior (predating knowledge of endocrine disruptors) and by extrapolation the “naturalness” of their own transgender variation from normative expectations of binary sex identification. A couple of interviewees spoke of reading books such as *Our Stolen Future* (Colborn, Dumanoski, and Myers 1996) and *The Riddle of Gender*, especially the chapter titled “Fear of a Pink Planet”, (Rudacille 2006) which introduced them to knowledge about the effects of endocrine disruptors on animal fertility and reproductive and sex organ development. Some interviewees noted a presentation on research conducted by Scott Kerlin (Kerlin 2004), as well as a DES Trans and a DES Sons listserv that they had been on. In many ways, interviewees extrapolated from animal research to humans arguing for the unnatural, but unavoidable, DES-exposure induced sex and gender disconnects that they experienced. At the same time, some interviewees established queer kin relations across species borders by pointing out the contiguity of human animal and non-human animal transgender behaviour.

As the research progresses further we are following up on the specific references interviewees make to the sources of knowledge that inform their understanding of the possible association between DES exposure and an LGBTQI identity. How does their encounter with these texts relate to their prior knowledge about DES or their access to queer and transgender positive social and medical environments?

Intergenerational Trans and Queer Exchanges

Are experiences, embodiments, and perhaps biologies of transness generational? Some of the interviewees talked about their generation's experiences of being transsexual or transgender as inherently different from the experiences of the millennial generation. They used wording like, "the transgender of my generation..." In some of these narratives, a well-articulated sense of "real transness" appears; a biologized transness that is perhaps associated with DES exposure. This "transgender" is differentiated from what some interviewees perceive as the culture of gender variance that seems to be part of a new generation. Yet, while there are decades of lived experiences between the interviewees in this project and the transgender youth and young adults they differentiate themselves from, they are "transitioning" within similar social moments and social movement contexts of the present. Thus, even though their seemed to be distinctions being made between a biological vs. cultural experience of being/becoming transgender, interviewees also pointed to intergenerational learning, coalition, and community building projects in which they are involved. They spoke about the ways in which their interactions with transgender and gender nonconforming young people are challenging some of their perspectives and requiring them to think through sex, gender and sexuality in new ways.

We are working to build on this theme, engaging in exploratory analyses that examine the paradigmatic shifts that underpin scientific understandings of homosexuality, transgender experiences, and intersex embodiment in order to interweave these with the interview narratives. In further research and analyses one could imagine engaging different generations in conversations about such interview excerpts in order to further generate understandings of the historically, politically, and culturally specific lived experiences of gender non-conformity in the context of circulating explanatory narratives.

Sharing Knowledge: DES Voice Articles and Presentations

An important part of the design of this project was to share the ideas and knowledge emerging from the research in a "real-time" manner to members of the DES-affected community. We did this primarily by writing articles that were included in Voice, the DES Action newsletter and a Facebook Live presentation, which was concurrently attended by Mount Holyoke College Alumnae at a reunion in May 2018. Additionally, examples from the project have been featured in a number of presentations and integrated into course material. We have listed these articles and presentations below. And, finally, we are sharing this report and hope that it will offer a sense of the numerous directions in which an initial idea has taken us in our exploration of, in many ways, the life narratives of people who identify as DES-exposed.

DES Voice newsletter articles

Luce, Jacquelyne. (2018). Gender/Sex/Sexuality and Experiences of Being DES-Exposed. Part 1: Introduction. *Voice – DES Action USA Newsletter*. Winter.

Luce, Jacquelyne & Karisa Poedjirahardjo (Gender Studies major) (2018). Gender/Sex/Sexuality and Experiences of Being DES-Exposed. Part 2: Notes on Terminology. *Voice – DES Action USA Newsletter*. Spring.

Albrecht, April (Gender Studies major) & Luce, Jacquelyne. (2018). Gender/Sex/Sexuality and Experiences of Being DES-Exposed. Part 3: Reflections on the Categories of DES Daughter and DES Son. *Voice – DES Action USA Newsletter*. Summer. #157

Luce, Jacquelyne & Albrecht, April (Gender Studies major) (2018). Gender/Sex/Sexuality and Experiences of Being DES-Exposed. Part 4: Barriers to Accessing Health Information and Care. *Voice – DES Action USA Newsletter*. Fall.

Luce, Jacquelyne (2019). Gender/Sex/Sexuality and Experiences of Being DES-Exposed. Part 5: DES Healthcare in later life. *Voice – DES Action USA Newsletter*. Winter.

Presentations

On May 18, 2018, Jacquelyne Luce gave a presentation at the “Back to Class” session for a reunion at Mount Holyoke College. The event was also streamed via Facebook Live, as part of the 40th anniversary celebration of DES Action, USA.

On October 18, 2018, Jacquelyne Luce delivered a presentation on the project to a first year Biology seminar at Mount Holyoke College.

On November 16, 2018, Jacquelyne Luce delivered a presentation to Gender Studies majors at Mount Holyoke College.

On March 8, 2019, Jacquelyne Luce presented a presentation entitled “Chemically queer / differentially Trans: Narrating hormonal re/production” during a Faculty Friday workshop at Mount Holyoke College.

On April 12, 2019, April Albrecht referred to her work on the project during her senior symposium presentation, “Queering Toxicity: Contemplating Contamination in Academia.”

On November 24, 2019, Jacquelyne Luce presented a paper entitled “Intergenerational Exposure: Narratives of Chemically-Induced Transgression” at the American Anthropological Association Meeting in Vancouver, British Columbia.

Additional Impacts

There are three key additional outcomes of this project to be highlighted:

1) The generation of awareness of the DES Action Archives and possible areas of future DES- related research

- Examples from the research were used in Feminist Research Methodologies (taught by Jacquelyne Luce) in Spring 2018 and Spring 2019, engaging students in learning about survey design, differences in technology use, enhancing inclusivity, etc.
- Reflections about how this research intersects with other work that Jacquelyne Luce does in the area of health and reproductive justice studies, led to the development of a proposal to design a course on “Feminist Engagements with Hormones” to be taught at Mount Holyoke College, for credit in the Five College Reproductive Health, Rights and Justice Certificate Program during Spring 2020. The proposal was awarded a course development grant of \$500.
- Throughout the project, the researchers have kept track of a number of interesting questions which could be addressed by students in future research.

2) The opportunity for undergraduate students to gain research experience

It is increasingly important for students in the humanities and social sciences to experience ‘doing research’ and producing knowledge in order to make the research undertaken in interdisciplines like women/gender/sexuality studies tangible and concrete and, thus, an imaginable future endeavor. As cited above, examples from the research have been used in Feminist Research Methodologies taught by Jacquelyne Luce in Spring 2018, engaging students in learning about survey design, differences in technology use, enhancing inclusivity, etc. The project has also enabled students to gain more extensive hands-on research experience in which they bring together LGBTQI studies, health studies, and women/gender/sexuality studies.

During the funded project period, 5 undergraduate research assistants became involved in the project. The funding provided the opportunity for 3 students (Karisa Poedjirahardjo, Ella Sevier and April Albrecht) to work intensively on a project to gain an understanding of the different phases of data collection and analysis and to participate in dissemination activities. Additionally, Cassie Pawlikowski and Olivia Solomon also carried out research on the project during this time.

Work on the project continued beyond the funded period. Following her work on the project as a summer 2018 research intern, April Albrecht completed two Independent Studies during her senior year in which she extended theoretical concepts she was working on in relation to the DES Project to explore broader questions about medicalizing and hormonalizing trans experiences and the social norms or toxicities which foreclose particular discussions and areas of research in academia. Em Pollack and Cassie Pawlikowski undertook a qualitative health research practicum in Spring 2019. Althea Finch-Brand was a research assistant in 2019. During the summer of 2019, Jacquelyne Luce supervised 3 summer research interns, designing internships that focused on topics and themes that had emerged during the ongoing analysis of the DES Project data. Two internships (Lainie LaRonde and Cassie Pawlikowski) were funded by Mount Holyoke College and 1 (Aleksander Meyer) by Hampshire College. The internships focused on: 1) Early relationships between diethylstilbestrol and gender transgressive and/or queer people (e.g. the use of DES in the clinical “management/treatment” of intersex or gay individuals); 2) a deeper exploration of the ways in which narratives of transness, DES exposure and pathology intersect; and 3) ciswomen’s narratives of sexual and reproductive health and their perceptions of risk in relation to taking other hormones. These internships have established a solid foundation for the integration of other students into future project work, as well as provided the means by which to use the DES Project data to explore “spin-off” topics. Many of the ideas emerging from this project were the inspiration for a new Gender Studies/Reproductive Health, Rights, and Justice Certificate course, “Feminist Engagements with Hormones,” which is currently being taught by Jacquelyne Luce.

Broadening understandings of the on-going questions and scholarship related to DES exposure

By aiming to share the knowledge and ideas we are generating toward a diverse audience, including those who have been exposed to DES and people interested in experiences of gender/sex/sexuality, the project has the potential to support conversations about lived experiences of gender/sex/sexuality across and beyond the normative social categories of sex, gender, and sexuality now and in the recent past. The project has already sparked many more ideas for future research.

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Principal Investigator's note: I have worked with incredible students and am grateful to have the chance to provide them with opportunities for hands-on research experience in Gender Studies. Thinking in community with students is one of the most rewarding and exciting privileges of teaching at a small liberal arts college. For their commitment, engagement, and analytically nuanced scholarship, I express my appreciation to each of the research assistants and summer research interns who have contributed to this project: April Albrecht, Althea Finch-Brand, Lainie LaRonde, Aleksander Meyer, Cassie Pawlikowski, Karisa Poedjirahardjo, Em Pollack, Ella Sevier and Olivia Soloman.

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